

**JRF programme paper:**  
A Better Life

# A better life for older people with high support needs in housing with care

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**October 2010**

This paper:

- examines what needs to change so that older people with high support needs can have a better life in housing with care;
- pulls together key themes and issues explored in greater depth in other expert reviews commissioned by the JRF as part of the Better Life programme;
- identifies possible areas of focus for future projects.

**The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its 'A Better Life' programme, to stimulate and inform thinking on alternative approaches to a better life for older people with high support needs.**

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The Joseph Rowntree Foundation has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy-makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of JRF or the Better Life programme.

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# 1. Introduction

## What needs to change so that older people with high support needs can have a better life in housing with care?

In order to begin to answer this question, JRF commissioned four expert reviews seeking to identify what was known and not known about issues in relation to older people with high support needs and housing with care. This paper pulls together key themes and issues explored in greater depth in four expert reviews:

1. Access and diversity – Nigel King and Jenny Pannell<sup>1</sup>
2. Decision-making and communication – Kritika Samsi and Jill Manthorpe<sup>2</sup>
3. Attitudes to frailty, disability and end-of-life – John Percival<sup>3</sup>
4. Workforce issues – Jill Manthorpe and Jo Moriarty<sup>4</sup>

These reviews are attached as appendices to this report. This paper aims to summarise the position and issues in these areas, and suggest themes for discussion within the advisory group which may warrant selection for investment by JRF as part of the Better Life programme. In so doing, the author will draw on information from the above papers and a range of other sources, including the paper by Imogen Blood on 'Equality and diversity and older people with high support needs'.<sup>5</sup> This paper also draws on the author's own knowledge and experience of housing with care.

## What do we mean by housing with care?

There is no universally agreed definition for housing with care (HWC). That used by Nigel King and Jenny Pannell<sup>1</sup> suffices:

...developments specially designed for older people, which offer self-contained accommodation together with 24 hour care and a wide range of leisure and other facilities on site with some meals provision.  
(King and Pannell, 2010)

Some key points about housing with care will help set out the context for consideration of the issues:

- It is a housing model, not residential care – its stated ethos is to support and promote independence, occupants have security of tenure and should have the right to control who enters their property and to choose the form their support should take.
- In another sense it is a hybrid – it does not have its own unique category in legislative and regulatory terms, and is covered by a raft of housing-related, community care and more general legislation and guidance which does not always dovetail.

- Similarly, in terms of staffing and service provision, it is different from both sheltered housing (with standard domiciliary care) and residential care, and has a very mixed workforce.
- In the context of the wider social care transformation agenda, housing with care is in a state of flux. The effect of personalisation on service commissioning and delivery is not clear.
- No two housing with care schemes are the same – despite common elements, there is great diversity in every aspect of the provision including: scale; ethos; target groups and entry criteria; ‘move-on’ practices; level and type of services; staff disciplines and skills; and financial arrangements and tenure. Thus, caution is needed in making generalisations.

## **What are ‘high support needs’ and who do we mean by older people?**

Older people of any age who need a lot of support due to physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old though some will be younger. Many will be affected by other factors including poverty, disadvantage, ethnicity or lifestyle. (JRF, 2009a)

Even within this definition there is much scope for different interpretations:

Defining ‘older people with high support needs’ is itself problematic: both ‘older’ and ‘high’ are used as relative terms and this begs the question of who decides: medical diagnosis, social care assessment, older people themselves or their families? Is it about how much support a person needs or how much they are entitled to? How much support is an older person entitled to – enough to make sure they can wash and eat, enough to prevent a costly admission to care, or enough to allow them to participate and contribute? (Blood, 2010)

Blood suggests that ‘we need to move from a needs-based medical model to a rights-based social model in order to effectively promote the equality of this group’.<sup>5</sup>

In this paper, the term ‘support’ is used to encompass any combination of general support, personal care and housing-related support. ‘Care’, unless otherwise specified refers to activities such as personal care which require registration with the Care Quality Commission (CQC). ‘Housing-related support’ refers to services that were eligible for Supporting People funding when that was a ring-fenced budget, and explicitly excludes personal care.

## **Broad themes**

The issues covered in this paper may be drawn together into four broad themes:

At point of entry to HWC:

1. Raising awareness, accessibility, acceptability and affordability of HWC for people from a range of diverse or marginalised groups.
2. Investigating the limits of HWC and its key variants as options for meeting the different high support needs of older people.

Once living in HWC:

3. Improving the quality of life of older people with high support needs living in HWC schemes.
4. Extending the likelihood of providing a home for life, including providing end-of-life care for those who want it

## **Criteria for determining priorities for the Better Life programme**

What criteria should be applied to decide what should be prioritised by the JRF Better Life programme? The following are a few suggestions:

- Does it accord with JRF's core values and priorities?
- Does it focus on:
  - older people?
  - high support needs, possibly with additional layers of disadvantage?
  - housing with care?
- Is the work likely to make a real and positive difference to the lives of this group of people?
- Should it focus on either one or other of the following:
  - areas which are likely to impact on the greatest number of people in this group?
  - those at the greatest disadvantage?
- What is the likelihood of other funders taking up the issue if this programme doesn't?
- Possibly a mix in terms of:
  - addressing at least three, if not all four broad themes outlined above;
  - different sorts of projects/initiatives rather than all being research projects.

## **Key themes**

Later in this paper is a list of specific project topics drawn out from the paper, but JRF could not possibly fund them all. The group may wish to consider the following as priority areas. These thoughts are put forward for discussion; it is not intended that the advisory group should be constrained by them. They are not ranked in any way, and the programme is unlikely to be able to address them all.

## ***Diversity issues***

Very little work has been done in relation to the housing and support needs of LGBT older people, and also those with multiple or complex needs who are at risk of being homeless, so work in these areas would be timely. Equally, the growing number of older people with a learning disability, and the likelihood that they will have experienced a life of disadvantage makes work in this area a high priority. The writer

feels that others in the project advisory group are better qualified to prioritise the diversity themes and identify what exactly would deliver maximum benefit.

### ***Affordability***

Several of the expert reviews highlighted the issue of cash poor/asset rich. Also, with the unusual circumstances of people growing older with a learning disability, there seems to be a need for alternative funding models. JRF has a good record in developing new funding models and has the credibility across the industry to help promote them. Work in this area would help to improve access to HWC, meeting the first of the themes under 'at point of entry'.

### ***Dementia***

Dementia is a massive and growing issue, yet so little priority is given to research into caring for people with dementia, particularly in the context of a housing with care setting. Yet the demand for provision that caters for this group is growing, and expectations are not always realistic or reasonable. There are now sufficient schemes using different approaches to evaluate their effectiveness and limitations. Research in this area could shape future HWC development to improve the lives of people with dementia. Depending on the precise research question(s), this could shed light on theme 2 under 'At point of entry' on the strengths and limits of HWC and its variants for people with dementia, as well as improving the lives of people with dementia once living in HWC.

### ***Maximising 'voice'***

While the principle of engagement and involvement is generally well accepted in HWC, knowing *how* to do this with individuals who have impairments, frailties or other barriers which make the usual approaches and channels unsuitable, is a different matter. Highlighting learning from other sectors would be a good start, and could be addressed through ideas and signposting in a skills handbook, but this area may also benefit from research specifically in the context of HWC. This would deliver on the two broad themes (numbers 3 and 4) under 'Once living in HWC'.

### ***Dynamics between those with and without support needs***

In addition to workforce competences and guidance in this area, research into community dynamics and fit/frail issues would help in the development of HWC schemes which better suited the people whose needs they were targeting, and in the process, possibly reduce some of the community tensions. In particular the author believes that research into links between levels of community tension and particular scheme features such as spread of fitness levels targeted, would be extremely valuable. Like the research suggested under the dementia heading, this work has the potential to shed light on the second of the broad themes as well as to improve the lives of older people with high support needs once living in HWC.

## **Workforce**

A project addressing workforce issues cuts across all the other themes in the paper and meets the 'priority' criteria. It is up to the advisory group which, if any, of the suggestions given later in this paper to follow. The writer's own view is that developing documents on the key skills and knowledge needed within HWC, in the form of core competences, and a guide/handbook, would be extremely valuable. Using the documents to influence policy, or using the development of the documents as a vehicle for encouraging improved cross-sector working at government and national level, could be part of this. This has the potential to deliver on both of the broad themes under 'Once living in HWC' i.e. improving quality of life and improving the likelihood of a 'home for life' across many vulnerable groups.

## 2. Summary of the expert reviews

This paper seeks to bring out the most important issues in the context of housing with care rather than giving all the issues covered in the expert reviews equal coverage.

### Access and diversity in housing with care

Blood<sup>5</sup> makes the point that by definition, older people with high support needs fall into two strands of disadvantage – age and disability. The particular diversity factors considered in King and Pannell's paper<sup>1</sup> are: ethnicity, sexuality, poverty, learning disability, mental health issues, sensory impairment and older homeless people.

In recognising that some diversity factors interact with, and compound others, Blood distinguishes between 'older people with acquired as opposed to pre-existing disabilities'<sup>5</sup> suggesting that the latter may have experienced the cumulative effect of a number of other strands of disadvantage impacting on old age, such as stigma, poor housing and poverty, which may not apply to the former. She also differentiates between 'older people who are disabled and ill or disabled but in good general health', an important distinction in measures aimed to improve quality of life. In the context of the JRF definition of people with high support needs, it may be sensible for the work of the Better Life programme to concentrate on the former. Blood points out that the needs of people in some diversity categories, such as sexuality and certain black and minority ethnic (BME) groups, are likely to be less visible than those of others who may already be known to public services, for example poorer people with ill-health. Ways need to be found to reach out to those who are hidden.

King and Pannell<sup>1</sup> observe:

In considering different groups who may find barriers to accessing HWC, it is striking how:

- often those at risk have multiple needs and could appear in several or even all the groupings used;
- broad categorisations are of limited use and can be misleading because within any group there is considerable diversity.

### Ethnicity

King and Pannell<sup>1</sup> report that:

- In the UK, there are about 4.5 million people from a BME background (7.9 per cent of the population).
- Eleven per cent of the UK's Black-Caribbean population are aged over 65 and seven per cent of the UK's Indian population are aged over 65.
- By 2030 the BME older population within UK will have increased tenfold from 175,000 to over 1.7 million.

Source: ONS Social Trends 2006, Table 1.5

There is growing awareness of the increasing number of black and minority ethnic older people in the UK and their needs. Information on developing culturally sensitive provision is increasingly available but local implementation is patchy and 'BME and refugee older people remain hidden from, and unaware of, mainstream services'.<sup>1</sup>

The UK evidence base tells us little about how well different models of housing with care work for different ethnic groups (Croucher *et al.*, 2006). King and Pannell<sup>1</sup> make the point that we need to know more about differences, similarities and transferrable lessons across the wide range of BME communities, which include:

- long-established communities, including black and mixed-race (e.g. Liverpool, London, Cardiff), Gypsies and Travellers;
- migrants from the Commonwealth and elsewhere;
- refugees and asylum seekers (including older Jews and Poles who arrived in the mid-twentieth century, and more recent arrivals e.g. Balkans, Africa, Middle East);
- recent arrivals from Eastern Europe.

## Sexuality

King and Pannell's paper<sup>1</sup> distinguishes between work focusing only on lesbian, gay and bisexual people (LGB) and that which includes transgender people (LGBT), for whom many issues are different. They report that 'there are no exact figures, but using the estimate of 5–7 per cent of the population would give a figure of 1 to 1.4 million LGB people aged 60 or over by 2031 (Musingarimi, 2008)'.<sup>1</sup>

Age Concern's *Opening Doors* programme, as reported by King and Pannell<sup>1</sup>, says:

The situation for most lesbian, gay and bisexual people ... is more positive, secure and affirming than ever before. However, ... older people have lived a large part of their lives in less liberal times and their experiences have made them understandably wary and cautious. In practice, this means [they]:

- are less likely to access services;
- face a number of unique problems as they age, from the attitudes of mainstream providers, who regularly assume all the older people they serve are heterosexual;
- have significantly diminished support networks in times of crisis<sup>1</sup>

King and Pannell<sup>1</sup> identify specific issues which affect LGBT older people and their ability or desire to access HWC:

- Difficulties with inheritance and passing on property (owner-occupied or tenancy) between partners, especially those with no civil partnership; this reduces opportunities to use equity to purchase HWC and can lead to

homelessness.

- Limited housing/care choices in later life: fear of discrimination and fear of disclosure in mainstream provision; lack of specialist provision.
- Different living and family situations: LGB older people are much more likely to live alone, have no adult children, and risk isolation in later life; if they do have 'families of choice' (partner, friends), these may be excluded from their care and support.

'There is a need for more UK-wide primary research on the housing, care and support needs of LGBT older people'.<sup>1</sup>

## **Poverty and affordability**

- Nine per cent of pensioners after housing costs and 14 per cent before housing costs live in persistent poverty (for at least three years with income below 60 per cent of median income).
- Pensioner poverty continues to be greatest among older and female pensioners, disabled pensioners not in receipt of disability benefits, and ethnic minorities.
- There is a greater likelihood of disabled people living in poverty.
- Relative poverty rates vary by ethnicity and are highest among those of Pakistani and Bangladeshi background at 52 per cent before housing costs and 60 per cent after housing costs.

*Source: HM Government: State of the Nation Report 2010*

As King and Pannell<sup>1</sup> identify, poverty in later life is often a result of poverty before retirement. While recent changes to the benefit system should have significantly increased the income of older people, poor take-up of benefits is known to be a particular problem for marginalised groups. A complex system is compounded by language barriers, cultural issues and lack of telephone or internet.

King and Pannell<sup>1</sup> identify three broad categories of older people:

- The 'really poor'. Provided they gain access to advice, information and support, they are usually entitled to state funding for most of their housing, care and support.
- The 'better-off', who for the most part can self-fund without financial assistance.
- The 'nearly poor', who may be entitled to some help.

Not all home owners (whose numbers will rise to 75 per cent of older people by 2026) are well-off, with a significant proportion being asset rich but income poor. King and Pannell<sup>1</sup> quote Peter Kenway from the New Policy Institute as saying:

It may very well be that the people whom one should be most worried about are not the poorest pensioners, i.e. those on or entitled to Pension Credit, but those just above that level who can find themselves paying nearly or even just as much as those much better off. Low-ish income owner occupiers are one such group, but I suspect it goes much further up the income distribution than that. The worry here is not just that those conventionally counted as being in poverty are not the whole group of concern, but rather that they may not be the group of concern at all.

(Peter Kenway, New Policy Institute)

Blood<sup>5</sup> has also identified this issue in her paper. King and Pannell<sup>1</sup> suggests exploring alternative funding models to match the circumstances of some groups including this one, and floats options which enable the exchange of equity for care in social housing, and shared ownership leases which can be 'staircased' down as well as up.

## Learning disability

The headline figures are of a population in England of nearly 800,000 adults (two per cent), with a learning disability. Of these about a quarter (224,000) are 'known to services'. This broadly equates to those with severe and profound learning disabilities. Most others with mild or moderate learning disabilities do not have access to social care support.

(King and Pannell, 2010)<sup>1</sup>

A growing number of people with learning disabilities are living into old age. King and Pannell report that 'Recent figures for learning disability show how the percentage in each age band of older people with learning disability rises sharply over 20 years from 2001 (Emerson, 2005)'.<sup>1</sup>

Emerson *et al.* (2001) note that 'as well as high levels of special healthcare problems among people with learning disabilities there is evidence of other additional needs or features of their disability'.<sup>1</sup> These include sensory impairments, physical disabilities, autism and mental health problems among others. 'People with Down's Syndrome now have a life expectancy of 50-60 but there is a 50:50 chance of early onset dementia in late 40s or early 50s'.<sup>1</sup>

King and Pannell highlight a general presumption in the learning disability field against registered care in favour of more 'ordinary lives' and independent living. 'More than half of those with learning disabilities known to services are still living with their families'.<sup>1</sup> Often this is with ageing parents who have their own health issues.

All these factors make older people with learning disabilities prime candidates of housing with care, yet the impression gained by King and Pannell and confirmed by other experts they consulted is that 'few local authorities have implemented coherent strategic plans, put in place policies and updated practice to respond to the small but growing number of older people with learning disabilities'.<sup>1</sup>

Whilst there have been innovative housing with care developments for people with learning disabilities, there is considerable debate about the best models for people with learning disabilities:

There is plenty of opinion about what people should have but little evidence for what is wanted; this is true of all people with learning disabilities, but probably particularly true of older people as they are less likely to have relatives advocating for them.  
(King and Pannell, 2010)<sup>1</sup>

King and Pannell<sup>1</sup> also point out that more attention needs to be paid to funding and home ownership options for people with learning disabilities, for example, using the benefit system or family trusts.

## **Mental Health**

### ***Dementia***

As people live longer, the number of older people developing dementia is growing significantly. There are an estimated 700,000 with the condition in the UK at present and this number is expected to double in less than 30 years (DH, 2009a). The impact on the lives of people with dementia and their families is massive and the level and quality of support is variable. The 2009 national dementia strategy *Living well with dementia* (DH, 2009a) sets out to improve the situation and includes housing with care as a provision which could contribute to helping people with dementia to 'live well'. There is still very little research into HWC for people with dementia.

The approach to people with dementia in housing with care varies from scheme to scheme and area to area. There are essentially four models:

- integrated/dementia-friendly;
- separate dementia 'wings' within 'mainstream' housing with care schemes;
- specialist dementia schemes; and
- hybrid approaches which might combine mainstream HWC and residential care on the same site, for example.

There is little evidence, however, as to the benefits and downsides of each of these approaches for people with dementia.

Older people with dementia can be ostracised and discriminated against by other residents, particularly if they move to the scheme when the dementia is relatively far advanced. There is general agreement that an early move to HWC is preferable, while the person can still learn their surroundings and build relationships. Entry criteria vary between HWC schemes, with some specifically excluding people with dementia and others specifically targeting them, but with little clarity as to any limits. Some models may be better at minimising ostracism and achieving integration than others. Some may enable a home for life better than others. There is much opinion but little actual evidence on these matters. We just don't know.

In considering the needs of those with extreme cognitive impairment and behaviours, Garwood asks:

If the individual is unable to gain fulfilment from the advantages afforded by a housing model – independence, self-determination and choice, if the tenancy is for all practical purposes meaningless, and the person needs a degree of intensive help and supervision which makes a fully self-contained flat at best a waste of money, and at worst an isolating hindrance, why move in to an Extra Care scheme?...These questions need open and honest debate and research.  
(Garwood, 2005)

These questions also need to be considered in the context of the legislative and regulatory framework, including the Care Standards Act as amended by the Health and Social Care Act and the Mental Capacity Act (discussed later in this paper).

Given the variations in vision and ethos, design and staffing levels etc, it is not realistic to expect entry criteria to be uniform across HWC, but it is important that all the features dovetail. In addition, where someone with dementia needs to move from their home in the wider community, it would be helpful to have some clarity:

- as to the benefits and limitations of HWC as an option for people with dementia;
- whether some models are better than others and in what ways;
- whether some people with dementia would be better off moving to other types of accommodation and care provision, and relevant criteria for making this judgement;
- and how these link in to the different stages and manifestations of dementia.

Dutton (2009) identifies other important evidence gaps:

- knowledge about outcomes for different types of individuals with dementia in relation to the key variables of extra care settings, e.g. design of building and environment, organisation of care, health care, recruiting and training staff, point of entry
- comparisons of extra care housing with available alternatives
- studies that address how best to implement research findings in practice.

Housing 21's 'Opening doors to independence' (Vallelly *et al.*, 2006) found that HWC provided a good quality of life for people with dementia. While a very valuable piece of research, this study did not focus on the relationship between the level/manifestations of dementia at point of entry and the outcome for the person with dementia in terms of quality of life. It looked at the outcomes for people who were already there. A home for life was provided in approximately 50 per cent of cases. 'Risk, challenging behaviours, conflict with staff and other residents, and appearance of distress were often reported as trigger factors resulting in moving on' (Vallelly *et al.*, 2006). There may be considerable scope for dealing with these issues more effectively in order to help people with dementia to live better lives and reduce the number who do need to move to other care settings.

Last year, Brooker *et al.* (2009a) reported on the findings of an action research project into the Enriched Opportunities Programme (EOP) in ten housing with care schemes. EOP included:

- a specialist lead to 'unlock any potential for well-being' called the 'locksmith';

- individualised assessment and case work;
- a varied, flexible and practical programme of activities and occupation;
- specialist staff training and support;
- management and leadership.

Brooker identified people in housing with care schemes who were at risk of having significant mental health problems, including dementia, and were vulnerable to exclusion. She compared the outcomes for people who were part of the EOP with those in control schemes where there were additional staff, but not the elements of EOP. Brooker found that well-being was improved and fewer people needed to move to a care home in those HWC schemes where the EOP was implemented. As Manthorpe and Moriarty<sup>4</sup> observe, 'while outcomes were highly positive, we know little of the long term impact' of the programme. Nevertheless, the implications of these findings for workforce development seem significant.

### ***Depression and other mental health issues***

Depression affects 22 per cent of men and 28 per cent of women aged 65 or over (Help the Aged, 2009). King and Pannell<sup>1</sup> report that 'it is the most common mental health problem in later life, severely affecting 2.4 million older people'. Issues such as alcohol and drug misuse and people growing older with severe and enduring mental health problems will become more pressing in the future.

King and Pannell draw attention to two major reports by Age Concern and the Mental Health Foundation (Age Concern and MHF, 2006; Age Concern, 2007), which bring together analysis of mental health in later life and set out how services could be improved, including housing. King and Pannell<sup>1</sup> observe:

Mental health and well-being are most influenced by:

- discrimination and the stigma attached to mental illness;
- participation in meaningful activity, having a sense of purpose – often an aspect of HWC;
- secure and supportive relationships – social isolation is a common risk factor;
- physical health;
- poverty as a risk factor for poor mental health.

The inquiry observed much could be done to improve services. Specialist housing like HWC has an impact on mental health by preventing isolation and depression while also offering a supportive environment. (Age Concern, 2007, in King and Pannell, 2010)<sup>1</sup>

To the author's knowledge, there are not many HWC schemes that specifically target older people with functional mental illness. Suffolk County Council, which has a number of schemes with specific units for this group, informally reports that their preference is to be grouped with others who understand their problems.

According to King and Pannell, 'the evidence repeatedly shows that while HWC offers opportunities to socialise and remain active, those with cognitive, sensory or physical impairments can be marginalised (Croucher *et al.*, 2006)'. We also know that many older people with high support needs are likely to have a combination of debilitating conditions: illness and general frailty, sensory impairments and mental health issues. Yet, once people are over pensionable age, they tend to be grouped together as 'older people' and many existing or developing mental health problems go unnoticed. Evidence from a study conducted by Brooker *et al.* as part of the Enriched Opportunities Programme, showed very little awareness amongst staff in extra care housing 'of psychiatric diagnoses or diagnostic criteria and the benefits of obtaining a diagnosis and treatment' (Brooker *et al.*, 2009b).

Once again the implications for the workforce are clear.

## **Sensory impairment**

A Medical Research Council study (Fletcher *et al.*, 2006) estimated that one in eight people aged over 75 and one in three people aged over 90 have serious (registerable) sight loss. Fifty-five per cent of people aged 60+ are deaf or hard of hearing (RNID, 2006).

The level of impaired sight in extra care and sheltered housing is high, based on recent, small scale studies by the RNIB. In one extra care scheme, 75 per cent of residents were found to have significant sight loss. (King and Pannell, 2010)<sup>1</sup>

A summary of recent studies of housing, design and care needs of people with visual impairment is 'Housing for People with Sight Loss' (Hanson *et al.*, 2002). They identify the following factors as important for people with sensory impairments:

- location;
- balanced information;
- support for people to express concerns in confidence;
- promotion of socialising;
- informing people of the option of extra care.

The number of people over 60 with significant dual sensory impairment is not certain but is said to be as high as two million and rising dramatically (Hodge and Douglas, 2007). 'Additional problems created by dual impairment are more than the sum of those created by impaired hearing and vision alone'.<sup>1</sup>

Lessons from the literature include the importance of raising awareness in staff so that they can spot when deterioration hinders everyday activities, and lighting, acoustics and assistive technology.

## **Older homeless people**

As King and Pannell<sup>1</sup> point out, the agreed definition of 'older' used in research on older homelessness is 50+ because older homeless people experience ill-health and

disability at a much younger age, and many die before reaching older age. Significant numbers of older people live in homeless hostels which are inappropriate for their health and care needs and many have complex needs.

If older homeless people are re-housed into inappropriate housing with inadequate care and support, they often abandon the tenancy and end up back on the streets or in hostels and shelters. Conversely, longitudinal studies of resettlement outcomes (Crane and Warnes, 2002) have shown that they can be resettled successfully into sheltered housing, HWC and residential care.

(King and Pannell, 2010)<sup>1</sup>

Yet there is a lack of information about numbers of older people who are homeless or vulnerable to homelessness, and their housing with care needs, nor are they included in strategic planning.

## Conclusion

King and Pannell<sup>1</sup> argue that for older people with high support needs, opportunities to benefit from HWC will depend on the following factors identified from studies or raised during their review:

- **Availability:** Do HWC schemes exist in the right area, of the preferred model, that are welcoming and affordable, with suitable tenures?
- **Awareness and availability of information and advice:** Particularly for hidden, marginalised groups, how can awareness of HWC be achieved, and do those giving advice and information know about HWC? Whilst generic knowledge of HWC is useful, because of the diversity of HWC schemes, detailed local knowledge is needed.
- **Access:** Potential barriers include professionals not knowing about HWC, access being routed primarily via Adult Social Care, entry criteria and allocation processes being too narrow, housing allocation policies excluding owner-occupiers, and stereotyping assumptions such as 'they look after their own'.
- **Acceptability:** How acceptable are available HWC schemes to people from the range of diversity groups? Specialist vs generic? Risk of isolation in a generic scheme? Do staff reflect diversity? Are there other demonstrations of diversity being welcome, e.g. design, publicity material, visitors, and cultural tailoring of services.
- **Affordability:** This includes costs and charges now and in the future, availability of benefit advice and benefits, range of tenures and financial models and independent advice culturally tailored.

King and Pannell<sup>1</sup> and Blood<sup>5</sup> make important points about voice, choice and control in the context of older people with high support needs:

The lack of voice, choice and control of many older people with high support needs in their own care planning has been highlighted by Bowers (2009). Where older people are also poor, minority ethnic, LGB or suffering from dementia or other mental health issues, they are likely to be in an even weaker position to make or assert informed choices. (Blood, 2010)<sup>5</sup>

Two elements which play a key part in limiting the exercise of choice, voice and control within this group will be considered in the following two sections: mental capacity and level of frailty, both of which are likely to apply particularly to older people with high support needs.

### 3. Capacity, decision-making and communication in housing with care

Opportunities for older people to be involved in decisions about care delivery and service development on an ongoing basis are increasingly seen as central to a sense of well-being. However, older people living in a range of residential settings appear to have relatively low levels of participation in such decision-making.  
(Evans and Vallely, 2007)

Within the context of housing with care generally, empowering residents to make decisions about their lives and environment, and communicating effectively with them for the purposes of consulting and involving them, as well as imparting information, are fundamental. It is probably fair to say that the tradition for working this way has been stronger in the housing than the care sector, and continues to grow. The focus of this section, however, will be on the issues regarding decision-making and communication in relation to occupants with high support needs for whom exercising their rights to make decisions, or participating in standard forms of communication, may be compromised.

'Evans *et al.* (2007) identify three features of the extra care environment as particularly important in supporting the independence of clients: freedom to come and go as they like within and beyond the housing scheme; maximising opportunities to 'do things for themselves'; and having choices about how to spend their time'.<sup>1</sup>

#### Capacity and decision-making

Advance care planning will be considered later in the paper in the context of end-of-life care. The focus of this sub-section will be on advance planning and decision-making in the context of loss of mental capacity, of which advance care planning is only one element.

The Mental Capacity Act (MCA) 2005 provides the framework for taking actions and decisions for someone who lacks the mental capacity to do so for themselves. It makes provision for people to plan in advance for a time when they may lack capacity to decide, and also provides the framework within a code of practice for those supporting someone who lacks capacity. Very importantly, mental capacity is not seen as absolute. It is time- and decision-specific. The MCA has five key principles: a presumption of capacity; supporting individuals to make their own decisions; entitlement to make unwise decisions; acting in the person's best interests; and adopting the least restrictive option.

The Act applies to all professionals and family carers working with people who may not have the capacity to do or decide particular things for themselves. It is relevant to HWC in a number of ways. For more information on its specific relevance to the housing sector, see Appendix 5.

The issues in supporting older people with impaired mental capacity are very challenging and the law in this area is a patchwork. Yet, as Samsi and Manthorpe found amongst the managers they interviewed, only 'five of the seventeen managers interviewed ... said they had mentioned the MCA to their staff, although this was at a general rather than systematic level'.<sup>2</sup> Merely mentioning the MCA does not inspire confidence, let alone failing to mention it at all. Some of the specialist providers have certainly developed policies, procedures and training in relation to the Act, though this writer's own, admittedly random, experience is that knowledge and understanding across both the housing and social care sector is patchy. Knowledge of the Act amongst the general public is likely to be even poorer. Its application in practice, therefore must be in doubt, excepting insofar as acts happen to coincide with pre-existing good practice.

Counsel and Care, as reported by Samsi and Manthorpe<sup>2</sup>, highlight the potential for disagreements and overriding the wishes of older people with impaired capacity:

Enquirers are worried about situations where the wishes and wants of the older person seem to be disregarded in favour of the opinions of professionals (or sometimes other family members) once the older person has been assessed under the Mental Capacity Act Code of Practice as having lost mental capacity for all decision-making.  
(Passingham, 2010)

Not only does this raise concerns that people still interpret the meaning of capacity as an absolute state, but highlights the important role that housing with care staff can play in advocating on behalf of an occupant whom they may have known for a long time, and whose wishes are known and need supporting. For people with high support needs, this tends to apply in two scenarios in particular – moving a HWC occupant with dementia to a more protected environment unnecessarily because a doctor recommends it to the family; and failing to respect the occupant's wishes in the context of end-of-life care and place of death. Taking a stand on behalf of an occupant requires skill, confidence and management support.

## **Conclusion**

Without knowledge of the Mental Capacity Act, it seems unlikely that staff will have the necessary confidence to: 'build capacity' and support occupants to make what decisions they can; know when they are justified in making a decision on someone's behalf themselves; determine when to consult or bring in expert advice; and effectively advocate on their behalf. Essential though training in the provisions of the MCA is, it is insufficient in itself to equip staff. Company ethos, supportive management, appropriate policies and procedures are all important.

## **Communication**

It is generally accepted amongst dementia specialists that the challenging behaviour of people with dementia is an attempt to communicate when they haven't the ability to use the standard modes of communication. This probably applies equally to people with a learning disability or stroke, and perhaps even to those with cultural differences and language barriers leading to the frustration of not being able to make

themselves understood. Samsi and Manthorpe<sup>2</sup> highlight advice from Chapman (2009):

The idea that, because verbal communication may be impaired then all communication is lost, has to be challenged; meaningful communication can still occur. In reality over 80 percent of our communication is nonverbal. Our facial expression, gestures, body posture and whether we make eye contact or not, all communicate something to the person.  
(Chapman, 2009)

Thus, to fulfil the second MCA principle of building capacity, staff need help and support both to understand what a given individual may be trying to convey through a particular behaviour, and tools to assist in communicating with him or her.

Learning as much as possible about an individual – his/her life experience, likes and dislikes – may provide clues to understanding particular behaviours. Although understanding is only the first step, and further skills are needed to deal sympathetically and effectively with that behaviour, it is an important step, and can make the difference between well-being and ill-being in HWC, as in any other setting.

Samsi and Manthorpe<sup>2</sup> point to a review of research by Law *et al.* (2007), who observe:

One of the key features of this group [meaning those with communication support needs (CSN)] is that, unlike those with more visible disabilities, their difficulties are less apparent and less easily recognised by the public. It is often difficult for the general public and service providers, when interacting with people with CSN to appreciate the nature of their experiences, and this can lead to false assumptions about the person's disposition, intelligence and mental health.  
(Law *et al.*, 2007)

To Samsi and Manthorpe, this suggests the value for housing with care services of 'ensuring that people with high support needs are able to access communication specialists from the NHS and for housing with care staff to build up experiences and skills in this area'.<sup>2</sup> Where staff are better equipped to communicate and empower occupants with high support needs, they are in a position to share their knowledge and provide support to family carers.

Some work has been done on specific communication tools, which may be of value in aiding communication – for example Talking Mats®, and CIRCA (a computer interactive reminiscence and conversation aid). These may be helpful to staff in assisting those with limited mental capacity to make individual day-to-day decisions, and engage in meaningful interaction which reduces isolation.

Another challenge for housing with care providers is how to give voice to, and communicate with, older people with high support needs when the usual channels of communication – newsletters, notice boards, meetings, surveys etc – are inaccessible to them, so that in addition to making individual day-to-day decisions,

they have the opportunity to take part in community life and influence community decisions, insofar as they are able. The enriched opportunities programme seems to be a good model for giving people with high support needs more of a voice, and improved quality of life, but there does not seem to be very much research on these matters to inform practice.

## ***Conclusion***

It is difficult to know to what extent HWC staff have had training in communication skills, decision-making, or dealing with challenging behaviour etc. As reported by Samsi and Manthorpe,<sup>2</sup> 'the National Audit Office found that there was little requirement for staff in care homes to be trained in communication' (NAO, 2010). There is no reason to believe the situation is any different or better in housing with care. There is even less evidence available as to the adequacy and effectiveness of training for staff and families where this is available and taken up. Likewise, the adequacy of support. Experience suggests this too is likely to be variable in HWC settings.

## **4. Attitudes to frailty, disability and end-of-life in housing with care**

### **Fit and frail in housing with care**

#### ***The importance of belonging***

Associated with the communication and 'giving voice' challenges outlined in the previous section is another facet important to the quality of life of older people with high support needs – their sense of feeling an accepted part of the community, of being able to participate and benefit from the social life of the HWC scheme.

Callaghan *et al.* (2009), in their study of the development of social well-being in new extra care housing schemes cite the importance of both 'close, emotionally supportive relationships' and 'casual relationships, which provide regular interaction and companionship' as being important for well-being in later life. The opportunity to take part in social activities provides the vehicle for the development of these, and 'research suggests that it is the quality of social ties and the supportiveness of the social network associated with participation in social activities that is related to well-being' (Callaghan *et al.*, 2009).

In housing with care settings, it has been found that people who are less likely to participate [in social activities] and more likely to be socially isolated are more likely to be frail, cognitively impaired or have mobility problems. (Callaghan *et al.*, 2009)

#### ***Tensions between fit and frail***

Various studies identify patterns of prejudice within some housing with care schemes, with the fitter residents displaying resentment and intolerance towards those who are frail and disabled. In a review of relevant literature in respect of housing with care settings, Croucher *et al.* (2006) note that a variety of studies indicate 'prejudice, hostility and discrimination towards those who are disabled'. Those with dementia and learning disabilities are targeted as well as those with visible physical disabilities.

As part of an evaluation of a retirement village which comprised two-thirds fit residents, and one-third with care needs ranging from low level to nursing needs, Garwood (2008) found significant intolerance amongst a group of the able-bodied residents. They voiced the view that there were too many people with care and support needs, and too many people using wheelchairs and electric buggies in the village, putting off visitors and potential applicants. 'We're virtually falling over them' and 'There is a widely held view amongst those who do become more actively involved that [the council] uses it as a dumping ground'. It was not clear how widespread this feeling was, or whether it was just the view of a vocal minority, but they certainly made those with visible care needs feel uncomfortable. Their 'faces didn't fit'. There also appeared to be a class/socio-economic status element to the prejudice.

Croucher (2010) reports similar tensions at the new village development in Hartlepool: 'It is the mix of fit and frail, alongside those whose behaviour is perceived to be problematic, that have caused problems within the community.'

A recent study by Evans (2009) 'describes a mixed picture, with some retirement village residents complaining about living alongside neighbours whom they perceive as 'decrepit', while others are helpful and supportive towards those less able'.<sup>3</sup> Croucher *et al.* (2007) echo these findings: 'The non-disabled people thought the disabled people should be somewhere with more care. Conversely, the disabled people thought the non-disabled people did not need to be in a 'place like this'. In other schemes where a number of people had moved from care homes, 'the integration between fit and frail seemed to work very well'. The picture is not clear cut, with tolerance and intolerance sometimes co-existing in the same HWC schemes.

Percival also highlights 'evidence from research in retirement communities that tenants' attitudes can soften over time as they adapt to living with peers who are more frail, a process that can involve 'fit' tenants assuming the role of helper to those immediate neighbours who are 'frail' (Croucher *et al.*, 2003)'.<sup>3</sup>

Research seems to suggest that there is greater intolerance toward newcomers who don't merge inconspicuously into the existing resident group, than towards those who develop infirmities when already part of that community. Sheltered housing residents 'can show antipathy towards peers with dementia or physical infirmities that require care services, especially when these tenants are new to a scheme and therefore not known as rounded personalities (Percival, 2001)'.<sup>3</sup>

### ***What might tensions signify?***

These dynamics reflect complex social and psychological issues. Percival<sup>3</sup> points to studies of sheltered housing environments that suggest that admitting one's frailty can undermine 'self-image' (Ballinger and Payne, 2002). Percival goes on to say:

Studies indicate that some tenants are put off socialising with neighbours whose disabilities or care needs are visibly obvious. One reason may be that this holds up a mirror of ageing and mortality, that reflects badly on the onlooker and which the onlooker prefers not to see or feels tainted by ... What seems apparent in the literature is that tenants need psychological elbow room and boundary because of their close proximity within the age-segregated community and its effects on their self-identity as an ageing person and also because of a fear that reaching out may have no limits and be taken advantage of in a setting where needs for help are increasing all the time.  
(Percival, 2010)<sup>3</sup>

Croucher (2010) puts forward the notion that retirement communities may not be like 'any other community'. She argues:

... perhaps there is something very particular about 'managing' communities of older people and the opportunities and challenges presented by large-scale schemes such as Hartfields ... We believe it is important to acknowledge that residents are at a certain point in the life course, and that this has influenced their decision to move to such environments, and must shape their expectations and experiences of living in such developments.  
(Croucher, 2010)

### ***Motivations for moving to housing with care***

There are 'push' factors and 'pull' factors motivating people to move to housing with care schemes (Bäumker, 2007, citing Lee, 1996). The primary push factors seem to be different for those needing care than for those who don't – Bäumker found health, access to services, daily tasks and mobility issues featured more highly for the former group than the latter. The pull factors (i.e. what attracted people to move to HWC) were similar for both groups – a combination of features that make extra care distinctive. Litwak and Longino (1987), as cited by Bäumker (2007), identify three stages of old age migration:

Stage 1: Healthy retirees plan ahead, facilities/social network.

Stage 2: Frailer, less independent, increase proximity to family/friends.

Stage 3: Involuntary move, informal care insufficient.

Bäumker (2007) found that overall, residents positively chose to live in HWC; it was not an involuntary move. Some HWC schemes target only those in stage 2 and 3, some primarily those in stage 1 with some in stage 2, and some all three. It tends to be the retirement villages which include significant numbers of those in stage 1, and although it is not totally clear, much of the evidence of fit/frail tensions seems to come from research in these villages.

Studies of ordinary sheltered housing indicate that good neighbourliness and informal care do take place but there is evidence that this outlook will vary according to whether 'fit' tenants perceive the environment as primarily a socially oriented setting or a care oriented one. Tenants of the former persuasion appear to be less inclined to tolerate frailty and its physical manifestations.

(Percival, 2010)<sup>3</sup>

### ***Possible remedies and the role of staff***

Diversity is a key feature of extra care housing in terms of age, care needs, health status, cognitive functioning and aspirations. Social well-being depends on a range of stakeholders understanding and tolerating this diversity, including tenants, family carers and professionals across housing, health and social care. Clear information and good communication are key to achieving this.

(Evans and Vallely, 2007)

Percival draws together other possible measures to achieve greater tolerance: informal gatherings in which various conditions and disabilities are discussed to

engender greater understanding and empathy; the use of different mediums including informal visits, presentations, and accurate and transparent written information for those considering a move to HWC, to maximise the chance of expectations being realistic; taking time to get to know individuals and supporting them to participate; developing links with the wider community to dilute the effects of introversion; and scheme design which facilitates opportunities for different sorts of gatherings.

... staff accept they have a role in managing discord between tenants, of whatever type and for whatever reason, and believe it is important to promptly confront and challenge any anti-social or negative comments.  
(Percival, 2010)<sup>3</sup>

Doing this requires very good inter-personal and community development skills. The skill and ingenuity of the scheme manager and staff are paramount in creating and maintaining an ethos of mutual tolerance and support.

## **Conclusion**

As we know, housing with care schemes vary enormously and it appears that none of the studies identifying these issues has looked at them in the context of a number of variables: size of scheme; ethos and way in which the scheme is portrayed; motivation for moving; and probably most significantly, the spread of fit and frail being targeted at point of entry. A study seeking to identify any correlation between levels of tension and any of these factors would help those developing housing with care schemes to decide which model best met their objectives. It may be that for those older people who already have high-ish support needs at point of entry, a model of housing with care which doesn't also target stage 1 'lifestyle choicers' would offer a better quality of life.

This is clearly an important issue for older people with high support needs, and a two-pronged approach seems appropriate – undertaking research as outlined above, while seeking to develop guidance and a suitable skill mix for HWC staff which will help HWC providers to minimise the risk of these issues, and enable staff to deal with them effectively.

## **Attitudes towards end-of-life**

### ***Impact of loss on occupants***

Percival<sup>3</sup> notes that loss resulting from the death of fellow tenants is 'keenly felt in retirement communities (Bernard *et al.*, 2004) and over time the frequency of loss may become a negative feature in housing with care settings (Croucher *et al.*, 2003)'.<sup>3</sup> The close proximity of death is an inevitable feature in age-segregated settings and affects morale and the atmosphere of the place. However, in addition to the understandable feelings of loss, and reminders of mortality, attitudes probably reflect society's attitude towards death and dying as being a taboo subject. The recent publication of the national *End of Life Care Strategy* (DH, 2008) is seeking to change these attitudes.

## ***A home for life?***

The notion of HWC providing a 'home for life' is not supported by evidence. In Croucher's *End of Life Care in Housing with Care Settings: Update on Policy and Recent Research* (2009) she reports:

Various studies indicated that significant numbers of residents were moving on into nursing homes and other care settings, most usually because their care needs increased, raising questions about the capacity of housing with care to provide end of life care.  
(Croucher, 2009)

For those with dementia, reasons for moving on include, amongst others:

... challenging behaviours and their impact on staff and other tenants; difficulties in providing the necessary levels and flexibility of care in response to increasing needs; availability of resources, including increasing demand for carers' time; the level of community nursing services available to tenants; and choices and preferences of tenants and their families.  
(Dutton, 2009)

In their study on Extra Care Housing and dementia, Vallely *et al.* (2006) identified that 'complexities in how long term care is funded, [in particular accessing continuing care funding in HWC settings] can impede the ability of extra care to provide a 'home for life''. They also found that of the residents who died over the course of the study, 66 per cent were in hospital at time of death. Most had been admitted a few days before they died because of a sudden illness.

## ***End-of-life issues including advance care planning***

Within the wider context of planning in advance under the MCA for a time when one might lose capacity, and general care planning in the context of community care, advance care planning is:

... a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline....and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.  
(Henry and Seymour, 2008)

Much of the research undertaken in this area and mentioned in Samsi and Manthorpe's review<sup>2</sup> appears to be based on residential care. There have been a handful of studies in HWC settings.

Croucher (2009) reports on a study by Crosbie *et al.* *Exploring End of Life Care in the Context of Housing with Care Settings* (2008). They found that residents' understanding of end-of-life issues and advance care planning varied, as did their wish to talk about such issues. Some had discussed their wishes informally with staff but none of the study participants had formally communicated their preferences for

the end of their lives, although they were clear what they did not want. They often reported finding it difficult to discuss such issues with their families. Staff were said to be 'keen to promote the idea of advanced care planning to older people' (Crosbie, 2008, as reported in Croucher, 2009) but were ambivalent about caring for people until the end of their lives. On the one hand they wanted to comply with occupants' wishes but on the other were concerned about the resource demands and lack of necessary skills. Care staff commented on it being demanding and emotionally draining.

*Is it That Time Already?* (Easterbrook and Vallelley, 2008) reports on a six month service improvement pilot project designed to enhance dignity and choice in end-of-life care. This work took place in three Housing 21 HWC schemes. Four key issues emerged during the project and its evaluation:

- promoting dignity and choice for older people and family carers;
- staff support and skills development;
- extra care and its links to wider health and specialist resources;
- commissioning and funding.

Clearly, within HWC, the part to be played by staff members will depend on their role – e.g. care assistant or scheme manager. But each has an important role to play and it is clear that at present few HWC staff have either the knowledge and skills or the confidence to play their part.

At the heart of effective personalisation and partnership working, everyone needs to have a shared understanding of their individual role(s) in helping the tenant achieve what the tenant wants at the end of his or her life ... What appeared to have been holding professionals and organisations back was essentially an uncertainty about what to do for the best, and a fear of doing something wrong. This is a particularly pertinent aspect, given our current overall tendency as a society to avoid talking about death and dying. It is not surprising, then, to find these personal reluctances carried into professional situations.

(Easterbrook and Vallelly, 2008)

### ***Recent housing- focused publications on end-of life and bereavement***

Two recent publications have sought to start filling this gap within the housing sector: H21 and NHS *End of Life Care Resource Pack* for housing, care and support staff in extra care housing (2009), and the *Good Practice Guide 11: End of Life Care and Bereavement* (CHS, 2010), for staff working in the housing sector, both valuable resources. The former focuses on the more direct aspects of caring for someone nearing the end of their lives. The latter concentrates on the potential role and requirements of housing-related support staff and their managers, from planning ahead using the tools of the Mental Capacity Act through to care after death.

## ***Role of housing with care staff***

Once again, the implications for workforce development are clear. In addition to care staff in HWC delivering hands on care to people reaching the end of their lives with external expert advice, HWC staff, if confident and knowledgeable, can facilitate discussion on end-of-life preferences, inform people of their rights and options, provide support, keep appropriate records, advocate on a resident's behalf, make referrals and act as a co-ordinator. They are unlikely to be the people to work with the occupant to develop an advance care plan as such, although this too is possible.

## ***Conclusion***

As Percival says, 'tenants' views and preferences in regard to end-of-life care have to be sensitively ascertained and incorporated in care planning, if the housing with care setting is to offer an individual and personal approach to end-of-life care provision and a home for life in reality'.<sup>3</sup>

The two studies into end-of-life care mentioned earlier were relatively small in scale. Percival concludes:

A more robust evidence base about housing with care would include greater attention to the setting's potential to provide end-of-life care ... For example, we do not yet know enough about how death and dying is experienced or dealt with in housing with care settings. Furthermore, we need to understand residents' information and support requirements when they are emotionally affected by a fellow tenant's end-of-life condition or death. We also need to know more about how housing with care settings can best bring about a culture of openness and good practice that encourages staff to carefully listen, ask open-ended questions and provide individual care that is attuned to the tenant's personality, life history and preferences.  
(Percival, 2010)<sup>3</sup>

## **5. Workforce issues in housing with care for older people with high support needs**

### **Housing with care: a unique hybrid**

As outlined in the introduction, housing with care is a unique hybrid which seeks to combine independent living with the availability of care and support round-the-clock. Many people living in HWC may be vulnerable and a balance needs to be struck for each individual between maximising autonomy, voice, choice and control on the one hand, and safeguarding, help and support on the other. Whilst HWC has features in common with both residential care and mainstream/sheltered housing, it also has aspects which make it distinctive.

### **Diverse disciplines, distinctive features**

#### ***Who are the staff in housing with care?***

Most housing with care schemes are staffed by people from a range of disciplines and professions. They manage and deliver at least two, possibly three fundamental components: housing/scheme management, housing-related support, and more general support and care. While the core of each of these activities is relatively clear-cut, the boundaries between them are quite blurred, and they are configured within HWC schemes in many different ways.

Housing and facilities management is generally undertaken by housing providers, but in HWC schemes they typically do much more than that. Currently many schemes provide 'housing related support' (or Supporting People services) delivered either by the housing or on-site care provider or both. A domiciliary care provider registered with the Commission for Social Care Inspection or Care Quality Commission usually provides round-the-clock care or support in an emergency. Up until now, this provider has also delivered care plans, ideally in a more flexible and responsive way than has been possible in the dispersed community. All these services may be delivered by a single organisation using an integrated management approach or by two or three separate organisations.

Included in the mix is facilitation of activities and community development, a very important aspect of most HWC schemes. Then there is a range of personnel undertaking any number of additional activities depending on the scale and model of the development – e.g. catering, cleaning, hair dressing, gym instruction, reception etc.

### ***Social care sector***

Care in HWC schemes fall into this category. As Manthorpe and Moriarty identify, with the recent development of a National Minimum Data Set for Social Care, the setting in which the care takes place can be identified (though it is not clear if HWC is a separate category), but there is difficulty 'distinguishing people with high support needs from others using care and support services'.<sup>4</sup> However, it may be safe to

assume that most of those in receipt of care in HWC have relatively high support needs, since fair access to care services (FACS) thresholds at substantial and critical are likely to have been applied.

A challenge facing the social care sector is the recruitment and retention of staff. Manthorpe and Moriarty highlight that the sector is characterised by low wages, high vacancy rates, and a shortage of suitably qualified applicants: 'It would be interesting to see if housing with care shares a general pattern of shortages and skills deficits'.<sup>4</sup> Most of the direct contact workforce are women, many working part-time. There is a strong reliance on migrant workers and 'there are concerns that new immigration controls may continue to restrict entry from outside the EU and that familiarity with local idioms, English language and care practices may be limited (Sale 2005; Smith *et al.*, 2008; Hussein *et al.*, 2010)'.<sup>4</sup>

In a separate management and service delivery structure, care providers in HWC need to work very closely with housing and support providers to deliver a cohesive service. In the best schemes they work as a team to synergistic effect, with the interests of the occupants taking centre-stage. Thus, in addition to all the standard care competences, they need to understand the ethos of HWC, and how it differs from working in someone's own home in the wider community, or in residential care.

### ***Housing provider***

The housing provider is frequently the manager of the HWC scheme and has the responsibility for working with the community to empower occupants, maintain community cohesion and harmony, and ensure the scheme is part of, and not isolated from, the wider community. He or she needs to work closely with staff from all other organisations to co-ordinate services and achieve jointly agreed outcomes.

Preliminary findings of the National Evaluation of Extra Care by PSSRU at the University of Kent indicate a high management turnover in retirement villages in particular, suggesting that recruitment and retention of people with the required skills is not easy. There is no obvious skill set or professional pool to draw on.

(Croucher, 2010)

### ***'Support' staff***

As clarified in the introduction, the term 'support' tends to be used in a number of different ways. Whoever provides it, general and housing-related support are part and parcel of the mix in most HWC schemes, and are an important filler between scheme management and care.

In a review of the use of the term 'support workers' Manthorpe and *et al.* (2010) observe that the term is being applied to a very wide range of roles and that the addition of, say, the word 'housing' to the term 'support worker' does not necessarily mean that there is any greater clarity of role. For people with high support needs a variety of terms such as 'care worker', or 'senior care worker', may be in use and the use of the term 'support worker' may be highly misleading. Manthorpe *et al.* (2010) recommend far greater clarity of

roles in the sector, highlighting the risks that may emerge if there is misunderstanding about a worker's level of skill and competence, or ambiguity about their role.

(Manthorpe and Moriarty, 2010)<sup>4</sup>

What is clear, however, is that 'support' workers may not provide *personal care* without registering with CQC (with certain key exceptions, e.g. personal assistants paid for privately or under direct payments), and providers of Supporting People services specifically have a relatively defined and narrow remit which excludes personal care. These are currently covered by the Supporting People Quality Assessment Framework (QAF).

## **Workforce requirements to support diverse older people in housing with care**

If there are to be even higher levels of disability and ill-health among new residents/tenants and if there is to be a reduction of care home places and consequent delay in entry to care facilities, then there may be higher expectations that housing with care workplaces will be ready to cope.

(Manthorpe and Moriarty, 2010)<sup>4</sup>

Previous sections of this paper have highlighted issues in relation to older people with high support needs. Staff need to have a good awareness and understanding of the cultural differences between people of different religions and ethnic backgrounds. They need to be sensitive to the issues faced by people who are lesbian, gay, bisexual or transgender. They need a much better understanding of mental health problems in older people, in particular dementia and depression. Increasingly, they will be supporting people who have both a learning disability and dementia. They need to be familiar with the provisions of the Mental Capacity Act both in terms of advance planning, and in working with people who lack the capacity to make certain decisions. They need more help in dealing with challenging behaviour and communicating with people for whom a conversation is not straightforward. They need to be alert to signs of multiple, including sensory, impairment.

In order to deliver holistic care, staff would benefit from selective training in certain low level health tasks such as applying ointments. Given that we are seeking to improve the lives of people who are elderly and have high support needs, an understanding of end-of-life issues, and advocating on residents' behalf to die well – as well as live well – in a place of their choosing, is fundamental. Safeguarding is another important area in housing for very vulnerable older people. Skills are needed to deal with community tensions and facilitate links with the wider community. Vital too are skills in enabling frailer individuals to have a voice and be actively involved, and in building communities that do not isolate and ostracise its frailer members.

## **Distinctive profile**

The implications of the above for the workforce in HWC are clear. While the knowledge and skills needed by staff in HWC are not unique, their combination is distinctive and in some respects different from both residential care and mainstream or sheltered housing. Irrespective of the particular posts in which these knowledge

and skills are located, if HWC is to improve the lives of people with high support needs, whilst preventing them from having to move to other care settings, we do need to see a skilling up of the workforce in these areas. Some documents exist which focus specifically on the workforce in HWC, but they are limited in detail and do not focus on the particular areas of expertise triggered by people with high support needs. Examples of these are the *Extra Care Housing Toolkit* (CSIP, 2006) and the *Housing Learning and Improvement Network (LIN) Factsheet No. 9 on workforce issues in HWC* (Shipleigh and King, 2005).

## **Developing a set of core competencies**

Crucially, it is not only care staff who need such knowledge and skills. In terms of standard setting and regulation, care staff fall under the jurisdiction of the Department of Health, Skills for Care and the Care Quality Commission. The housing sector (including housing-related support) is not covered by these. Communities and Local Government, Asset Skills, and the Tenant Services Authority (as well as Supporting People Administrative Authorities and QAF for Supporting People services) appear to be very approximate equivalents. Housing National Occupational Standards include some elements which relate to vulnerability, but this focus is limited. Not all scheme managers will have a housing qualification, and even if they did, it may not equip them for the challenges of housing very vulnerable older people. Yet, particularly in models where housing sector staff have high profiles in HWC, they have the power to improve or diminish the quality of life of the people living there by their attitudes and actions. In some schemes, the 24/7 cover is provided by support agencies who are not registered to provide care at all. So it is a mistake to concentrate only on the knowledge and skills of care staff.

Whilst not all staff members need the same level of knowledge and skills, there should perhaps be a baseline level of competences for key personnel working in HWC. Additional skilling would then depend on the profile of the particular resident or target group, and the particular role of the staff member. There is little doubt that whether a worker is generic or specialist, the better their knowledge and understanding of the key issues faced by older people from a range of disadvantaged groups with high support needs, and how best to support them, the better the lives of those older people are likely to be. It also appears to be the case, although this is worth testing out, that staff working in specialist schemes (e.g. dementia) tend to be better equipped to work with their occupants than their counterparts in generalist schemes. Some large housing with care providers have specialist advisers, for example in dementia. Anecdotal evidence suggests they help to raise standards, but the writer is unaware of any systematic evidence to this effect.

Manthorpe and Moriarty suggest that 'one key area for research could be to assist in the development of a consensus about the skills and competencies of housing with care staff'.<sup>4</sup> There does seem to be a good case for pulling together the key knowledge and skill requirements in HWC schemes to support those with high need levels. Core competences could be developed using existing suites of national occupational standards as a starting point, picking out those relevant from both care and housing sets, and identifying any that are missing. An accompanying handbook

which includes good practice tips and signposts to other sources would be a valuable addition.

## Training

Training is seen as the answer to almost all the problems of social care, including difficulties of the social care workforce (Manthorpe, 2008). It is cast as a way of improving recruitment and retention and of ensuring that workers have the skills to meet the demands of their role. Of course, it is not a 'magic bullet' as the provision of training may not be enough on its own to improve the quality of care (Wanless, 2006) but, for a number of reasons, training is seen to be crucial.

(Manthorpe and Moriarty, 2010)<sup>4</sup>

As Manthorpe and Moriarty point out, training is not a 'magic bullet' and 'many direct care workers may lack some of the skills needed to learn effectively'.<sup>4</sup> She also raises the issue of funding for training and whether it will be sufficient to meet requirements.

This writer's perception is that within HWC, training routes and qualification requirements vary. Some care, housing and housing-related support providers offer relevant training in-house, as do a range of other organisations, but the picture is patchy both in terms of offer and take-up, particularly in those areas necessary to support those with high need levels effectively. Although the focus here has been primarily on support skills broadly defined, housing management and housing-related support specifically are also important because they help to reinforce that this is indeed a housing model, not an institutional one. Where several organisations work together in a HWC scheme, joint induction and training helps to clarify roles while encouraging effective joint working.

## Support and leadership

Defining core competences and providing training is important but not sufficient if we are to see the workforce contributing effectively to improving the lives of older people with high support needs. Leadership and support from management is also essential.

Recent consultations with front-line workers in dementia services reveal that they feel that they receive little managerial support in their day-to-day practice. JRF (2009b) concludes that because work with people with dementia is emotionally demanding for both staff and managers, training will not be effective on its own. JRF's view is that 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 would be worth investigating (JRF 2009b).

(Samsi and Manthorpe, 2010)<sup>2</sup>

Brooker *et al.*'s research (2009a) endorses this view and Dutton (2009) identifies strong management and leadership as one ingredient that has been shown to 'effectively enhance the quality of life for people with dementia living in extra care

settings'. The same is almost certainly applicable to staff working with all older people who have high and complex support needs.

## **Key questions for commissioners**

Manthorpe and Moriarty<sup>4</sup> identify four key questions for commissioners in the context of personalisation and the reprovision or closure of care homes:

- the impact of personalisation;
- evidence that housing with care can meet desired outcomes;
- greater clarification of expectations of the role of staff in the context of extensive variations, including funding levels and sources;
- the role of assistive technology.

## ***Personalisation and service configuration***

Manthorpe and Moriarty<sup>4</sup> mention a number of possible effects of personalisation on the workforce, some positive, some less so. In the context of HWC, a key question is how changes in the way the support services are commissioned and configured in housing with care settings will affect the quality of the service. Hitherto, the most usual approach has been for Adult Social Care to procure a single domiciliary care provider through a block contract to deliver both emergency and planned care in a HWC scheme. While this approach has certain downsides, it was arguably cost-effective and enabled the provision of a flexible, responsive and co-ordinated service.

The personalisation agenda provides an extra imperative to deliver person-centred support which responds to the wishes of individuals, and ensures they have the opportunity to exercise as much choice and control as they wish, and for which they have the capacity. Truly personalised services should contribute significantly to making the lives of older people with high support needs in HWC schemes better. This writer's perception is that most HWC schemes present themselves as providing support in this way but there is much scope for improvement.

With the implementation of personal budgets, care and support in HWC, like all other support commissioning, is in a state of flux. There seems to be a move within HWC towards the minimum core of 24/7 cover being commissioned by Adult Social Services, with occupants using their personal budgets to buy planned support from the provider of their choice. Whilst this maximises individual choice, it is not yet known in what direction the choices made will take HWC. Most residents may choose to use the on-site provider, but there is a possibility that there will be many support providers coming in to HWC schemes to provide support to individual occupants. If this turns out to be the case, the result is likely to be a fragmentation of the service with less flexibility, responsiveness and co-ordination. Such a service configuration may disadvantage certain older people with high support needs, for example those with dementia. There may also not be a consistent staff group upon whom to focus the detailed training outlined earlier. 'If care teams become fragmented, will training and skills development wither away?'<sup>4</sup>

## ***Meeting outcomes***

Manthorpe and Moriarty suggests that good use could be made of the National Minimum Data set if HWC providers recorded training and staffing data, and sought to influence Skills for Care 'to refine data collection to make it more relevant if necessary'.<sup>4</sup>

On the broader subject of outcomes, there is currently very little robust information on the cost-effectiveness of housing with care, an area of research made extremely complicated because of the challenge of developing robust costing models, and the huge variations in housing with care schemes making generalisations difficult. The Personal Social Services Research Unit (PSSRU) has done some work in this area and continues to do so.

## ***Loss of Supporting People ring-fence***

A further unknown is the impact that the absorption of Supporting People funding into area-based grants will have on the funding of support in HWC, and therefore the focus on lower level preventative and independence-boosting approaches.

## ***Assistive technology in housing with care***

There is one further area which bears consideration in the context of improving the lives of older people with high support needs in HWC – the role of assistive technology. Studies of care in HWC, as in residential care and standard domiciliary care, highlight the often rushed and task-focused nature of the care delivery contacts. Assistive technology devices may have the potential, if used ethically, to free up time for more meaningful contact between carer and cared for. More than that, it has the potential to reduce intrusive checking, increase levels of freedom and independence for people with dementia, and reduce risk. Whilst devices such as occupancy sensors, exit monitors, safety plugs, fall detectors etc are being introduced into Extra Care schemes, we do not know how systematically this is the case, what safeguards surrounding their use are put in place, nor how effective the outcomes are. Furthermore, Manthorpe and Moriarty point out that 'workforce needs and capacities are underdeveloped here'<sup>4</sup> and cites Tinker *at al.* (2007), who 'caution that all such technology needs to have able but also willing staff to operate such systems'.<sup>4</sup>

## **Conclusion**

On the subject of workforce issues, Manthorpe and Moriarty conclude:

... if current policy to reduce the reliance on care homes (DH 2009b; HM Treasury, 2009) by English local authorities continues, then there may be opportunities that housing with care employers may wish to consider. These include; raising the quality of staff recruited (seeking specific evidence of skills, achievements and experiences); considering specific skills gaps in work units or teams; deciding upon a refresher or transfer model of training or induction to transmit values to and share learning with staff who are being

recruited from other sectors. Engagement with any new NVQ curricula seems imperative.  
(Manthorpe and Moriarty, 2010)<sup>4</sup>

Within what appears to be a thorough review of relevant literature, Manthorpe and Moriarty have identified only a small number of research studies which include a focus specifically on workforce issues in HWC. Research into the home care and residential care workforce cannot be assumed to apply in all aspects to HWC staffing and excludes a significant swathe of the HWC workforce. Manthorpe and Moriarty ask:

How far can studies relating to the workforce and its performance in care homes be inclusive of housing with care? And if they are, can they compare the two approaches rather than assume them to be the same? ... How can research on the social care workforce (which is extensive) be of greater use to housing with care stakeholders? (without presuming that the workforces are identical or unique)?  
(Manthorpe and Moriarty, 2010)<sup>4</sup>

So, could the JRF Better Life programme do anything to exert influence on these matters at national level? And could the programme fund the production of material that recognises the unique position of HWC in meeting high support needs of older people, developing a set of core competences and guidance?

## 6. Possible focus for projects

The following is a list of important issues emerging from this paper:

### Diversity

#### BME

- How do we reach out and get information to BME older people?
- Research into different models of HWC for people from different ethnic groups.
- Are there transferrable lessons across the range of BME communities with regard to HWC?

#### Sexuality

- Can we help raise awareness and understanding amongst HWC staff?
- Is there a need to try to influence policy amongst housing providers to introduce greater flexibility and discretion in succession rights in HWC?
- Research into different models of HWC for lesbian, gay, bisexual and transgender (LGBT) older people.

#### Poverty

- Any way of improving accessibility of information and advice on benefits?
- Asset rich, cash poor – developing and promoting alternative funding models.

#### Learning disability

- Any way of getting commissioners to improve inclusion of this group in strategic planning?
- Development of funding and home ownership options.
- Research into housing with care model preferences.

#### Dementia

- Improving practice in HWC schemes.
- Research into pros and cons of different models of HWC for people with dementia.
- Research into strengths and limits of HWC for people with cognitive impairment and challenging behaviours.

#### Functional mental health problems

- Raising staff awareness and understanding.
- Research into HWC model preferences.

#### Sensory impairment

- Raising staff awareness and understanding.

#### Homelessness

- How many older people are homeless or at risk of being homeless?
- Research into the type of provision best suited to meet the needs of older homeless people with high support needs, especially drinkers.

### Diversity general

- A project aimed at improving dialogue between ‘the industry’ and people representing disadvantaged and hidden groups, to raise awareness, access and acceptability of HWC.
- Staffing to reflect diversity – how?

## **Decision-making and communication**

### Capacity

- Need for greater awareness of the Mental Capacity Act at all levels.
- Research into level of management support given to staff trying to advocate on behalf of frail older people.

### Communication

- Inclusion of communication skills and tools, understanding dementia, and dealing with challenging behaviour in core competences and training programmes.
- Research into how to give greater voice to people with high support needs who are likely to be marginalised.

## **Fit, frail and end-of-life**

### Fit and frail

- Research into the distinctive characteristics of managing communities of older people.
- Need for inclusion of inter-personal skills and neighbourhood and community development skills in core competences, and a knowledge and skills handbook (see workforce issues).
- Research into the impact of different scheme features on levels of tolerance and intolerance, and whether therefore, some models of HWC are better suited to those with high support needs than others.

### End-of-life care

- Need to raise awareness, understanding and confidence – include in core competences and handbook.
- Research into how death and dying impacts on staff and occupants, and is dealt with in HWC.

## **Workforce**

- Seek to influence relevant bodies across housing and care to work together to skill HWC staff appropriately, and development of HWC standards.
- Pull together all the distinctive skill and knowledge requirements of HWC into a set of core competences.
- Develop an accompanying handbook giving basic guidance and signposting to other sources of information and training.
- Research into the number and composition of the HWC workforce.
- Research into available training.
- Research into the effect of personal budgets on service configuration in HWC and impact on older people with high support needs.

- Does the use of assistive technology in HWC improve the lives of older people with high support needs? Which sorts of high support needs?

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*These are split between the five expert reviews and other sources. The other sources are either referred to directly by the writer of this paper, or via one of the expert review authors. Where the latter applies, the accuracy of the citation rests with them. All direct quotations from the expert reviews are clearly marked.*

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## **Appendix 1:**

# Access and diversity in housing with care

**Nigel King and Jenny Pannell**

## Executive summary

This is a review of what we know and do not know about access to extra care housing (HWC) by older people who risk being marginalised or discriminated against. It covers ethnicity, sexuality and a range of mental health problems and disabilities. The paper draws on a selection of studies, contributions from practitioners and interviews with experts.

This summary concentrates on cross-cutting issues and themes. Details on seven different groups appear in subsequent sections.

In considering different groups who may find barriers to accessing HWC, it is striking how:

- often those at risk have multiple needs and could appear in several or even all the groupings used;
- broad categorisations are of limited use and can be misleading, because within any group there is considerable diversity.

## What we know

Diversity factor	Specific guidance on HWC	Design knowledge HWC	Examples of specialist HWC	Examples of improving access to mainstream HWC
Ethnicity	Yes	Yes	Yes	Yes – in some areas
Learning Disability	Yes	Yes	Yes	Yes – examples in a few areas
Mental Health	Yes, particularly dementia	Yes	Yes	Yes, but a debate
Poverty	No	n/a	n/a	n/a
Sensory impairment	Yes	Yes	Yes	Yes
Sexuality	Very little	No	No	No
Complex needs/ homeless	Very little	Very little	Yes – very few	Yes – examples in a few areas

## **Overall issues across different needs groups**

For older people with high support needs across our groups, opportunities to benefit from HWC will depend on the following factors identified in studies or raised with us during our review:

- Is HWC available?
- Are they aware of HWC and can they get adequate, understandable information and advice?
- How do they access HWC?
- Is HWC acceptable to them?
- Is HWC affordable for them?

Taking each broad question, it is possible to spell out in some detail the key questions relevant to marginalised or more vulnerable groups.

### ***Availability***

- Is there any HWC in their locality, and in the right local area?
- Is there specialist HWC to meet their preferences in their locality, or are they prepared to move to another area to access specialist HWC?
- Is there generic HWC which is welcoming and accessible to them?
- Is the HWC mixed tenure (rented, and shared and outright ownership) or is it only for rent, or only for sale?
- Is there sufficient HWC to make it available within a suitable timeframe?
- What steps are being taken to provide or increase HWC options, and are marginalised groups included in this process?

### ***Awareness raising and information and advice (I&A)***

- Does the older person know about different HWC options?
- Do friends/family/carers (if any) know about HWC?
- Do their community and social networks know about HWC?
- Do they, or people supporting them, have internet access?
- Is specialist or generic I&A available on HWC and related issues, and are they (or people supporting them) aware of I&A services?
- Are there local partnerships to improve I&A e.g. Age Concern working with BME groups?

### ***Access***

- Is the older person known to professionals (e.g. health staff)?
- Do these professionals know about HWC?
- Is there a robust and effective multi-agency referral system into HWC?
- If access is controlled by a panel, does it encompass consideration of alternative needs in addition to age?
- Has there been planning for individual future needs (housing, health, care)? e.g. for older learning-disabled person living with family carer

- Are older owner-occupiers excluded because of housing allocation policies?
- Are older people excluded because of stereotyped assumptions (frontline staff, or strategic planning)? e.g. 'Asian families look after their own'.

### **Acceptability**

- Would the older person prefer specialist HWC for people with similar needs/backgrounds/lifestyles?
- Is generic HWC welcoming and accessible to them?
- Will they be the only person from their background in a generic HWC scheme?
- Do existing residents and staff reflect diversity?
- Are visitors made to feel welcome? e.g. lesbian/gay friends visiting
- Do published materials, e.g. brochures and notice boards, show sensitivity to diversity issues?
- Are there other aspects showing diversity? e.g. amongst non-residents using restaurant.

### **Affordability**

- Is expert advice available on welfare benefits?
- Will housing and care costs be met by benefits or will the older person have to self-fund some or all of these costs?
- Will future service charges/rent and care/support charges remain affordable?
- Is practical support and financial help available for moving e.g. through Home Improvement Agency?
- Does the older person have savings or equity to pursue ownership options?
- Is there mixed tenure HWC (rent, sale, shared ownership) locally?
- Is independent advice available on financing ownership, including advice respecting cultural issues e.g. Sharia finance?

### **What we need to know more about**

For most groups considered, there is:

- debate about whether to develop specialist or exclusive schemes (or parts of schemes) or to facilitate access to mainstream HWC. This is especially in relation to dementia, learning disabilities, gay/lesbian, complex needs and some ethnic groups;
- a good deal of information on design and good practice but a question about the extent of actual adoption on the ground;
- demand for specific training and better awareness and sometimes additional specialist resources to add to skills-set of staff;
- demand for better, clearer information on HWC; confusing, inconsistent terminology can be a barrier to access.

For some groups there are as yet few or no specialist HWC schemes especially learning disability, gay/lesbian and complex needs. This is partly because of the

conflict between the scale of development required to run a cost-effective HWC scheme and the relatively small number of people in any one locality. One of the useful areas of future study and/or dissemination of expertise is around how best to achieve economic development and care or support services, including meals, in small scale HWC.

In considering affordability:

- There is an absence of thorough cost-benefit analysis of HWC to allow policy-makers to judge this option against others, or to help people with personal budgets make well-informed choices. Studies available are generally small scale, sometimes with arguable methodology. This is a general observation but possibly more significant for many of those considered here because costs of individual care tend to be higher, particularly for those with mental health problems, complex needs or learning disabilities.
- There is scope for exploring alternative funding models to match the circumstances of some groups and extend their options. This includes those who are more disabled, as well as older people who are simply 'asset rich, cash poor'.
- There have been several high levels reviews of the Government's Low Cost Home Ownership Programme<sup>1</sup> in England over the last decade, but no detailed thought (indeed hardly any attention at all) to contemporary low cost ownership models for older people. For example, the Homes and Communities Agency rules and leases give shared owners the right to staircase up, but for older owners a right to staircase down would be more relevant, similarly models that enabled older people to trade equity for care in social housing.

Several experts suggested that the HWC allocation process, whereby a panel make the decisions, tended to exclude many of the more marginalised groups. They argued that pressure on adult social care from hospital discharge and demographic changes meant HWC, whatever the policy on maintaining a mixed community might be, would increasingly be used as an alternative to residential care. As panels are strongly influenced or led by representatives from the local authority older people's team they were more likely to prioritise their 'cases' and be unaware of or give less weight to older people that might come through other routes such as the community learning disability or mental health teams. It was also suggested application forms and criteria failed to adequately recognise the needs of some groups, including those with sensory impairments. How allocations work for marginalised groups is a potential area for study.

## Introduction

This is one of a series of short reviews commissioned by JRF to support a programme of work to ensure 'a better life and better choices for older people who need high levels of support'.

The brief was:

- to pinpoint what we know and do not know about access, acceptability and affordability of housing with care (HWC) for marginalised groups;
- to comment on effectiveness of different approaches to improving access and equality, and the key questions around funding and commissioning.

The primary purpose of the review was to guide decisions on future JRF work.

JRF was particularly interested in:

- ethnicity;
- sexuality;
- poverty;
- learning disability;
- mental health issues;
- sensory impairment;
- older homeless.

## Method

This commentary is based on:

- illustrative studies about older people in the marginalised groups listed;
- contributions following an invitation to provide data, views or examples distributed by the Department of Health (DH) to local authorities and HWC agencies;
- telephone interviews with relevant experts;
- the authors' previous work in connection with housing for marginalised groups.

## Terminology

Housing with care and extra care do not have a statutory definition. The terms here are used to describe developments specially designed for older people, which offer self-contained accommodation together with 24 hour care and a wide range of shared leisure and other facilities on site, with some meals provision.<sup>2</sup>

# Ethnicity

## What we know

- In the UK, there are about 4.5 million people from a BME background (7.9 per cent of the population).
- Eleven per cent of the UK's Black-Caribbean population are aged over 65 and 7 per cent of the UK's Indian population are aged over 65.
- By 2030 the BME older population within UK will have increased tenfold from 175,000 to over 1.7 million.

Source: ONS Social Trends 2006, Table 1.5

Awareness has been growing about the increasing number of Black and Minority Ethnic (BME) older people and their future needs. There have been detailed studies by the Policy Research Institute on Ageing and Ethnicity, University of Leeds, and by JRF. Organisations and groups such as the Black and Minority Ethnic Elders Group, Scotland, and the Chinese Housing Consultative Group bring together older people from diverse or specific cultural, religious and ethnic origins. The direction of travel is clear – this is an issue that needs addressing, and there have been many initiatives and research – but local implementation still appears to be patchy.

The Housing Learning and Improvement Network (LIN) website includes a section on BME and HWC with links to work including:

- Research on housing needs of specific groups e.g. South Asian older people (Patel *et al.*, 2008) and in localities e.g. Bristol (Smart, 2005).
- The development of specialist HWC schemes e.g. African Caribbean, South Asian, Irish, Jewish.
- Tools to help commissioners measure needs and develop strategies e.g. The *At Home* toolkit (HOPDEV, 2006).
- Advice on scheme design for BME older people in sheltered housing and (forthcoming) HWC.

Specialist schemes for BME older people have been developed in areas of higher population density. In areas with more mixed communities or fewer BME older people, the emphasis has been to improve access more generally to all HWC schemes. Both approaches are discussed in *Developing extra care housing for BME elders* (Patel and Traynor, 2006). This summarises key issues and provides a self-assessment checklist for commissioners and providers. It also emphasises the importance of information and advice, so that BME older people understand their options, otherwise, as one older person is quoted, it's 'Don't know, don't hear, don't get'.

Some local Age Concern BME projects include information and advice (I&A) and advocacy. Recent research on the I&A needs of BME older people included focus groups with Vietnamese, African Caribbean, Iraqi and South Asian older people, and found they lacked access to I&A for housing, social care and other services (Zahno and Rhule, 2008). It draws on wider work for JRF on I&A and advocacy for older people (Dunning, 2005).

Age Concern England commissioned research on HWC and care homes for BME older people (Jones, 2006). It identifies key issues, good practice, and gaps in research and services. The evaluation of the HACT Older People's Programme also found that BME and refugee older people remain hidden from, and unaware of, mainstream services (Riseborough and Fletcher, 2007).

Further studies include:

- *Multi-Cultural Services and Design within Extra Care* (Hanover, 2009, for future publication)
- How BME older people access housing (including HWC) and how to improve access: University of Birmingham for Nehemiah UCHA (a BME Registered Social Landlord), five West Midlands local authorities and DH Housing LIN (work in progress).

## **What we need to know**

A systematic literature review by the Centre for Housing Policy, University of York (Croucher *et al.*, 2006), concluded that 'The UK evidence base tells us little ... about how well different models of housing with care work for different ethnic groups.'

We need to know more about differences, similarities and transferable lessons across a wide range of BME communities, which include:

- long-established communities, including black and mixed-race (e.g. Liverpool, London, Cardiff), Gypsies and Travellers;
- migrants from the Commonwealth and elsewhere;
- refugees and asylum seekers (including older Jews and Poles who arrived in the mid-twentieth century, and more recent arrivals e.g. from the Balkans, Africa, Middle East);
- recent arrivals from Eastern Europe.

There may be scope for sharing ideas across BME groups. For example, one respondent spoke of inter-faith links with the Muslim community, who want to learn from a planned Jewish HWC scheme in Bournemouth. Common interests include design issues linked to religious requirements (e.g. kitchen to prepare kosher or halal meals), and a day centre providing a hub for isolated older people and also familiarising them with HWC.

There has been work on spirituality and older people.<sup>3</sup> Respondents suggested that very old people may become more interested in their faith and returning to their roots, linked to cultural norms (e.g. burial customs).

# Sexuality

## What we know

This section discusses issues concerning older people who are lesbian, gay, bisexual (LGB) and sometimes transgender (LGBT). Not all work includes transgender people, because many issues (including legal position regarding discrimination) are different. In this section we distinguish between work on LGB and LGBT.

There are no exact figures, but using the estimate of 5–7 per cent of the population would give a figure of 1 to 1.4 million LGB people aged 60 or over by 2031 (Musingarimi, 2008a).

Despite work by a few agencies since the 1990s, there has been a general lack of awareness and research on LGB(T) compared to other minority groups discussed in this review.

Opening Doors,<sup>4</sup> Age Concern England's programme of work for and about LGB older people, describes the current position:

The situation for most lesbian, gay and bisexual people ... is more positive, secure and affirming than ever before. However, ... older people have lived a large part of their lives in less liberal times and their experiences have made them understandably wary and cautious. In practice, this means [they]:

- Are less likely to access services;
- Face a number of unique problems as they age, from the attitudes of mainstream providers, who regularly assume all the older people they serve are heterosexual; Have significantly diminished support networks in times of crisis.

There are specific issues that affect LGBT older people and their ability or desire to access HWC:

- Difficulties with inheritance and passing on property (owner-occupied or tenancy) between partners, especially those with no civil partnership; this reduces opportunities to use equity to purchase HWC and can lead to homelessness.
- Limited housing/care choices in later life: fear of discrimination and fear of disclosure in mainstream provision; lack of specialist provision.
- Different living and family situations: LGB older people are much more likely to live alone, have no adult children, and risk isolation in later life; if they do have 'families of choice' (partner, friends), these may be excluded from their care and support.

The main study, *As we grow older* dates back to 1995 (Hubbard and Rossington, 1995). The study surveyed 131 lesbian and gay older people: it pre-

dates HWC, but some respondents clearly described something like HWC as their ideal:

Flats with warden and call system and a nursing home attached. Communal facilities ... restaurant ... complementary medicine and holistic nursing care (Female, 59, participating in *As we grow older*, Hubbard and Rossington, 1995)

Many respondents were worried about going into a mixed care home, and some found it difficult when there:

I don't think my care home is a particularly easy place for a gay man to live ... I have to be discreet ... my gay friends tend not to visit me any more, not being made to feel welcome and also feeling that it could make life difficult for me.

(Male, 88, participating in *As we grow older*, Hubbard and Rossington, 1995)

This fear was voiced in two more recent studies in England and Scotland, though with small samples (Croucher, 2008; Communities Scotland, 2004). *As we grow older* also found a preference for lesbian or gay specialist accommodation amongst 83 per cent of all participants (91 per cent of lesbian women). However, the Scottish and English studies found most respondents preferring improved mainstream services to help them remain in their own homes as long as possible.

People with different sexual orientation ... this is less talked about with the current client group, however as awareness is raised and customers feel more comfortable, it is becoming increasingly more prevalent. Access could be improved in the future ...

(Large National Registered Social Landlord)

In 2008, Stonewall Housing, Age Concern England (now Age UK) and Polari (succeeded by Age of Diversity) worked with the International Longevity Centre UK to produce short UK-wide policy guides (Musingarimi, 2008a, 2008b, 2008c, 2008d).

Recent good practice guidance applying to HWC includes:

- Guidance and advice on the Opening Doors website (Knocker, 2006) on meeting the needs of older LGB people living in care homes and extra care housing.
- A checklist for organisations to improve services and increase access (Communities Scotland, 2005).

## **What we need to know**

There is a need for more UK-wide primary research on the housing, care and support needs of LGBT older people, to update and develop the 1995 study. The International Longevity Centre – UK guides confirm the lack of research (Musingarimi, 2008a; 2008b, 2008c, 2008d).

There are new developments in joint agency working, with plans for regular meetings between Stonewall Housing, Age UK and Age of Diversity on older LGBT housing and support needs. This would provide a forum to clarify the best way to research the diverse LGBT population. This would need to include older people with more than one diversity (e.g. BME and LGBT), and could examine the merits of different HWC solutions.

# Poverty and affordability of housing with care

## What we know

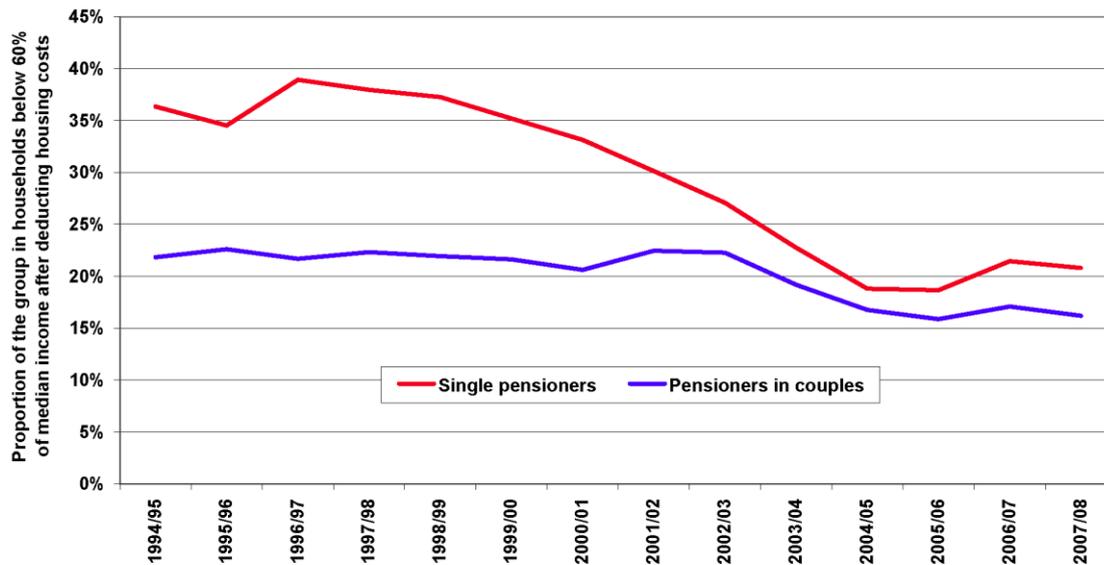
A broad definition of poverty involves not only financial hardship but also limited social participation and social exclusion. Poverty in later life is often a result of poverty before retirement (for example no occupational pension; no housing equity).

Recent changes to the benefits system should have significantly increased the income of older people. Pensioner benefits have increased ahead of earnings and more than benefits for others. Overall, the number of single pensioners and couples in poverty has declined (Palmer *et al.*, 2008), but:

- Improvements have relied on people claiming means-tested and disability-related benefits, but there is still significant under-claiming.
- Over the past ten years the rate of benefit take-up has worsened.
- Poor take-up is known to be a particular problem for marginalised groups.
- The benefits system remains complex (despite some improvements) and disadvantaged groups face further barriers (e.g. language, no phone, illiteracy).
- BME pensioners are poorer overall than white pensioners and there are differences within BME communities (e.g. Bangladeshi pensioners are poorer than Indian and Caribbean pensioners) (Platt, 2007).
- Some people (e.g. asylum seekers, UK citizens returning from abroad) may have no or limited income, savings, or entitlement to benefits.



The proportion of single pensioners who are in low-income households has halved over the last decade, with smaller falls for pensioner couples



Source: Households Below Average Income, DWP; UK; updated Aug 2009

These two graphs (from [www.poverty.org](http://www.poverty.org)) show that:

- Single females are more likely to be income-poor than single males, but there is little difference by age.
- Older couples are more likely to be income-poor than younger couples.
- There has been a sharp reduction in the proportion of low-income single pensioners but very little reduction for couples.

Sharp rises and falls in pensioner poverty defined this way reflect the way that pensioner incomes are much more bunched around the poverty line than working age incomes ... while the forces making for future fragility might well be different from those making for fragility in the past, the risk of fragility cannot be dismissed.

(Peter Kenway, New Policy Institute)

## What we need to know

Poverty and affordability issues will affect the accessibility and acceptability of HWC. Low income is not the only factor. For example, although most older social housing tenants are on low incomes, they are more likely to be in touch with services, and receiving benefits and advice, than private tenants and owner-occupiers.

Those less well off/living in poverty – if these people are known to social services, they will have full accessibility for application and admission to our services.

(Large national Registered Social Landlord)

In other words, those not known to social services will not be able to access HWC.

HWC is available in many areas now, either to rent or to buy (outright or through shared ownership). There are cost implications for different options. Housing and care costs will depend on both the charges made and help through benefits and the local authority (Fairer Charging).

There are three broad categories of older people, who will receive different levels of help with their housing costs (whether they rent or buy) and their care costs:

- the 'really poor' i.e. those with low income and no (or modest) savings, usually entitled to 100 per cent funding;
- the 'nearly poor' i.e. those with slightly higher income (often a very small occupational pension) or savings, usually entitled to some help;
- the 'better off' with higher income (e.g. good occupational pension) and/or higher savings, who have to self-fund with no help.

Sixty-eight per cent of older people were home-owners in 2001 (rising to 75 per cent by 2026). However, not all are well-off. Many older home-owners are asset-rich but income-poor. Some live in very poor conditions, as evidenced by the work of Home Improvement Agencies. Research on equity release models (King *et al.*, 2008) found that many older owner-occupiers (especially women) prefer to rent and escape worries about future repairs and maintenance. Mixed tenure offers varying shares of equity so they can invest sufficient to reduce savings and become eligible for benefits.

Self-funders in sheltered housing worry about affording the costs:

Some people have left here because of the expense. It's a big worry for those of us not on benefits – will we be able to afford to stay here?  
(Older person self-funding in sheltered housing, in King *et al.*, 2009)

We can assume similar concerns amongst older people thinking about HWC for the future, and existing HWC residents, because HWC costs are higher.

It may very well be that the people whom one should be most worried about are not the poorest pensioners, i.e. those on or entitled to Pension Credit, but those just above that level who can find themselves paying nearly or even just as much as those much better off. Low-ish income owner occupiers are one such group, but I suspect it goes much further up the income distribution than that. The worry here is not just that those conventionally counted as being in poverty are not the whole group of concern, but rather that they may not be the group of concern at all. NPI might be able to analyse the Family Resources Survey to work out how many pensioners and of what type (single/couple, owner/tenant) there are in each category.  
(Peter Kenway, New Policy Institute)

# Learning disability

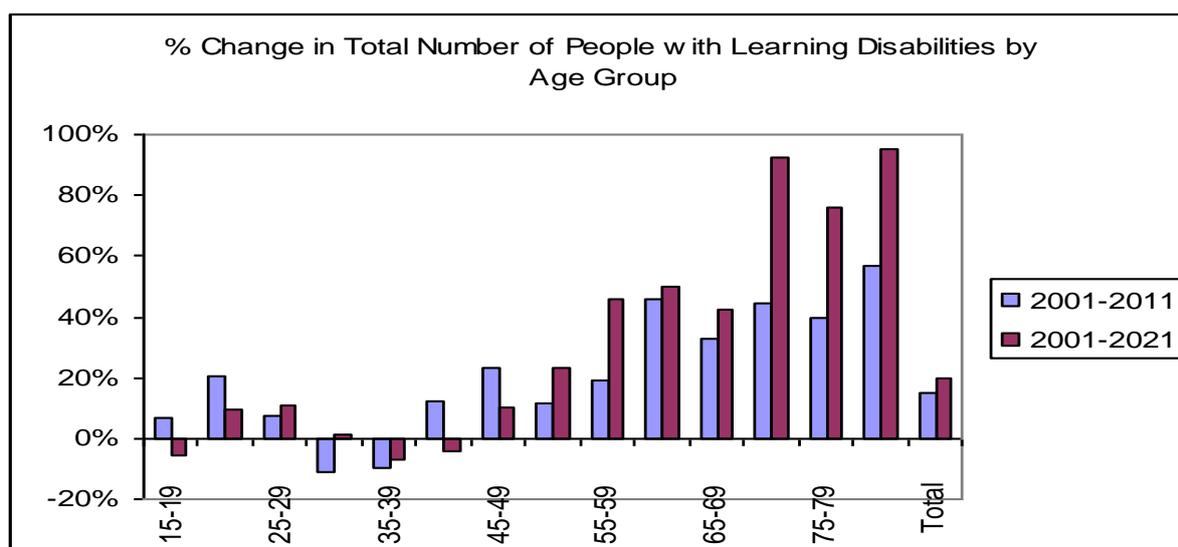
## What we know

People with learning disabilities are amongst the most socially excluded and vulnerable groups in society today. Very few have jobs, live in their own homes or have any real choice of who cares for them.  
(Senior practitioner, City Council)

The headline figures are of a population in England of nearly 800,000 adults (two per cent), with a learning disability. Of these about a quarter (224,000) are 'known to services'. This broadly equates to those with severe and profound learning disabilities. Most others with mild or moderate learning disabilities do not have access to social care support (Emerson and Hatton, 2008).

A significant trend is the growing proportion of older people with learning disabilities.

## Older people with learning disabilities



Source: Emerson (2005)

Recent figures for learning disability show how the percentage in each age band of older people with learning disability rises sharply over 20 years from 2001 (Emerson, 2005).

In *Fundamental Facts*, Emerson *et al.* (2001) note that as well as high levels of special healthcare problems among people with learning disabilities there is evidence of other additional needs or features of their disability:

Sensory impairment	48%
Dual sensory impairment	18%
Physical disabilities	20–30%
Epilepsy	20–30%
No verbal communication	20%

Autism	35+ %
Challenging behaviour	5–15%
Mental health problems	25–40%

The minimum age for entry to extra care is 55 years. The life expectancy of people with a learning disability has extended. Many people with a learning disability have the same problems as older people but at a much younger age. So for example, people with Downs Syndrome (a common source of disability) now have a life expectancy of 50-60 but there is a 50:50 chance of early onset dementia in late 40s or early 50s (as estimated by the Downs Syndrome Association).

Much of our knowledge comes from 13 studies sponsored by the Foundation for People with Learning Disabilities (FPLD, 2002). This highlighted that older learning-disabled people may 'find themselves in older people's residential services or nursing homes at a much younger age than other residents leading very restricted lives'. It also underlined the number of older relatives providing care at home.

With the current policy objectives of Public Service Agreement 16 and for a real choice of where and how people live, many of those living in older services will need to move. There is a general presumption in the learning disability field against registered care in favour of more 'ordinary lives' and independent living.

More than half of those with learning disabilities known to services are still living with their families and this represents the growing future demand for new places. In *The Housing Timebomb*, Mencap estimated 29,000 living with older carers in the UK – say 24,000 in England (Mencap, 2002). Studies by the Housing and Support Partnership for various local authorities have found between 25 and 33 per cent of adults with a learning disability known to services want to move.

The characteristics of a high incidence of multiple disabilities in combination with a high incidence of early onset dementia and dependence on benefits makes older people with a learning disability prime candidates for HWC.

There have been two strands to thinking:

***1) The development of small extra care schemes exclusively for people with learning disabilities***

The Department of Health funded a pilot programme of ten extra care schemes just for this group. The evaluation illustrated the diversity of what was labelled extra care and pointed out the similarity between the pilot schemes and modern supported living. Relieving older carers was a driving force for several schemes and some incorporated accommodation for carers in the development. A model of 'mini-extra care' was beginning to emerge (King and Maxwell, 2008).

Advance Housing and Support, a Registered Social Landlord which specialises in providing for people with learning disabilities and mental health problems, is just completing a small scheme (ten flats) of this type which incorporates extensive assistive technology.

Very recently there have been some larger extra care schemes, just for people with learning disabilities.

### **Beaumont Place – Extra care for people with a learning disability**

Care is provided by Tameside MBC Adult Services within each of the 25 apartments. Extensive communal facilities have been provided to give extra care. The scheme has two large communal lounges, a dining room, a commercial kitchen, a quiet room, two assisted bathrooms, a laundry and various staff facilities. All locks are electronic, and flooring and signage is colour coordinated to help any resident or visitor fully use the building. New Charter (the developer) provides the main meal of the day for residents.

*(Example provided by New Charter Housing Trust)*

## **2) Letting a small number of properties in mainstream extra care and providing enhanced/different support**

Pennine Court, an example of remodelling sheltered housing to include extra care for people with learning disabilities is described by Latto and Crookes (2007). This strand of thinking is particularly common in DH funded extra care (Pannell, 2006). While Valuing People was careful to say all options remain open, there is a strong presumption against more large 'intentional communities' such as the large complexes/villages specifically for disabled people. Some commentators have been opposed to extra care, seeing it at odds with independent living principles, separating people from the community, despite the fact that it is self contained and older people report high levels of satisfaction with extra care (Croucher *et al.*, 2006).

## **What we need to know**

There is plenty of opinion about what people should have but little evidence for what is wanted; this is true of all people with learning disabilities, but probably particularly true of older people as they are less likely to have relatives advocating for them.

The National Survey 2003–4 (Emerson *et al.*, 2005) identified the importance for residents of safety, privacy, security, location, freedom from noise and harassment. Other local surveys (but not of older people) note space, not being isolated, living in areas where they have existing networks, e.g. being near friends, family, and access to shops, work and leisure amenities as being important to quality of life.

One of the few and limited surveys (McGlaughlin *et al.*, 2002) asked about the kind of accommodation required. Many do want to share but usually with only a few others – preferably with people they know. Some will choose self contained accommodation but would like it to be grouped with others, for example in a local network like KeyRing or on a single site as in HWC, in order not to feel isolated. There is an increasing interest in ownership and low cost home ownership.

Our impression, confirmed by the experts consulted, is that few local authorities have implemented coherent strategic plans, put in place policies and updated practice to respond to the small but growing number of older people with learning disabilities.

Issues include which team is responsible for commissioning and managing services (older persons or learning disability?). There is often a lack of reliable facts and figures on numbers, profile and needs (including those not known to services).

Around 40 per cent of all people with learning disabilities known to services are on the autistic spectrum if properly diagnosed. Numbers identified with autism have risen very sharply, partly through the statementing process for education. The first distinct autism strategy has recently been published, but does not include the proposed section on housing. Little has been done in relation to older people with autism. This has been a largely hidden population and must be an emerging issue.

Little attention has been paid to more imaginative funding options that would allow older people with learning disabilities to buy property outright or on shared ownership terms (or other terms) in HWC. HWC providers frequently appear unaware that Support for Mortgage Interest (SMI) and Housing Benefit can be a route into shared ownership, even for those with profound disabilities (King, 1996). This model is commonly used for younger people buying ordinary street properties. MySafeHome (a specialist mortgage adviser) has helped nearly 1000 people with learning and other disabilities into home ownership, mainly through the Home Ownership for Long-term Disabled (HOLD) programme in England. They say similar models could apply to HWC.<sup>5</sup>

Three out of four people now retiring are home owners. More than half of all people with a learning disability live in the family home, supported by (ageing) family carers. Because people with learning disabilities are living longer, many more could have access to substantial assets (either directly or via a Discretionary Trust). There is scope to develop different, imaginative financial models to provide security, protect assets and also provide a source of funding for HWC providers.

# Mental health

## What we know

Mental health here includes older people with functional mental health problems such as depression or schizophrenia (which may or may not be a long-standing illness); and those who develop dementia.

- One in three people who die aged 65 or over have dementia.
- Nearly 700,000 people are estimated to be suffering from dementia in the UK in 2007 and, by 2025, the number is expected to rise to one million. By 2051, it is projected to exceed 1.7 million.
- Dementia affects one person in five over 80, one in four over the age of 85 and one in three people over 90.
- Depression affects 22 per cent of men and 28 per cent of women aged 65 or over.

*Source: Older People in the UK (Factsheet), October 2009, Help the Aged*

Thanks particularly to the work of Stirling University Dementia Service Development Centre, we know quite a lot about good design for those with dementia (Judd *et al.*, 1998; Marshall *et al.*, 2002): small domestic scale; easy to navigate spaces; the use of light, objects, texture and sound to aid orientation; designing areas it is safe to wander in; the role of assistive technology. Services ideally are 'person centred' and staff have specialist training.

Housing for people with dementia should:

- compensate for disability;
- maximise independence, reinforce personal identity, and enhance self-esteem/confidence;
- demonstrate care for staff;
- be orientating and understandable;
- welcome relatives and the local community;
- control and balance stimuli.

The general view is that an early move to HWC is preferable. Other residents are more likely to accept and support someone they have got to know before more severe symptoms appear. Accommodating people with dementia in larger schemes can be a challenge for other residents and staff, if behaviour becomes extreme or aggressive. Staff require additional skills and training to manage well.

There are programmes of action research in place specifically concerned with improving life for people with dementia and functional mental health problems in HWC settings.

One recent example used an 'Enriched Opportunities Programme' (Brooker *et al.*, 2009) made up of:

- a specialist lead to 'unlock any potential for well-being';
- individual assessment and case work;
- programme of activity;
- staff training;
- leadership through an 'opportunities coach'.

Positive results are reported in reduced moves to care homes and less time in hospital, better treatment and services. Residents rated quality of life more positively with less depression.

Two major reports by Age Concern and the Mental Health Foundation brought together an analysis of mental health in later life and set out how services could be improved, including housing (Age Concern and MHF, 2006; Age Concern, 2007).

We need to take action on the mental health problems for which there is strong evidence of what works (such as depression, anxiety, delirium, dementia) and we need to pay more attention to problems that have been invisible to date but which will become more pressing in the future, such as older people with alcohol and drug misuse problems and people growing older with severe and enduring mental health problems.  
(Age Concern, 2007)

The Inquiry into Mental Health and Well-being in Later Life concluded:

No further research is required to decide on the actions that are needed. However, the issues are complex and overlapping.  
(Age Concern and Mental Health Foundation, 2006)

Depression is the most common mental health problem in later life, severely affecting 2.4 million older people. Mental health and well-being are most influenced by:

- discrimination and the stigma attached to mental illness;
- participation in meaningful activity, having a sense of purpose (often an aspect of HWC);
- secure and supportive relationships (social isolation is a common risk factor);
- physical health;
- poverty as a risk factor for poor mental health.

The inquiry observed that much could be done to improve services; housing support enables older people with mental health problems to live in their own homes but its role is often overlooked. Specialist housing like HWC has an impact on mental health by preventing isolation and depression while also offering a supportive environment (Age Concern, 2007).

## What we need to know

Unresolved debates centre around:

- The pros and cons of different models for meeting the needs of people with dementia (i.e. separate wing, integrated approach, specialist schemes or hybrid developments).
- The benefits and limitation of a housing model for people at different stages/manifestations of dementia – at point of entry and as dementia progresses once in situ – compared to residential care and other alternatives i.e. When is a housing model best or are there circumstances where a housing model is not best? Garwood (2004) asked ‘Does there come a point where the requirements for security and supervision so outweigh the need for and ability to be independent that a model based on housing and domiciliary care becomes phoney?’

In one study, within two years, half of those admitted to extra care with dementia had moved on because of challenging behaviour, conflicts with staff and residents or distress (Vallelly *et al.*, 2006).

Two other areas flagged by those who contacted us are:

- Cost benefit analysis of HWC for people with dementia compared with other approaches.
- Interdisciplinary training initiatives and/or good practice guides for the housing sector on mental health in older people.

# Sensory impairment

## What we know

- Findings from a Medical Research Council trial (Fletcher *et al.*, 2006) indicate that one in eight people aged over 75 and one in three people aged over 90 have serious (registerable) sight loss;
- Fifty-five per cent of people aged 60+ are deaf or hard of hearing (RNID, 2006).

We know what constitutes good, acceptable design for people with visual impairment and how to get it implemented in HWC. A summary of recent studies of housing, design and care needs of people with visual impairment is *Housing for People with Sight Loss* (Hanson, *et al.*, 2002). From the experiences of 400 participants, there is little difference between good practice for this group and the general older population:

- Location is important.
- Provide information that is balanced.
- Support people to express concerns in confidence.
- Promote socialising.
- Inform people of the option of extra care.

The evidence repeatedly shows that while HWC offers opportunities to socialise and remain active, those with cognitive, sensory or physical impairments can be marginalised (Croucher *et al.*, 2006).

The RNIB and Thomas Pocklington Trust produce excellent guidance on housing for those with impaired sight (Thomas Pocklington Trust and Habinteg Housing Association, 2008). They have also developed a room by room process of thinking about design and RNIB offer a technical advice service. Good practice focuses on things like lighting, colour contrast, non-reflective surfaces, non-slip floor covering, use of texture, building shape, layout and so on. Much constitutes good design for any development for older people.

There is a difference between Wales and the rest of the UK in how positively good design is promoted in HWC. In Wales, grant funded extra care housing has to follow a guide specifically developed by RNIB. The RNIB also have a dedicated worker who offers specialist advice and vets and accredits developments submitted by the ten leading Residential Social Landlords (RSLs) building extra care in Wales. There is no such system elsewhere in the UK.

The level of impaired sight in extra care and sheltered housing is high based on recent, small scale studies by the RNIB. In one extra care scheme, 75 per cent of residents were found to have significant sight loss. In another sheltered scheme the warden put the number of residents with poor sight at 7 per cent but an assessment by the RNIB found 26 per cent had significant sight loss.

Some attention has also been given to those who are both deaf and blind (Sense, 2006). The number of people over 60 with significant dual sensory impairment are not certain but are said to be as high as two million and rising dramatically (Hodge and Douglas, 2007).

Combined loss of vision and hearing makes the person even more at risk of social isolation and accidents. Deterioration in a second sense, having adapted to one impairment, can have a considerable impact.

People who have adjusted to hearing impairment may lose the ability to lip read as their sight fails and individuals with visual impairment may lose the ability to hear clearly... there is likely to be increased isolation arising from the loss of not only essential information and interactive routes like conversation, but also some solitary leisure pursuits like reading, listening to the radio... (Roberts *et al.*, 2007)

Additional problems created by dual impairment are more than the sum of those created by impaired hearing or vision alone.

Lessons from the literature relevant to HWC include:

- Raising awareness in staff so they can spot when deterioration hinders everyday activities.
- Training in simple, non-technical forms of assistance.
- Importance of lighting, acoustics and assistive technology.

## **What we need to know**

Issues identified by the RNIB include the exclusion of cash poor, asset rich older people from HWC. A linked debate is whether resources would be better diverted to refurbishing older people's existing homes (to appropriate design standards) rather than investing in expensive new facilities available to only a few people. Shared ownership would be one answer for this group, possibly through the Home Ownership for Long-term Disabled (HOLD) programme in England. Bromford Housing Group worked with the Resource Centre for the Blind in Dudley to offer low cost home ownership to people with visual impairment in HWC using HOLD, but this is an unusual example.

The RNIB also raised concerns that people who have a sensory impairment but who are otherwise fit have a low priority for social rented housing because of the way allocation systems work. Questions concentrate on ill health and not, for example, vulnerability or risk. Someone who is blind but coping, albeit at great risk or with difficulties, will only get priority if they have additional physical difficulty or ill health.<sup>6</sup>

Thomas Pocklington Trust identified the confusing terminology on HWC as a barrier to access by older people who are understandably unsure what the 'product' really is. This also raises doubts about the validity of studies which purport to evaluate 'extra care'.

## Older homeless people

We have included older people who are homeless, or vulnerable to homelessness, because some have very high support needs and they cut across a number of the other categories. The lessons learnt would also apply to other older people with multiple and complex needs even if they have not been homeless.

### What we know

Older homelessness has risen up the policy agenda in the past decade, and there is a UK-wide programme of awareness-raising and research through the UK Coalition on Older Homelessness (now within Homeless Link).<sup>7</sup> The agreed definition of 'older' used in research on older homelessness is 50+ because older homeless people experience ill-health and disability at a much younger age, and in fact many die before reaching older age.

There are significant numbers of older people living in homeless hostels: some have been there for many years, and many have high support needs (Pannell, 2004). Such accommodation is inappropriate for their health and care needs. Following the Supporting People funding regime and the Places of Change programme, homeless hostels are not supposed to be long-stay and residents are expected to move on within two years. However, many localities do not have suitable accommodation and support services, so older people remain in hostels unless there is another reason to move (e.g. hostel closures).

If older homeless people are re-housed into inappropriate housing with inadequate care and support, they often abandon the tenancy and end up back on the streets or in hostels and shelters. Conversely, longitudinal studies of resettlement outcomes (Crane and Warnes, 2002) have shown that they can be resettled successfully into sheltered housing, HWC and residential care.

A minority of older homeless people have chaotic lifestyles and multiple and complex needs, typically including two or more of the following:

- mental illness;
- substance misuse;
- dementia (including Korsakoff's, linked to alcohol misuse);
- physical frailty;
- sensory impairment;
- learning disability (usually mild/undiagnosed);
- behavioural issues;
- institutionalisation, dependency and lack of life skills.

Many older people still on the streets and some older hostel residents have complex needs (Warnes and Crane, 2000). They do not fit easily into either sheltered housing or residential/nursing care. Other residents (and some staff) do not accept them. Their lifestyle and history is likely to be very different. Registered care may also be unaffordable because it is very difficult to get funding, and unacceptable to

continuing drinkers because they do not want to be left with the minimal income for people in registered care.

#### **Example: London Borough of Camden**

The London Borough of Camden surveyed older people's housing and care needs and found around 400 older residents (50+) in homeless hostels. Hostel residents were on average 10 years younger than sheltered housing residents, but with similar care and support needs. Hostel residents also needed more support because they lacked the additional help from friends and family enjoyed by one-third of sheltered housing residents. Camden is now developing a pilot to enable some of the older hostel residents with high support needs to access mainstream provision (sheltered housing, residential care, and ordinary housing) and will be putting in extra specialist support to achieve this. Camden is also considering a specialist extra care scheme for older homeless people.

*Source: Personal communication, November 2009, UK Coalition on Older Homelessness*

#### **Examples: Provision for older homeless people**

- Southampton included older homeless people's needs in its strategic Vision for Extra Care Housing.
- St Eugene's Court, Birmingham, provides HWC for 44 older Irish men who have experienced social exclusion and who have additional support needs around their health, living skills or alcohol use.
- Willow Housing and Care (London Borough of Brent) has re-housed older homeless people into mainstream HWC, sometimes with additional support from St Mungo's Tenancy Sustainment service (for older people with alcohol problems).

*Source: Pannell, J. (2005) Extra Care Housing Models and Older Homeless People, DH Housing LIN Factsheet 16*

### **What we need to know**

At national level, tackling homelessness, rough sleeping and homeless hostels have been priorities. Older homelessness is now acknowledged as an issue, although funding for accommodation and services remains scarce.

Except in a few localities, like the examples above, major gaps remain at local level:

- A lack of information about numbers of older people who are homeless or vulnerable to homelessness, and their housing and care needs. Homeless Link Older Homelessness project has developed an audit tool for local authorities to measure numbers and needs in their older homeless population.

- Failure to include the needs of older homeless people in strategic planning for older people and for homelessness prevention: homelessness has been ignored in planning for older people, and older people have often been invisible in homelessness plans.
- Specific provision for older homeless people with high support needs, especially drinkers.

## Notes

1. The Joseph Rowntree Foundation Task Force produced *Swamps and alligators; the future of low cost home ownership*, (Martin, 2001). In 2003 the Deputy Prime Minister set up a Government Task Force on Low Cost Home ownership. This reported in November 2003, producing *A home of my own*, (Housing Corporation, 2003). The Office of the Deputy Prime Minister (ODPM) consulted on these proposals, publishing the results and the Government's conclusion as *HomeBuy – expanding the opportunity to own; Government Response to Consultation*, (ODPM, 2005). This led to reform of the Housing Corporation Low Cost Home Ownership programme and the introduction of three main HomeBuy programmes; Social HomeBuy, Open Market, and New Build replacing the previous shared ownership programmes.

In the 2006 Budget the Chancellor announced yet another joint review by the Treasury and Department of Communities and Local Government producing *Report of the shared equity task force*, (HM Treasury and DCLG, 2006). The House of Commons Committee of Public Accounts considered this and also a report by the Comptroller and Auditor General *A foot on the ladder; low cost home ownership assistance*, reporting itself in March 2007 (National Audit Office, 2007).

What is striking is that these reviews consistently fail to consider or often even mention the place of low cost home ownership in the housing of older people. There is even less low-cost home ownership for this age group available in Wales.

2. Several respondents said confusing, inconsistent terminology and uncertainty as to what HWC means was a barrier to access. One referred to a rather futile academic discussion on definition. It would arguably be more useful to see HWC as a class of provision which legitimately comes in a variety of forms. A simple typology is set out in 'Models of Extra Care Housing and Retirement Communities', N. King, Factsheet 4 [www.dhcarenetworks.org.uk/housing](http://www.dhcarenetworks.org.uk/housing).
3. Personal communication from a respondent, who was working on an extra-care scheme for the Jewish community in the Bournemouth area.
4. See [www.ageconcern.org.uk/openingdoors\\_about.asp](http://www.ageconcern.org.uk/openingdoors_about.asp).
5. From communication with MySafeHomes Ltd.
6. The RNIB have numerous case study examples to evidence this contention e.g. elderly couple, both blind, living in private accommodation, about to become homeless, rejected by three associations, or a blind man of 70 who needed a guide dog but could not be supplied with one because he lived on a 3<sup>rd</sup> floor flat also given very low priority when asked to move to ground floor.
7. See [www.homelesslink.org.uk](http://www.homelesslink.org.uk) and [www.olderhomelessness.org.uk](http://www.olderhomelessness.org.uk); research includes McCrum (2002) and Pannell *et al.* (2002).

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## **Appendix 2:**

# Decision-making and communication in housing with care

**Kritika Samsi and Jill Manthorpe**

## Introduction

Housing with care provides independence and choice to adults with varying support needs and enables them to remain in their own home. Government policy supports the expansion of extra care housing to groups with high support needs and this brief review focuses on some of the key issues around decision-making and communication that need to be considered when providing housing with care for older people with high support needs. As specified in the project brief, four key areas for exploration are included in this review:

- confidence and skills in decision-making support;
- the role of Advance Care Planning (ACP), or similar terms, in housing with care services;
- staff (and family) access to support and training in communication and decision-making;
- the adequacy and effectiveness of support and training for staff and for families.

The review draws on existing evidence, knowledge and understanding gained from published material, including grey literature from reports, interim research papers, discussion papers, and so on. A set of brief telephone interviews and exchanges have helped ensure that the material is up to date and that relevant matters have been covered. The review outlines what is known, what needs to be known, and barriers and facilitators in this complex area where communication and decision-making are affected by law, organisational and cultural practices, professional guidance and service values. In essence, it both maps the range of literature in this field and sets out where gaps in the evidence base may lie.

The review started with an initial search of the key databases, websites and bibliographies from major reports and studies. The project brief specified the inclusion of families and friends as well as other supporters in volunteer capacities, in addition to a range of professionals/practitioners. The review concentrates on older people with high support needs but touches on other groups with high support needs where decision-making and communications feature in housing with care services.

A case example provided by Sue Garwood as part of a training set on the Mental Capacity Act to the Housing Learning and Improvement Network (LIN) sets out some of the key areas covered by this report at a (anonymised) personal level:

Fred Smith moved into Pinewood Court EC (extra care) scheme several years ago. He was perfectly capable of signing his own Tenancy Agreement. Over a period of years, Fred develops dementia. He becomes disinhibited, making unwanted advances to the female residents. Staff try to explain to him that his behaviour is upsetting but he cannot retain the information or modify his behaviour. At night he is prone to walking around the scheme and on a number of occasions has entered the flats of other residents, even climbing into the bed of one on one occasion. However, it is the fact that he is physically very fit and frequently leaves the scheme that is of greatest

concern. Several times staff have had to fetch him back, and twice he has been found wandering miles from the scheme. Staff are finding it increasingly difficult to cope, other tenants are becoming intolerant, and he is becoming aggressive if he feels thwarted or if someone gets in his way. (Garwood, 2008a)

While this example may be an extreme, it touches upon many of the areas covered in this review. In this example, there are several efforts at communication; there are conflicts and rising anxieties. There seem to be uncertainties. There are decisions to make, and risks seem to be escalating, but responsibilities are multiple. While Mr Smith may have family or friends, it may be that he does not have anyone to support him other than people who are paid to do so. Lastly, the scheme's staff doubtless have to explain what is happening to the police and other emergency services, their neighbours in the locality, perhaps adult social care services, and possibly adult safeguarding staff. As this example shows, communication and decision-making are very much part of the roles of scheme managers and of frontline staff in housing with care services.

In recent years, policy-makers have been taking active interest in the needs of an ageing society by providing frameworks within which individuals can remain independent, leading healthy and fulfilling lives (DWP, 2008). Improving the lives of people with disabilities has also become a policy priority with the establishment of the Office for Disability Issues, set up in 2005 to ensure equality in all of the government's policies. Furthermore, the Department of Communities and Local Government (DCLG) produced a document that addressed the challenge of housing in the context of ageing populations and outlined plans to provide appropriate, sustainable housing for the future (DCLG, 2008).

In the context of personalisation in social care, there is also growing awareness of the need for health, social care, voluntary and private sectors to work together as they aim to 'put people first' (DH, 2007). Here, the organisation In Control addressed the practicalities of 'self-directed support' by raising the importance of managerial support, realistic expectations, effective communication, clearer systems for understanding eligibility criteria, ensuring accessible and successful training (Brewis, 2007). These themes of 'A Voice and A Choice' appear highly relevant to housing with care services as they too seek to better support and empower people with high support needs.

## Confidence and skills in decision-making support

Decision-making tends to be cast in the light of the difficulty of making 'serious' decisions but a variety of studies reveal that day-to-day decision-making and choice may be just as important for quality of life (Stanley and Manthorpe, 2009). Evans and Vallely (2007) comment that:

Opportunities for older people to be involved in decisions about care delivery and service development on an ongoing basis are increasingly seen as central to a sense of well-being. However, older people living in a range of residential settings appear to have relatively low levels of participation in such decision-making.

(Evans and Vallely, 2007)

These observations reflect the context of working with people who have a combination of frailty and high support needs. Nonetheless, extra care and very sheltered housing espouse particular attention to enhancing the rights of tenants and owners to exercise choice. This may start from the process of taking up a tenancy or lease transfer. In the quote below, one provider sets out for staff how this should be done:

Obtain life history immediately and from the resident as much as possible as their [views of their] life will be different from [those] of their family and friends. This will assist communication by including areas of their life in the conversation. Behaviours that challenge the service almost always come from an inability to clearly communicate. If the behaviour can be linked to life events there is a clearer path for communication and therefore an ability to work more positively with individuals and steer their behaviour into less challenging and more normative areas.

(Suffolk County Council, 2009)

This type of communication may be the responsibility of the scheme manager or there may be effective transfer of information between former care providers or families if the individual is not able to communicate well. While housing with care staff may complain about the limited adequacy of the information they receive from others, we know little of how housing with care providers communicate with other agencies, notably in terms of providing information to other care providers or what internal recording systems work most effectively. Croucher (2008), for example, notes that:

For frailer residents and particularly those suffering from dementia-type illnesses, the evidence regarding social isolation, and the capacity of these models to provide an alternative to residential care and provide a home for life is more muted. All studies reviewed indicated that some residents moved on to residential or nursing home care.

(Croucher 2008, p. 55)

There seems to be little information about how effectively housing with care staff relay information to other professionals. In the case of someone like Mr Smith, described at the start of this review, would the scheme's manager be able to supply

a possible new care setting with information about a man who has lived in the scheme for many years, and who may have lost links with former family and social networks? Would this be in the form of a life history or would it be more service-focused?

Confidence and skills in the area of support for decision-making among tenants and lease-holders have featured considerably in debates about ways to improve end-of-life care in extra care settings. Easterbrook and Vallely (2008) report on the six month service improvement pilot project designed to enhance dignity and choice in end-of-life care in three extra care housing settings in north-east England and East Anglia. Four key issues were identified: promoting dignity and choice for older people and carers; support and training for staff; links to wider health and specialist resources; and commissioning and funding. As the next section shows, until recently there has been uncertainty about the legal framework but also a lack of confidence in care homes and housing with care services that their staff would be given the support tools to help people at end-of-life.

The DH *End of Life Care Strategy* (DH, 2008) is an important policy initiative advocating more effective systems of communication between palliative care, emergency care and primary care teams and housing with care and care home sectors. There is a call for sensitive and open communication between individuals, families, friends and staff to underpin all planning and activity and that this needs to be part of *core competences and principles for end of life care* (National End of Life Care Programme, 2010). Support tools that are commonly cited include the Gold Standard Framework, pain assessment tools, assessment for discomfort tools, and ways of improving symptom recognition, especially pain. There is a wide range of service development and training programmes focusing on these changes in practice and systems. For non-NHS organisations, such as housing with care services, the DH Quality Markers on end-of-life care may be implemented as part of the contracting process to set out core requirements around the competencies of staff within any organisation that provides care to people at the end of their life (see the description of Callendar Court in DH, 2009a).

Confidence may however, be less evident when, for example, supporting people with dementia living, rather than approaching end-of-life, in extra care housing. Evans *et al.* (2007) identify three features of the extra care environment as particularly important in supporting independence of clients: the freedom to come and go as they like within and beyond the housing scheme; maximising opportunities to 'do things for themselves'; and having choices about how to spend their time. As the example of Mr Smith shows, these are among the very indicators that may be compromised by disabilities such as those experienced by people with dementia or other high support needs, leaving staff in the position perhaps of feeling that their skills are low level and that they are failing their tenants.

It is important to note that the legal obligations of staff in extra care settings (as in other parts of social care) are not easily communicated to anyone, regardless of their levels of training. The Law Commission (2010) casts law in this area as a 'hodgepodge' (it is currently working on a new legal framework for adult social care), with Dow (2006) identifying some of the main legal complexities involved in developing extra care housing for people with dementia as: whether some extra care

schemes need to register under the Care Standards Act 2000 as a care home; do people with cognitive impairment have the mental capacity to enter into or give up tenancies (illustrated in the case of Mr Smith above); and how the Disability Discrimination Act 1995 should be considered with regard to landlords' actions in accepting or ending tenancies. Small wonder perhaps that confidence around decision-making may prove difficult and that scheme managers may need to rely on central or head office for expert advice.

Vallelly and Kaur (2009) state 'Put simply, extra care offers housing with the full legal rights associated with being a tenant or home owner in combination with 24 hour on-site care which can be delivered flexibly according to a person's changing needs'. This 'mission' may present managerial staff with difficulties that they cannot resolve on their own. Patterns of communication between scheme managers and their own managers and support services are not well understood. As with adult social care managers, there is little information about their activities or their views.

The literature reflects greater interest in features of environment and design and how this affects communication and decision-making; for example, in relation to elimination of hazards. Croucher (2008, p.55) notes, however, that in housing with care services 'Sensory and cognitive impairments appeared generally to be less well understood or addressed in design terms'. This lack of attention may need to be rectified. There is great emphasis on the design of extra care housing to provide housing that is evidently different from a care home and where aspects of it may be used by the community, as outlined in the remodelling evaluation undertaken by Tinker *et al.* (2008). Meeting this objective of community accessibility, augmented by facilities and equipment to meet the support needs of people with perhaps profound disabilities, may require very skilled design. Moreover, regardless of design, different professional and personal definitions of 'risk' may contribute to and affect the culture of any housing with care service (Vallelly *et al.*, 2006).

Finally, confidence in providing support can be easily undermined and staff may feel at risk:

The personal impact of BPSD (behavioural and psychological symptoms of dementia) can be enormous; for example if a person with dementia has a delusional (i.e. false) belief that somebody is stealing from them, this might lead to worrying accusations targeted at those around them.  
(Lowery and Warner, 2009)

In a climate of concern about adult safeguarding there are risks to staff of 'false positives' (unfounded allegations). In light of the risks in this area, there may need to be much greater attention not simply to the identification of mistreatment and neglect, but to the skills and confidence needed by housing with care services to respond to allegations, to undertake investigations and to manage and communicate the outcomes of these responses. While there is yet no national study of the prevalence and incidence of elder abuse in care settings (including housing with care), such harm will affect a housing with care provider, its staff and residents, and also its standing in the community. More work on responses to allegations in this sector may be warranted.

## Summary

Decision-making is as much a matter of skill as it is of having the confidence to do so effectively. Literature identifies features that appear to influence decision-making, such as the type of housing with care scheme; and features that contribute to confidence levels, such as use of previously-obtained life histories of the tenant/owner, managerial support, clear legal standards and frameworks and the culture of the housing with care scheme itself. Housing with care schemes face particular challenges in communication with other organisations that may underpin their support to tenants/owners with high support needs.

## The role of advance care planning in housing with care services

Advance care planning (ACP) may be defined as the provision of an opportunity to express or discuss future choices and preferences about care, treatment and personal matters, in the event of possible loss or lack of ability to make decisions about care, treatment and personal matters. In England and Wales, the framework for this was substantially revised and regularised by the Mental Capacity Act 2005, implemented in 2007. The potential for this to affect housing and care services was recognised during the implementation period of the Act, such as the training programmes developed by the DH (Stanley *et al.*, 2007) which included the sending of a DVD containing the training materials to all registered care settings.

In addition, the DH funded material designed for housing with care settings around end-of-life care provision (see *National End of Life Care Programme*, 2010 and research by Froggatt *et al.*, 2008) have provided a baseline of practice in care homes prior to the Act's implementation. In their study of care homes, managers reported variable staff training across different end-of-life care skill areas. Most care home managers said their staff had received recent training (within the last three years) in palliative care (74%, n=157), communication and listening skills (74%, n=158) and bereavement care (67%, n=143). Fewer reported staff had been trained in ACP (44%, n=94), religious practices at the end-of-life (35%, n=74) or spiritual care (39%, n=84).

While these figures may reflect provision across housing with care services nationally, it is possible that they overestimate skills and confidence. A recent study by Manthorpe *et al.* (in press) of care home staff's knowledge and experiences of the Mental Capacity Act, after implementation, revealed patchy knowledge among frontline care workers about the MCA. Only four of the 15 care workers interviewed in a selection of homes had heard of the MCA and none had received any specific training on it. Two recollected some mention during other training they had undertaken or demonstrated awareness, mainly through word of mouth.

Five of the seventeen managers interviewed in this study said they had mentioned the MCA to their staff, although this was at a general rather than systematic level, including a staff meeting or putting items on a notice board to convey the 'basics'. At least two managers reported varying levels of interest amongst their staff; some did not seem interested and others just skimmed through literature on the Act. However, two had discussed the Act with staff in relation to specific instances where the residents' choices about aspects of their care were contentious. Furthermore, a minority of managers said that they had not seen any written guidance on the Act or any new types of paperwork to assist their work, other than general literature about it. Some were not aware of any guidance, or of whether the legislation had been implemented. Two managers were anticipating the introduction of new care plans from 'head office' that would explain more about the MCA and how to use it in their work. One manager was aware that the new care plans would record residents' entitlement to an Independent Mental Capacity Advocate, if major treatment or moves were on the horizon.

The implications of this for housing with care providers are threefold; first that they should not presume that staff moving to work in housing with care services who have backgrounds in social care are aware of the MCA generally and, specifically, its provisions for ACP; second that there are cultures of training and information provision within organisations that may not be robust or sufficient and that these cultures may affect the practices at local level, despite head office information and injunctions; third that the impetus for staff interest in the possibilities of ACP or the provisions of the MCA are best evoked by actual care practice or questions. This suggests that there may be benefits from training that builds on experiences.

From a study undertaken prior to the Act's implementation, Froggatt *et al.* (2008) recommend 'Accredited training courses that address all elements of ACP need to be developed and delivered to multi-disciplinary teams (internal and external to care homes) that are involved in the ascertaining and implementing of people's wishes'. There may be other models of learning, of course, and it might be that housing with care staff and managers would wish to develop learning materials to cover other wider issues as covered in the section above.

The many interests involved in this area, have been noted by the Housing LIN as potentially having major implications for a provider organization. If as a result of the four step test of capacity included in the MCA, a person is considered to lack the capacity to make a particular decision, then that 'decision' becomes a preference. In that scenario, if by acting upon it, the person comes to harm which could have been anticipated; those with a duty of care (the housing with care manager and staff) could be deemed negligent. Garwood (2008a) adds, 'Most housing staff would not be expected to be experts in assessing capacity but must have a "reasonable belief", based on the MCA 2-stage test and objective reasons, that the tenant concerned lacks capacity'. This may be the approach that could be taken with Mr Smith at the start of this review.

In cases such as stroke, obtaining the consent of the person before proceeding with treatment is essential, as participation is central to success of the treatment. This has implications for people knowing and understanding the principles of the MCA, especially in terms of advance statements of wishes generally, and Advance Decisions to Refuse Treatment more specifically. The National Clinical Guideline for Stroke recommends that professionals take the initiative with these discussions sooner rather than later, and emphasises the inclusion of these discussions in routine practice (Intercollegiate Stroke Working Party, 2008).

There are other issues to consider alongside staff attitudes to ACP, namely attitudes which the public and mainstream media may hold towards ACP (Fried and Drickamer, 2010). Work by Froggatt *et al.* (2008) demonstrates that the presence of an ACP in a file does not necessarily link to actions based on it; in fact, they found it difficult to obtain evidence of anyone using them. Preliminary findings from other studies in this area suggest that, for older people, it is not the hypothetical possibility of becoming seriously debilitated that encourages them to want to discuss preferences, but the experience of something they do not want to repeat (e.g. hospitalisation) that galvanises them (Goodman *et al.*, 2010).

Research on the details of ACP and the other elements accompanying the MCA has recently commenced. Some of the earliest work was undertaken by Redley *et al.* (2006; 2008) on the Independent Mental Capacity Advocate (IMCA) scheme. Langan and colleagues are shortly to embark on a study of the Deprivation of Liberty Safeguards (DOLS) at the University of Bristol where Williams and her colleagues are also exploring the process of best interests' decision-making.

All these studies may have findings relevant to the housing with care sector. Findings may also emerge from the Mental Health Foundation's action learning approach to social care personalisation and its effect on services for people with dementia (the Dementia Choices project). Even more accessible may be the new Social Care TV training materials on the MCA. Housing with care services may wish to evaluate the use of these materials for their staff. Results from these studies are likely to influence future services, as well as the availability of other resources such as the MCA Audit tools that each service can independently use (see Social Care Institute for Excellence website).

An imbalance of this research focus is that many address major dilemmas or risk decisions rather than the day-to-day decisions and practices that are often evident in housing with care schemes. There is no evidence yet as to the wider take-up of the provisions of the Act by older people generally. Future tenants or residents, particularly those with suspected or early stages of dementia, may be more likely to make use of the provisions of the Act and would expect that its principles underpin the support they receive. This may be interpreted in terms of people having freedom to make day-to-day choices, such as continuing to live the way they did when in their own home, even if they could not remember what this was like. However, there are indications that enacting the provisions of ACP or the MCA may not relieve managers from the general role of negotiation and mediation when the views of tenants or leaseholders with high support needs, for instance, occur in the face of families' opinions, which might conflict.

We know little of how managers will balance these possibly competing demands, or how they will engage with relatives and others who have been given powers to act as the tenants'/leaseholders' proxy decision-maker. Counsel and Care has been among the first to point to the potential for conflict about the provisions of the MCA among professionals, family members with differing views and the relative concerned.

Enquirers are worried about situations where the wishes and wants of the older person seem to be disregarded in favour of the opinions of professionals (or sometimes other family members) once the older person has been assessed under the MCA Code of Practice as having lost mental capacity for all decision-making.  
(Passingham, 2010)

While aspirations for family involvement may usually be without contention, this situation is possible, leaving managers to seek support if they have serious concerns. Material about extra care housing may need to acknowledge that not all families act in their relative's best interests at all times:

Each resident will be encouraged (where they have expressed a wish) to participate in all decision-making processes and express their views. Where this is not possible a family/advocate or representative will be available. (Suffolk County Council, 2009)

## **Summary**

The MCA 2005 sets out clearly the value of ACP for people who face the potential of losing their capacity to make decisions for themselves and research is being undertaken in this area. Getting ACP right involves a number of macro factors, including staff training, family support, and positive public perceptions of ACP. It appears that public education campaigns that focus on ACP as a procedure to set out preferences of what one wants rather than just as a means of refusal may further enhance the potential for empowerment and safeguarding of ACP (Fried and Drickamer, 2010; Samsi and Manthorpe, 2010) and thus may change the culture of care and support for people with high support needs.

## **Staff (and family) access to support and training in communication and decision-making**

In this section we outline research findings about staff and family members' access to support and training. In many ways this is largely conceived as staff providing support to relatives in a rather unidirectional way: 'Staff make sure that tenants and relatives are kept informed and are given the chance to have their say' (extract from extra care brochure of Pennine Homes). There is a strong suggestion that, while staff may not have high levels of technical training, 'communication and listening skills' are attributes that are commonly desired. The implications of this for housing with care services are that such training may be shared locally, may be relatively inexpensive and that housing with care services together with social care providers may be able to build up local skill sets and experiences (Froggatt *et al.*, 2008).

There may be scope to address the training needs of staff not providing care directly in housing with care services, particularly auxiliary and housing related staff (cooks, housekeepers, gardeners and so on). In a recent consultation (February 2010), the regulatory body, the Care Quality Commission, recognised that individual and public expectations about care and personal choices are on the increase, as a result of which they prioritised the supply of relevant and timely information to enable and support people to make choices and decisions for themselves and their lifestyles. This suggests that choice, control and decision-making are likely to become of greater concern in housing with care services.

Research has identified barriers and facilitators to good communication and supported decision-making, especially for people with high support needs. Morris (2004) in work that focuses on people with mental health problems, observes that this is not a technical matter: 'Access is also about communication and attitudes. People appreciated when professionals used accessible language and had good communication skills'. Managers' and supervisors' role modelling in this area may influence the culture of the work. The employment of many staff whose levels of spoken English is not good has been identified as a problem in the area of communication by some researchers studying settings outside housing with care (only ten per cent of Scottish social services employers offer language support to staff whose first language is not English, Scottish Social Services Council, 2009). The impact of this in housing with care services is likely to be similar.

These attributes may be all the more important when we consider that it is not just interpersonal skills that are needed but that many people lack the support services that they need to be able to communicate. According to the newly established Adult Communication Coalition England (ACCE) (2009) at least 1.5 million people in England have Speech, Language and Communication Needs (SLCN); but many adults with SLCN do not receive the communication support, equipment and services they need, with wide geographical variations in access to these services. Without such support, the Coalition argues that people with SLCN are being denied opportunities to live independently or to participate in social activities and engagement. The Coalition calls for greater priority to be given to the needs of adults with SLCN through a national strategy. It proposes a national audit to assess service provision for adults with SLCN and to identify problems with access to assessment

and support. Housing with care services would then be able to benchmark their services with other provision.

Among people with high support needs, communication problems may be hidden by other disabilities or health care problems, such as stroke, deafness or visual impairment. Complications with aphasia can mask ability and people may be excluded from the decision-making process, highlighting once again the importance of specialist skills (Rowland and McDonald, 2009). Of concern is the finding from the National Audit Office (NAO) that there is little requirement for staff in care homes to be trained in communication (NAO, 2010). Guidance is available for people with other specific communication impairments, such as dual sensory impairments that suggest that individuals should be part of any decision-making for themselves and their lifestyles, and that all information and options should be made accessible to them. Furthermore, case records in housing services should include the preferred mode of communication for deafblind people (Lewin-Leigh, 2007).

In a review of research, Law *et al.* (2007) observe:

One of the key features of this group [meaning those with communication support needs (CSN)] is that, unlike those with more visible disabilities, their difficulties are less apparent and less easily recognised by the public. It is often difficult for the general public and service providers, when interacting with people with CSN to appreciate the nature of their experiences, and this can lead to false assumptions about the person's disposition, intelligence and mental health.

(Law *et al.*, 2007)

This suggests the value for housing with care services of ensuring that people with high support needs are able to access communication specialists from the NHS and for Housing with care staff to build up experiences and skills in this area.

Furthermore, there is the related importance of acknowledging ethnic diversity and any resulting differences in language use, or preferences for different styles of communication across tenants, families and staff. There is emphasis on informed choice within an inclusive environment that meets individual needs related to ethnicity, culture and migration status (Jones, 2008). There are, however, profound shortages of expertise and it may be that older people's services may find it helpful to access training and support from other traditional 'client group' areas. Research indicates that many service areas share similar pressures.

The Foundation for People with Learning Disabilities (2001) reviewed the communication needs of people with high support needs, concluding that people's choices are severely limited. Little or no verbal communication means that, even when they are expressing choices in their own way, there may be no recognition by those around them that they are doing this. It notes that people with high support needs can communicate choice, within their own experience, but other people (staff and families) have to be sensitive, aware and responsive to their ways of doing so. Key findings were that through building relationships, over time, staff learned to recognise different individual forms of communication. However, communication is only effective in the context of knowing the individual well and for many people with high support needs their communication may be seen as 'challenging behaviour'.

The costs of ignoring support and training in this area are therefore substantial for the public purse as well as profoundly impacting potentially on people's quality of life. Lowery and Warner (2009) comment, in the context of dementia care, that:

Heightened empathy and understanding might encourage greater persistence and more tolerance when caring for someone displaying BPSD (behavioural and psychological symptoms of dementia). Training care staff in simple behavioural techniques can help avoid the onset or limit the impact of BPSD. (Lowery and Warner, 2009)

The impact of the extensive investment in brief psychological therapies in primary care on housing with care services appears to be unknown.

In terms of availability of training, many resources are available on the internet and freely downloadable. The Housing LIN, for example, provides details of relevant toolkits for staff. Other types of training material (for example, about the Mental Capacity Act) are also generally available from websites. There is, of course, the assumption that staff will seek these resources of their own volition, and perhaps it is at this point that more could be done to advertise the availability of these resources, to audit their take up, and to ensure that induction of all staff includes communication.

There is a risk of seeing communication as purely instrumental, as a means to an end. From the United States, Seipke (2008) explored communication by 25 older women (aged 72-99) about their transition to assisted living (the US equivalent of housing with care) and their personal sense of self. In this study the effects on women's self-identity of their move were symbolised for them by their loss of identity as home-makers. There seems to be a paucity of studies from the UK into how adjustment to housing with care may be negotiated. There appears to be no information on how this transition might be eased by access to counselling or volunteer befrienders in housing with care settings.

## **Summary**

For people with high support needs, such as dementia and stroke, as well as other conditions that may compromise communication, specific training guides and tools can be beneficial to all staff as well as to family members. Understanding that all communication needs to be in the context of individual personalities and preferences can be part of skills development, supervision and role modelling.

This recognition also has significant implications for understanding 'challenging behaviour' or needs at end-of-life amongst people with high support needs. Training at local level can be accessed through communication with local networks such as Skills for Care, as well as local and national networks of housing providers across sectors. Models of local partnership around training and skills development seem most promising – especially at a time of financial stringency but also to take account of the part-time status of many staff.

## The adequacy and effectiveness of support and training for staff and for families

During our visit to a resident in local authority sheltered housing, we heard of elderly residents' frustration over the lack of consultation and communication by the local authority as to how services were delivered. It was claimed that residents were not consulted about changes to their services and that the local council tended to convene meetings relating to sheltered housing in venues which were inaccessible to elderly people. We also heard that communications with residents from the local authority and health services were confusing, leading to a lack of understanding amongst residents as to what services were available to older people in the area.

(The Supporting People Programme – Communities and Local Government Committee, 2009)

There is a danger of judging the adequacy of support and training at the level of frontline staff rather than organisationally as indicated in the quote above. It is not clear how good practice at the organisational level develops. How do the activities observed by Garwood (2008b) in one extra care facility include residents and their families? Are these the best routes of communication or are there other channels? How are these accessed by people with high support needs?

Formal opportunities through monthly street meetings followed up by 'Streetwise' (a newsletter), Residents' Association meetings, specific topic panels, surveys, suggestions, compliments and complaints as well as continuous informal opportunities for exchange. These also include regular meetings with Arena's Executive team and service panels. Notice boards and white boards around the village are used for posting information, including 'what's on'.

(Garwood, 2008b)

Such communications need to ensure that informal opportunities for communication 'in the present' are perhaps recorded and monitored to ensure that people with high support needs are not overlooked. As the Joseph Rowntree Foundation observed in its submission to the Select Committee on the Dementia Workforce (JRF, 2009), there are groups who may be overlooked in the development of training strategies. These include night-time staff supporting people with dementia and staff supporting people who have learning disabilities and dementia. This latter group may be increasingly taking up opportunities to live in housing with care services. We know little of the possible adaptation of models of supervision from different professional settings to housing with care services and what works best in terms of staff support and outcomes. One alternative model that may be worth investigating is the growing experiences of people employing their own care and support staff (see Williams *et al.*, 2009) and what they want to see included in support and training. How relevant could these experiences from disabled people and from their Personal Assistants be in housing with care services?

The idea that, because verbal communication may be impaired then all communication is lost, has to be challenged; meaningful communication can

still occur. In reality over 80 percent of our communication is nonverbal. Our facial expression, gestures, body posture and whether we make eye contact or not, all communicate something to the person.  
(Chapman, 2009)

This observation means developments of techniques such as Talking Mats® provide new opportunities for enhancing the repertoire of staff skills in communication and decision-making with people with dementia. JRF research (Murphy *et al.*, 2007) reveals that conversations using this tool are more effective for people with dementia than unstructured (ordinary) or structured conversations, and seem to lead to improvements in the participants' understanding, engagement, ability to keep track and to make their views understood. Staff will need to be trained and confident in using Talking Mats; and they will need to find their place in records; in multi-disciplinary discussions and of course they will need the time to undertake such work as well as being able to participate in regular management support (Macer and Murphy, 2009). The nature of support for staff continues to be less of an object of concern and research interest than training.

Recent consultations with front-line workers in dementia services reveal that they feel that they receive little managerial support in their day-to-day practice. JRF (2009) concludes that because work with people with dementia is emotionally demanding for both staff and managers, training will not be effective on its own. JRF's view is that 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 would be worth investigating (JRF, 2009).

## Gaps in the research

There may be similar needs across housing, health and social care services for greater concentration on communication and decision-making support. Law *et al.* (2007) suggest that all staff working in healthcare would benefit from communication training which fosters awareness and understanding of the needs of people with communication support needs. Tailoring this to housing with care settings needs different nuances: notably, the need to develop skills among groups with highly varied needs or wishes; balancing communication internally and externally and between different staff teams with different roles, functions and employers. We also know little of the role of supervision and opportunities for reflection, in extra care or similar schemes, although studies indicate its importance in managing distress and conflict (Bernard *et al.*, 2007).

Law *et al.* (2007) argue that simple changes to the physical environment may improve communication between people with communication support needs and healthcare staff. Has the housing with care sector got it right? Are housing with care IT systems able to capture structured conversations (e.g. about end-of-life care) as well as informal engagements (e.g. the presence or absence of family or volunteer social interactions)? Can housing with care services make the most of auxiliary staff such as cooks and gardeners to assist when the worlds of tenants/leaseholders perhaps begin to shrink as individuals become frailer?

Furthermore, Law *et al.* (2007) identify that gaps in the research literature around housing include the subjects of limitations of choice, lack of privacy, abuse and exploitation, and increased probabilities of social deprivation. While these may have been covered slightly more rigorously in clinical and care settings, they are not explicitly addressed in many housing with care studies. There is a tendency in research in this area to see all communication as positive, missing the risks of bullying, discrimination or mistreatment.

In the context of current policy that suggests re-provision and closure of some care homes (DH 2009b; HM Treasury 2009), the demand for and pressure on housing with care services is likely to increase. This may subsequently impact on recruitment and training for skilled staff as people with profound disabilities are likely to stay on in housing with care services for longer. If the current system of NVQs (Non Vocational Qualifications) changes as they are set to do at the end of 2010, it will be interesting to see whether they recognise the importance of communication and decision-making skills in housing with care services.

Finally, while communication and decision-making are features of practice with older people with high support needs in housing with care settings there is little attention to safety for team communication, handovers and knowledge transfer amongst the team. While safety in NHS settings is sometimes constructed as a technical matter, within housing and care services it may bring new elements of quality of support that may help to underpin aspirations for quality of life. The growing international interest in safety outside healthcare settings may be a feature of future research.

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## **Appendix 3:**

# Attitudes to frailty, disability and end-of-life in housing with care: a brief review

**John Percival**

## Introduction

In preparation for this review, amongst others, two operational staff and one housing strategy officer were contacted for their immediate thoughts on attitudes to frailty, disability and end-of-life in housing with care. One estate manager with responsibility for a large housing with care scheme, which opened a year ago, said that at least half the tenants are 'very negative' towards those with a physical disability or frailty and added:

I have found that residents of an older generation are generally scared of what they see and [they] believe [frail residents] should not be in extra care facilities ... It is the attitude that they should be out of sight.  
(Estate manager for large housing with care scheme)

A care manager working in a housing with care scheme also remarked on a certain level of unease at the manifestation of frailty when she told me, 'they [fit tenants] are more tolerant of people who do not have a 'visible' difference than those who have a dementia or are confused'.

As we will see in this short review, perceptions of the 'other' as in some way different and threatening can figure largely in the minds of older people who are living in close proximity to peers with obvious deficits. The 'community' environment in which extra care tenants live brings into sharp focus, and perhaps helps foster, attitudes and behaviours that at times seem reminiscent of childhood friendships, conflicts and exclusions. Indeed, the housing strategy officer I spoke with referred to the 'bullying' that sometimes takes place when tenants' dislikes are enacted, behaviour she summed up as 'playground stuff'. This officer went on to say that the residents' committee had recently 'fallen apart' as certain tenants were no longer talking to each other.

Although examples of tension were readily called to mind, all three informants were careful to point out that this is one side of the coin and that significant numbers of tenants living in housing with care settings can and do get on as good neighbours and, sometimes, as good friends, regardless of differences in physical or cognitive ability. The fact that both tensions and tolerance co-exist makes for an interesting, if at times perplexing and challenging, environment and also prompts members of staff to consider ways in which tenants can be helped to get on better.

This review will explain and expand upon some of the current knowledge in respect of attitudes towards frailty in housing with care settings. It will also include attention to areas of practice and development about which we need to know more, as well as the priorities and initiatives that could be further explored.

## What we know: key evidence

### Social cohesion and relationships between 'fit' and 'frail' tenants

Maintaining good social relationships is a major factor contributing to older people's quality of life and their mutual support is a valued aspect of life for tenants living in sheltered housing schemes and retirement communities (Phillips *et al.*, 2001). Tenants' attitudes towards each other are important for a number of reasons, not least the effect on experiences of quality of life. Oldman (2000) has drawn attention to research that suggests tenants who have dependencies because of frailty view their relationships with peers, their social activity and their self-determination as key aspects of quality of life. Tenant interaction can, for example, help prevent deterioration in those with dementia (Kitwood *et al.*, 1995).

We can infer, therefore, that it is in tenants' best interest to get on with their neighbours in housing with care settings. Living alongside a preponderance of frail older people can, however, emphasise the more negatively experienced features of an age-segregated setting, particularly for younger, independent or socially oriented tenants (Percival, 2001). We know, moreover, that there are 'segregationist impulses' at work in 'ordinary' sheltered housing schemes that accommodate both 'fit' and 'frail' residents (Fennell, 1986, p. 75), with the former sometimes showing a lack of tolerance and a level of resentment that can effectively exclude or marginalise the latter, especially when physical or sensory impairment or cognitive deficits feature.

Studies of ordinary sheltered housing reveal a number of reasons why 'fit' tenants may be intolerant of those seen as 'frail'. Tenants with care or support needs may demand more time of the 'warden' or estate manager, make more use of limited laundry facilities in a scheme, slow down the pace of social activities in which they participate, or have poor personal hygiene that challenges the onlooker's sensibilities. An overriding concern is the perception that the setting increasingly resembles a nursing home rather than a dynamic, self-affirming social environment (Percival, 2001).

Studies also indicate that in housing with care settings, tenants with physical frailties, impaired mobility and cognitive impairments are less socially integrated and have lower levels of social interaction compared to peers who are more able bodied (Evans and Vallely, 2007; Croucher *et al.*, 2006). In a review of relevant literature in respect of housing with care settings, Croucher *et al.* (2006) note that a variety of studies indicate 'prejudice, hostility and discrimination towards those who are disabled'. A recent study by Evans (2009, p. 96) describes a mixed picture, with some retirement village residents complaining about living alongside neighbours who they perceive as 'decrepit', while others are helpful and supportive towards those less able.

### Attitudes towards tenants with dementia

As many as one quarter of tenants living in housing with care settings has a diagnosis of dementia (Henwood, 2009) and this proportion is increasing (Evans,

2009). A recent longitudinal study of the benefits of extra care housing for tenants who have dementia has found that this resource can provide a good quality of life and maximise independence (Vallelly *et al.*, 2006). This population may also be at risk of social isolation and loneliness (Henwood, 2009; Evans, 2009) or being stigmatised (personal correspondence from a housing with care estate manager; Garwood, 2008).

Garwood (2008) highlights environmental and social factors affecting tenants' well-being, citing a relative's concerns at the very large spaces and long corridors, as well as a group of tenants perceived as 'forceful characters', leading to the individual's social isolation. Garwood concludes that to succeed in housing with care settings, prospective tenants have to be motivated to live independently, able to cope with the scale of the environment, able to 'hold their own' in a large heterogeneous community and have a level of dementia not likely to cause isolation or disorientation.

We know from studies of social interaction in residential care homes that dementia can lead to or emphasise antagonism, for example if residents misidentify their neighbours or misplace possessions (McGrail *et al.*, 2001). As regards sheltered housing, Kitwood *et al.* (1995) indicate that tenants with dementia are more readily accepted if they are in good physical health and sociable and seen to be well supported. Studies generally tend to conclude that housing with care settings can adequately support tenants with mild levels of dementia but struggle to deal with the personal and social challenges presented by those with higher levels of dementia (Evans, 2009).

One American study has found that a reason why residents with dementia have to leave their assisted living environments and move to nursing facilities is because of behaviour that is at odds with community norms (Aud, 2002), a finding that resonates in housing with care settings in the UK (Henwood, 2009). Bernard *et al.* (2007, p. 570) found that both residents and staff in a retirement village had difficulty coping with residents who wander and that this behaviour was 'not acceptable'.

There is some evidence that tenants in housing with care settings can be supportive of individuals who have dementia and in some cases form close friendships, although this positive interaction may not extend to welcoming the involvement of people with dementia in a scheme's social activities (Vallelly *et al.*, 2006). Overall, research indicates that many if not the majority of tenants with dementia enjoy relatively few opportunities for meaningful social engagement with fellow tenants or, indeed, with staff (Evans and Vallelly, 2007).

Furthermore, it is clear from Croucher *et al.*'s (2006) literature review that tenants with cognitive impairments are often socially marginalised in housing with care settings. Specialist units in housing with care settings for people with dementia may provide focused care and attention but integration and social interaction with other tenants in the setting are limited (Evans, 2009).

## Impact of level of fitness/frailty at point of entry on peer relationships

We know that sheltered housing residents can show antipathy towards peers with dementia or physical infirmities that require care services, especially when such tenants are new to a scheme and therefore not known as rounded personalities (Percival, 2001). We also know that established tenants who develop significant physical or cognitive deficits are more tolerated and treated more compassionately than those who are similarly disabled but new to the sheltered housing community (Lloyd, 2004a; McGrail *et al.*, 2001; Percival, 2001). Indeed, Wright *et al.* (2009) indicate that some providers are prepared to offer places to people with mild dementia on the assumption that they will become known and tolerated by other tenants, before the condition worsens.

As regards housing with care settings, Wright *et al.* (2009) describe how established tenants can resent newer tenants if they appear 'sick', have a sensory impairment such as deafness, or otherwise present with obvious support or care needs. Similarly, Garwood (2008) makes the point that tenants seem to accept that fellow tenants may over time become unwell and/or develop care and support needs but are less inclined to accept this of new tenants, who are criticised for changing the atmosphere of the scheme to one resembling a nursing home. Garwood adds that established tenants complain that not enough younger, fit tenants are moving in, that the environment is 'turning into a hospital' and that 'they don't seem to get people in who want to volunteer'.

Very similar sentiments and, indeed, remarkably similar language is used by tenants talking about social life in ordinary sheltered housing schemes, where tenants complain that people who are 'sick' should not be placed there as they 'don't want to come down and join in the jollification' (Percival, 2001). The contention that a balance of tenant abilities offers the potential for fit tenants to exercise leadership (Wright *et al.*, 2009) may be theoretically robust but it is clearly also important to acknowledge the practical implications of community dynamics and personal priorities in age-segregated environments.

A housing with care community is sometimes characterised by hierarchies and elites who operate a pecking order, noted by Garwood (2008) when a tenant with support needs spoke of her face not fitting because there are fellow tenants who are the 'elite' and who 'take over the place' and 'bully' her and tell others they can't wear slippers in the main lounge. Indeed, there are subtle but significant ways in which 'outsiders' – those new to sheltered housing schemes or seen as somehow different – are introduced to and integrated with the social and cultural norms of community life in a scheme (Percival, 2000, 2001).

Goffman (1990, p. 12) suggests that newcomers are initially judged on first appearances and given a 'virtual social identity' and only further evidence can reveal an 'actual social identity'. Therefore, if the actual personal identity is to be acknowledged and respected, fit tenants will have to make an effort to get to know the frail individual and their previous life experiences. Operational staff in housing with care settings revealed that new tenants are more readily accepted if they are 'subservient' rather than 'willing to voice an opinion', an indication that established

tenants in such communities wish to maintain their status and standing as dominant within the community and expect new tenants to be demure and respectful rather than demonstrative and independently minded.

As we go on to discuss in more detail, the effort needed to get to know and empathise with frail tenants is further complicated by the effects on self-esteem of living closely with other older people in a mixed ability, age-segregated community.

### **Ways in which attitudes and levels of understanding about frailty and disability affect the housing with care community**

The experience of and meanings attributed to the word 'community' are key to understanding social interactions in age-segregated settings. Studies of ordinary sheltered housing indicate that good neighbourliness and informal care do take place but there is evidence that this outlook will vary according to whether 'fit' tenants perceive the environment as primarily a socially oriented setting or a care oriented one. Tenants of the former persuasion appear to be less inclined to tolerate frailty and its physical manifestations, such as wheelchairs, putting forward the view that the scheme was set up for older people who are independent and socially inclined, not for those who are dependent on carers or who are unable or unwilling to mix (Percival, 2001; Lloyd, 1995).

Studies of sheltered housing environments also suggest that admitting one's frailty can undermine 'self-image' (Ballinger and Payne, 2002, p. 305) and reveal a vulnerability that tenants fear may put at risk their housing security (Percival, 1999; Riseborough and Niner, 1994). Independent tenants are therefore sometimes inclined to distance themselves from those who are frail and it follows that some tenants in housing with care settings, where there is usually a mix of abilities, will harbour similar attitudes. Indeed, in their study of retirement communities in Britain, Phillips *et al.* (2001, p. 204) suggest that negotiating the 'boundaries' of frailty-acceptance is problematic, as tenants are anxious about possible future status. Tenants sometimes talk of care provision changing their own and others' perception of the scheme.

The relationship between environment and self-image is also addressed by Garwood (2008), who notes that antipathy may arise because tenants do not want to live 'side-by-side with reminders of their own possible decline in health'. Garwood reports that some tenants complained about the large numbers of fellow tenants with support needs or who required wheelchairs, leading one respondent to comment 'we're nearly falling over them' and others to allude to the environment as a 'dumping ground'. Studies indicate that some tenants are put off socialising with neighbours whose disabilities or care needs are visibly obvious. One reason may be that this holds up a mirror of ageing and mortality that reflects badly on the onlooker and which the onlooker prefers not to see or feels tainted by. Indeed, this perception perhaps reflects society's negative attitude towards ageing and the primary role of physical appearance in the social construction of age categories (Featherstone and Hepworth, 1993), a perception heightened in age-segregated settings.

However, the picture in retirement communities is not all gloomy. As Phillips *et al.* (2001) point out, mutual support, compassion, reaching out and sharing are positive

features of social interaction between 'fit' and 'frail' tenants. Evans (2009) also points out that retirement village residents can be supportive towards their less able neighbours and earlier studies of ordinary sheltered housing settings find similar examples of reaching out to those less able (Middleton, 1987; Jerrome, 1992; Percival, 1998).

There is also evidence from research in retirement communities that tenants' attitudes can soften over time as they adapt to living with peers who are more frail, a process that can involve 'fit' tenants assuming the role of helper to those immediate neighbours who are 'frail' (Croucher *et al.*, 2003). This perception is also held by operational staff, one of whom reported that 'there is a certain degree of comradeship amongst the residents', though this worker went on to say that that this comradeship is 'dependent on whether you are seen to be befriending the right people, as with all groups of people they can be very cliquey'.

What seems apparent in the literature is that tenants need psychological elbow room and boundaries because of their close proximity within the age-segregated community and its effects on their self-identity as an ageing person and also because of a fear that reaching out may have no limits and be taken advantage of in a setting where needs for help are increasing all the time. There is, therefore, a tendency to reject frail fellow tenants and wish them to be 'out of sight', as one housing with care manager recently told me. There is also some indication that sheltered housing staff can become demoralised if a scheme houses significant numbers of frail tenants (Parry and Thompson, 1993).

### **Actual or possible impact of attitudes on capacity of schemes to offer a home for life for those with high support needs**

We have little empirical evidence of how housing with care settings operate on a day-to-day basis in regard to maintaining social equilibrium between tenants. As a result, it is very difficult to speculate about the possible link between attitudes to frailty and perception or capacity of the environment as a 'home for life'. Bernard *et al.* (2007) found that residents living in retirement villages were not confident that they could remain there if their health deteriorated; a significant minority of residents questioned whether their retirement village could meet end-of-life care needs, some indicating that a nursing home environment would be more suitable because of the ready availability of trained staff who would be on hand to provide personal care. The study concluded that the retirement village did, in fact, provide support rather than care for residents, which naturally casts doubt on the setting's ability to be a home for life for its more disabled residents.

Generally, the available evidence does not support the contention that housing with care provides a home for life for people with high level care needs, those with challenging behaviour, or those with a higher than moderate level of dementia. As discussed, this is partly because of antipathy by fellow tenants, and sometimes by staff, but also because providers may have difficulty maintaining a skilled and trained workforce or delivering sufficiently flexible care and resources, especially the case if adequate social services funding is not available (Croucher *et al.*, 2006).

According to Vallely *et al.* (2006) extra care housing is providing a home for life for about half of residents who have dementia. Many tenants with high support needs such as dementia cannot be cared for indefinitely in this setting because staff do not feel equipped to provide the levels of care required or because fellow tenants will not tolerate challenging or worrying behaviour that may occur (Henwood, 2009). Although schemes may promote themselves as homes for life, in practice this has to be realised on an individual basis and those with severe dementia may require more care than can be provided in the housing with care setting (Garwood, 2008).

## **Ways in which severe impairment, end-of-life, death and loss are addressed and articulated**

Bereavement appears to be keenly experienced in the ordinary sheltered housing environment and may exacerbate other feelings of loss encountered in old age (Percival, 2001). Loss resulting from the death of fellow tenants is also keenly felt in retirement communities (Bernard *et al.*, 2004) and over time the frequency of loss may become a negative feature in housing with care settings (Croucher *et al.*, 2003).

We know from studies on death and dying in residential care and nursing homes that end-of-life care issues are complicated by staff members' lack of confidence, personal unease and difficulty talking on the subject to residents (Percival and Johnson, 2009). Such concerns are emerging in housing with care settings and the small scale studies so far conducted in these settings indicate that staff support and training needs have to be better understood so that they can be adequately planned and provided for. At the same time, tenants' views and preferences in regard to end-of-life care have to be sensitively ascertained and incorporated in care planning, if the housing with care setting is to offer an individual and personal approach to end-of-life care provision and a home for life in reality.

Retirement village staff in the study carried out by Bernard *et al.* (2007) had concerns about their ability to support bereaved residents, while residents and their families expressed unease at the frequency and proximity of death in the age-segregated setting, affecting residents' morale and the atmosphere of the place. In Garwood's study (2008), there was evidence that tenants with terminal care needs were enabled to live and die in the scheme, where appropriate nursing care was provided. However, scheme staff are also pivotal and need to work in productive partnership with community care professionals. Croucher (2009) outlines recent research that considers the delivery and effectiveness of end-of-life care in housing with care settings. Croucher concludes that staff in such settings benefit from close working relationships with community-based palliative care professionals, which helps bring about a more integrated service for relevant tenants.

In the study reported by Crosbie *et al.* (2008), cited in Croucher (2009), there was no formal mechanism for recording tenants' views or preferences regarding end-of-life care. It was also found that staff were ambivalent about providing end-of-life care, because of the resources required, their lack of palliative care skills, uncertainty about whether talk about dying would upset tenants and the emotional effects on staff when dealing with death in a scheme. These feelings and perceptions are not unique to staff in housing with care settings and are commonly noted in studies of residential care and nursing care homes (Percival and Johnson, 2009).

In the small study reported by Easterbrook and Vallely (2008), cited in Croucher (2009), schemes where staff and tenants were informed, consulted and supported in respect of end-of-life care issues were more likely to have provided effective and open communication, as well as suitable recording, in comparison to schemes not involved in this pilot work, although a certain amount of staff ambivalence was also evident. Additionally, staff were more knowledgeable about symptoms and signs of deterioration and how to respond, and were also more informed about local specialist services and how to access these. Recommendations of this report include the need for clear and concise information about housing with care, of use to tenants and their families as well as housing and social care agencies.

An important message coming out of Croucher's (2009) report is that communication about end-of-life care is a pivotal issue for tenants and staff in housing with care schemes and that, additionally, staff require good up to date information and training on the subject. Furthermore, while care needs are important, individuals' personal, spiritual and cultural values must also be taken into account. Death and bereavement are part of life in housing with care settings and staff indicate a need for relevant skills training in order to provide bereavement counselling (Bernard *et al.*, 2007).

### **Available learning about ways in which attitudes change or can be changed and how residents with different levels of need can be encouraged to support and engage with each other**

In recent communication with operational and strategic workers involved in housing with care, I was told that staff accept they have a role in managing discord between tenants, of whatever type and for whatever reason, and believe it is important to promptly confront and challenge any anti-social or negative comments. In addition, staff are of the opinion that promotion of group activities and facilitation of attendance by tenants with support needs will help raise the profile of the latter and establish their right to inclusion in future groups. To this end, staff encourage coffee mornings and 'invite people to discuss topics around illnesses and disabilities to make residents aware of support and encourage understanding of others', a good example of direct communication about the issues that give rise to intolerance and segregation of others.

Such staff initiative raises questions about training and resources. Staff need to be both assertive and tactful (Garwood, 2008) and have adequate training and support so as to manage group dynamics and conflict amongst tenants (Bernard *et al.*, 2004). Staff need to create an ethos of tolerance from the opening of a scheme and persistently thereafter (Garwood, 2008). Some of the behavioural challenges presented by tenants with dementia can be positively managed when staff receive relevant training that helps them put into practice good quality person-centred support (Evans *et al.*, 2007).

It is therefore important for staff in housing with care settings to have more time to sit down, chat with and get to know tenants as individuals, offering much needed interaction for those who are frail and have few if any social contacts (Evans and Vallely, 2007; Lloyd, 2004a). One other potential benefit of such interaction is the

greater knowledge obtained about socially isolated individuals and their particular interests and aptitudes, which could, in turn, help resourceful members of staff initiate bonds between that individual and other tenants with similar interests or experiences.

Studies suggest that providers of housing with care schemes have a role in informing and raising awareness of all tenants in respect of dementia and its possible consequences, in order to allay fears (Vallelly *et al.*, 2006). This educational role within housing with care settings could, perhaps, be extended to help build tenants' awareness, understanding and skills so that they can confidently and effectively communicate with neighbours who have a range of physical, sensory or cognitive deficits.

To the author's knowledge, there are currently no initiatives that focus on this educational role in respect of work with tenants, although organisations such as the Sheltered Housing Network (SHN) organise training events for staff that are expected to provide them with necessary skills to raise tenants' awareness and understanding on issues such as dementia, mental illness and alcohol and drug use (personal correspondence from the head of research at SHN). Direct work with tenants, to raise their levels of understanding of and empathy with those who are frail, is recognised as an important but as yet unfulfilled aspiration (Lloyd, 2004a).

One very important but often overlooked aspect of staff responsibility for tenants' social engagement is the pivotal role of the scheme manager. There is much anecdotal evidence that the operational staff manager of a sheltered housing scheme significantly influences the social atmosphere of the scheme and directly affects the ways in which tenants perceive the scheme as a socially inclusive setting (Percival, 2000). As Evans and Vallelly (2007) have noted, the philosophy of care operating in housing with care schemes can directly affect the social setting and levels of well-being, which should alert us to the roles of those in charge of such settings and their impact on that philosophy and the social atmosphere that ensues.

### **Skills, information and models of care that would equip staff to fulfil a facilitation role**

It is important that those responsible for providing housing with care are clear and honest at the outset about its aims, so as to promote greater tolerance and understanding of those with care needs (Evans and Vallelly, 2007) and to do this in writing, or on tape for those with vision impairment, rather than simply rely on verbal information (Sue Garwood, personal correspondence). Garwood (2008) also makes the point that providers need to be more transparent about the levels of care they cater for, so that all prospective tenants are well informed and, implicitly, better prepared for life in a scheme. In addition, Garwood advocates providers being clear that schemes will house people who are frail and very old, some of whom will have dementia or learning disabilities.

Garwood also suggests that policy wording has to be clearer so that 'home for life' comes across as a 'determined aspiration rather than a promise'. Information about housing with care therefore needs to be explicit and include reference to the

environment as a care setting as well as a social setting, so that tenants are aware at the beginning that they are entering a mixed ability community.

It is also the case that providers should exercise caution in promoting the social advantages of life in housing with care schemes and need to be prepared for, and understand, the shifts in social motivation that characterise daily life in age-segregated settings (Percival, 2001). One particular way in which providers could usefully provide accurate information would be within group discussions set up for those older people who have expressed an interest in possibly moving to a housing with care scheme. At such meetings, prospective tenants could learn and ask questions about daily life in their local schemes.

It is now recognised as good practice to arrange trial visits and assign a staff member to oversee the moving in process, in order to help people manage the transition to residential care homes (Help the Aged, 2009). In a similar way, a model that seriously attends to the information and support needs of prospective tenants of housing with care settings would establish a mechanism for preparing people for the social, support and care community they are about to enter. Facilitators of and participants in such groups may usefully refer to the experiences of Dutch older people who attend preparatory meetings for group living (Brenton, 1998).

Support for the growing population of tenants with dementia requires models of care and staff training that recognise the tensions and challenges involved as well as a balanced approach to risk (Evans, 2009). Studies suggest that staff in housing with care schemes need more specialist training about dementia, particularly in respect of the behaviours that can result from this condition (Vallelly *et al.*, 2006). It is important to recognise that staff cannot do everything; indeed, staff levels are often low at critical times, for example after 5pm and at weekends. In addition, the development of links between housing with care schemes and local neighbourhoods may help foster greater opportunity for tenants' social interactions with other older people and, in so doing, could go some way to reduce the tendency for clique formation and other manifestations of social introversion within schemes, most obviously beneficial to those who feel socially isolated or excluded within a scheme.

Although staff-led social activities are the norm in housing with care settings, there is some evidence that, in comparison, tenant led social activities may offer opportunities for social engagement with a greater number of tenants (Evans and Vallelly, 2007). A further development worth considering is that of employment of an outside facilitator, perhaps funded through Supporting People, to work with groups of tenants to help raise awareness and understanding of disability and associated needs, a model already established in some ordinary sheltered housing schemes, albeit with an emphasis on support to individuals rather than groups of tenants (Lloyd, 2004b).

The design of housing with care schemes and, particularly, the layout and configuration of corridors and sitting areas, can affect opportunities for incidental and small scale social meetings that may appeal to those who eschew, for whatever reason, social gatherings in large communal lounges (Percival, 2001).

## What remains to be learned about relationships between the ‘fit’ and the ‘frail’?

Current research regarding housing with care suggests we do not yet know enough about what constitutes well-being and social cohesion in such settings (Evans and Valletly, 2007), nor whether they provide an adequate service to tenants with widely different needs and abilities (Bernard *et al.*, 2007). The evidence base is also limited in regard to the social engagement and quality of life of tenants with dementia (Henwood, 2009) and generally we know little of daily life from tenants’ perspectives (Bernard *et al.*, 2007), nor the extent to which older people living in housing with care settings experience or overcome potential social fissures. In short, there are no clear indications about whether housing with care can successfully support diversity (Evans, 2009).

It would also be interesting to explore generational aspects of intolerance and exclusion of fellow tenants who are frail or disabled. There is some suggestion, recently put forward by two operational staff I talked with, that the older cohort of current housing with care tenants grew up in a time when ‘people were ashamed and did not accept people who ‘were not right’’. These fit and older tenants are also seen to be more ‘insular’ than others. Although contemporary society is by no means fully accepting of citizens with disabilities, it is likely that future cohorts of tenants will have lived in comparatively more tolerant times and may therefore hold more inclusive views towards neighbours who are frail.

We can infer from relevant studies (Evans *et al.*, 2007; Aud, 2002) that better staff training and resulting good quality person-centred care for tenants with dementia will help in the management of behaviour that challenges community norms and this would be a fruitful area for further research. There is some evidence that tenants are prepared to extend the hand of friendship on an individual basis to neighbours who have dementia but are less inclined to do so in the social activity forum.

This interaction differential merits further investigation, particularly as engagement in social activities is a good way in which tenants with dementia and those who cannot easily socialise outside the scheme can improve their quality of life (Valletly *et al.*, 2006; Evans and Valletly, 2007). We also need to discover why staff in housing with care settings appear to provide little meaningful interaction with residents with dementia and whether attitudinal changes, key-working patterns or other initiatives can promote better practice and, by implication, provide a setting that is an actual home for life, an important concept albeit one that is poorly defined in respect of housing with care.

A more robust evidence base about housing with care would include greater attention to the setting’s potential to provide end-of-life care (Henwood, 2009). To date, studies carried out in respect of end-of-life care in housing with care settings have been interesting, although small scale and limited in number, and a range of larger studies would provide greater detail and information about how these settings can support people with their end-of-life care needs. For example, we do not yet know enough about how death and dying is experienced or dealt with in housing with care settings. Furthermore, we need to understand residents’ information and

support requirements when they are emotionally affected by a fellow tenant's end-of-life condition or death.

We also need to know more about how housing with care settings can best bring about a culture of openness and good practice that encourages staff to carefully listen, ask open-ended questions and provide individual care that is attuned to the tenant's personality, life history and preferences. It would be useful to explore how staff can develop local networks and shared understanding with relevant professionals working in the wider community.

We also need to consider more concertedly the relationship between environment and social behaviour in housing with care settings. For example, an interest in friendliness has to be 'tempered' by respect for privacy and personal space in shared living settings, where overtures of friendship can be seen as intrusive at close quarters (Cooper *et al.*, 1994, p. 22). This finding suggests that the size and layout of corridors and flats within schemes may influence attitudes to social engagement between tenants, an aspect that would benefit from further exploration in the housing with care environment, as would the potential benefits of more informal, chance meeting places in schemes. It would also be useful to investigate ways in which the role and characteristics of the scheme manager influence the potential for social inclusiveness in housing with care settings, a subject of research that, to the author's knowledge, has not been probed sufficiently.

Finally, we need research that attempts to evaluate the actual or potential for housing with care to provide a home for life. More concerted research, such as that outlined above, would inevitably serve to illuminate this issue.

## Key opportunities for and constraints on engagement and progress

Government commitment to the development of housing with care is apparent in the £180 million it allocated to provide additional extra care housing between 2004 and 2006 (DH, 2003) and a further £80 million for the period 2008 to 2010 (DH, 2009a). What are the drivers for such investment?

The National Service Framework for Older people (DH, 2001) promotes service provision that maximises opportunities for choice, independence, security and social inclusion, features often highlighted in marketing material about housing with care. The Sure Start to Later Life (ODPM, 2006) policy is also a key initiative focused on well-being for all older people. In relation to health and social care, the report states that all older people should have access to a fair and transparent health and care service, delivered with dignity and respect, responsive to the needs of individuals, accessible to communities and forward looking and preventative in its approach.

For some time, traditional forms of housing for older people have had a poor image and been seen to undermine dignity, respect and independence (Wright *et al.*, 2009; Fisk, 1999). The Department of Health (DH, 2005) indicates that housing with care is a suitable alternative to residential care as it offers the individual greater opportunity for maintaining independence and choice, benefits enshrined in a recent Green Paper (DH, 2009b), which emphasises a central policy to help people stay independent in their own home for as long as possible. The National Housing Strategy for an Ageing Society (DCLG, 2008) emphasises the beneficial role of housing in regard to health and quality of life, highlights the need for specialist housing for people with mental health needs and also points out that retirement housing has a role in supporting diversity and social interaction. Furthermore, the Government emphasises opportunities for the preventative role of extra care housing in regard to people with high level care needs (DH, 2006) and as a resource suitable for people who are both 'fit' and 'frail' (ODPM, 2003).

Recent policies, including the Government's *National End of Life Care Strategy* (DH, 2008), focus on ensuring that older people maximise choice and control over their lives and also over the place of their death, which has implications for housing with care settings and those tenants who view their scheme as a home for life. The End of Life Care Strategy draws attention to the importance of workforce training and development, which is likely to be an ongoing need in housing with care settings, as it is in residential and nursing care homes.

Good quality care that enables people with dementia to remain living in assisted housing settings relies upon a relatively high staff ratio (Aud, 2002). Resource constraints and pressure on staff time can severely limit the availability of social activities, provision that helps foster social interaction, friendship and well-being, not least for those who are isolated and/or who have dementia (Vallelly *et al.*, 2006; Henwood, 2009). The uncertainty over funding implications of individual budgets has been noted, specifically in relation to the extent to which this will impact on tenants' desire to buy in support from outside the housing with care scheme (Croucher, 2009).

## Summary and priorities for further research and development

Housing with care developments, in their various manifestations, are growing and evolving in nature. As with the ordinary sheltered housing environment, the housing with care setting is more than bricks and mortar with staff support services attached. For those living in such a setting, it is also a community of their peers, a place where they spend considerable amounts of their time and in which they invest meaning, purpose and hope. This community is not, however, one that is likely to be familiar or which the individual has purposefully chosen, more a by-product of a need for suitable accommodation and appropriate support, and it is therefore an aspect of life that incomers have probably not fully considered or been prepared for prior to the move. Moving into a community in later life, when other circumstances impinge on quality of life, is most likely to be a challenge of significant proportions. This is because all communities are characterised and even defined by diversity, difference and conflict about social norms (Evans, 2009), aspects that may be exacerbated in the close but unfamiliar environment of age-segregated housing.

As regards priorities for further research and practice development, a number of important issues are highlighted that would benefit from further exploration, including:

- The meanings attributed by tenants to the housing with care 'community' and their views on maintenance of self-esteem given its age-segregated nature.
- Tenants' expectations and preferences in regard to social life in the housing with care setting, given their lifestyles and previous patterns of valued social interaction.
- The extent to which older and younger tenants with a range of disabilities interact and their views on the age range as well as ability mix of a scheme's population.
- The ways in which tenants with a mix of disabilities achieve neighbourliness or friendships and the identification of any lessons from this as regards promoting positive attitudes towards those who are frail.
- How negotiations of private and public space affect personal and social identity, as well as their impact on social cohesion between fit and frail tenants.
- Staff training and resource needs in regard to meeting the needs of people who have various levels of dementia or who require end-of-life care.
- Effectiveness of particular types of staff awareness/training programmes in fostering greater confidence and skill in dealing with tenant antipathy and conflict.

- The potential for, and benefits of, tenant awareness and educational programmes in respect of living in close proximity to people with various disabilities, whether facilitated by internal staff or outside personnel.
- The benefits of an 'induction' programme, to include clear and frank information sessions about tenants characteristics and social aspects of schemes, for people considering moving to housing with care settings.

Finally, on the basis of work carried out for this review, serious attention should be given to how staff may work with tenants to construct individually-tailored and personally meaningful social engagements, work enshrined within the personalisation agenda but, to the author's knowledge, not yet developed or evaluated within the housing with care setting.

The question of attitude and disposition towards fellow tenants who require more support or care is one that rightly deserves greater attention if we are to seize and harness the potential benefits of housing with care settings and understand interventions likely to tackle social isolation as well as promote social well-being in these settings.

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## About the author

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## **Appendix 4:**

# **Workforce issues in housing with care for adults with high support needs**

**Jill Manthorpe and Jo Moriarty**

## Background

Four key areas for exploration were outlined in the project brief for this review:

- skills and competencies;
- resources and support, including training;
- the role of specialism;
- key questions for funders and commissioners.

### Identification of sources for this review

The review draws on existing evidence, knowledge and understanding gained from published material, including literature from reports, research, discussion papers and so on. It outlines what is known and perhaps what needs to be known. In essence this is a scoping review that both maps the range of literature in this field and sets out the gaps in the evidence base.

This scoping review started with an initial search of the references from major reports and studies already known to the project team, such as the reviews by Croucher *et al.* (2006) and Dutton (2009), together with the materials contained on the Housing Learning and Improvement Network (LIN) site. This helped inform the search strategies. The inclusion criteria were as follows:

- published in the UK after 2000;
- included the range of professionals with housing support, care and treatment roles (managers and direct staff), as well as less qualified workers;
- excluded family members or carers and other supporters in volunteer roles.

The importance of ancillary workers, such as cleaners or kitchen staff, has emerged but there is very little research focusing on this workforce in housing with care settings (or indeed in social care). The review was conducted in relation to adults, particularly older people (as outlined in the project brief) although there is a very small body of literature applying to other adults. The following electronic bibliographic databases were searched:

- Applied Social Sciences Index and Abstracts;
- Social Care Online and the SCIE research register;
- Google (with specific terms).

The third stage involved the searching of the following websites (and any others that emerged) for relevant studies or reports:

- Centre for Policy on Ageing;
- Thomas Pocklington Trust and other providers of housing with care in the third sector and the commercial sector, as well as the statutory sector;
- Beth Johnson Foundation;
- Department of Health;
- Department of Communities and Local Government;

- Age Concern/Help the Aged;
- Skills for Care;
- Housing LIN;
- Elderly Accommodation Counsel.

A set of telephone interviews and discussions were undertaken to confirm the saliency and continued relevance of the published material. In an iterative process, comments were received on drafts of this review to achieve greater confidence that material was up to date and that relevant matters had been covered.

## The social care workforce: brief policy summary

Recent years have seen a steady increase in policy attention to the social care sector in England and its workforce. Government has sought to improve standards of care and support through initiatives such as the first ever national adult social care workforce strategy for England (Department of Health (DH), 2009a) with a view to meeting the aspirations for more personalised adult social care, set out in the ministerial concordat *Putting People First* (HM Government 2007). While the workforce strategy (DH 2009a) does not mention extra care or housing with care by name, it notes that what it terms 'primary social care staff' work with the wider frontline social care workforce in sectors such as housing and it remarks on the progress in integrating public services workforces (para. 87).

At the same time, the social care sector has undergone considerable structural and workforce change, most obviously with the continuing move from local council to private and voluntary sector provision, but also in the attempts to tailor services to new goals. Central to these changes has been the ambitious shift of the personalisation agenda (HM Government, 2007) with its purpose of facilitating greater choice and control among people receiving social care support. While this is generally applied in the context of home based care; it is also being thought about in the context of housing with care services, relating, for example, to the ethos of '*More Choice, Greater Voice*' (CSIP, 2008) that sets out a typology of housing with care services.

In talking of raising standards and improving choice and control for users of social care, the need to develop a deeper understanding of the workforce often arises. But there is a tendency to see the workforce as part of the problem (responsible for poor quality care, inflexible services, building based provision) as well as part of the solution (able to provide more personalised and relationship based care, enhance independence and dignity). These themes thread through this review.

But first, we need to explore the workforce supporting older people with high support needs in housing with care provision. In this review we focus on the paid workforce, acknowledging that many families and volunteers provide significant amounts of care and support. We focus on staff in housing with care services; noting the importance of visiting NHS practitioners or other more specialist staff (these may be a key resource in helping staff manage difficult behaviour or distress, or supporting people who are dying). As well as care or support staff, the sector includes other components of the housing with care workforce, such as scheme managers, activities co-ordinators and ancillary workers (the latter not always explicitly mentioned in studies).

However, the very size of the sheltered housing and extra care sector is uncertain. At the moment there are about 4,000–5,000 non-regulated (by the Care Quality Commission) residential care-providing establishments in England according to Eborall *et al.* (2010, para 3.3.3). While these include staffed hostels and small group homes, this does include much extra care provision, the latter offering an estimated 20,000–35,000 units. These estimates will be revised following the start of CQC regulation of supported living and extra care housing under the Health and Social

Care Act 2008, being implemented in October 2010. From this, we are likely to know much more about tenants and owners, and importantly, about staff.

It is hard to distinguish workers providing care and support in housing settings from other members of the social care workforce (or indeed those working with people with high support needs from others). Only recently have systematic data emerged on the estimated 1.75 million paid jobs in adult social care (Eborall *et al.*, 2010), in line with information on the health and education workforces. Through substantial investment, development of IT systems and in co-operation with the approximately 17,300 employers in the sector (including 40,600 establishments), Skills for Care (the social care sector skills council), has been generating a National Minimum Data Set for Social Care (NMDS-SC), including a classification of job roles (see Box 1).

The importance of this wider workforce to housing with care services is widely noted. Dutton argues:

The focus of research, policy, and providers needs to shift from silos and competing interests to common issues that cut across settings. E.g. recruitment and retention of care workers is a problem for all long-term care settings including extra care, nursing homes and home care. (Dutton, 2009, p. 37)

Key features of the social care workforce overall are its low wages, its large numbers of part-time staff (facilitating some flexibility) and its horizontal and vertical gendered segregation – the former term used to describe the tendency for women to be in different jobs or occupations to those of men and its high morale and well-being (vertical segregation means that, within a particular occupation, women tend to hold the lower status and lower rewarded positions).

### **Box 1 Summary of the National Minimum Data Set for Social Care**

The National Minimum Data Set for Social Care (NMDS-SC) is the first attempt to gather standardised workforce information for the social care sector. It is developed, run and supported by Skills for Care and aims to gather a 'minimum' set of information about services and staff across all service users' groups and sectors within the social care sector in England. The NMDS-SC was launched in July 2007 and since then there has been a remarkable increase in employers completing the national data set. At the time of writing, there is under-representation of local authority employers as the NMDS has concentrated on the independent sector.

Two data sets are collected from employers. The first provides information on the establishment and service(s) provided as well as total numbers of staff working in different job roles. The second data set is also completed by employers; however, it collects information on individual staff members. Skills for Care request that employers advise their staff they will be providing data through the completion of the NMDS-SC questionnaires. No written consent from individual members of staff is required, however, ethnicity and disability are considered under the Data Protection Act to be 'sensitive personal data', thus consent for passing on these two items needs to be explicit.

The question arises whether it is possible to separate the workforce supporting people with high support needs in housing with care services from other staff groups in terms of data analysis and workforce strategies. At the moment, the NMDS-SC presents data by location and type of worker, so that some sheltered housing social care staff are distinguished from care home workers, for example. As Eborall *et al.* (2010) point out, some sheltered housing and supported living services are recorded in the UK Standard Industrial Classification of Economic Activity under SIC2007 68210 (renting and operating of Housing Association real estate). This is different from the division covering social care – 87 for residential social care activities.

In both sectors, direct care workers are distinguished from ancillary and other non-direct contact staff, although the contribution of workers such as cleaners, gardeners, cooks and so on is clearly important to tenants or residents. In light of the difficulty in distinguishing people with high support needs from others using care and support services, it may not be possible to identify which groups of staff work with people with high support needs, other than by registration status of the care provider. Overall this provides an important indication, but the moves to encourage continuity of care mean that boundaries are increasingly blurred. The brief points below outline two 'hot spots' of workforce issues in this sector overall.

**1) The vacancy rate in the social care sector** is double that for all types of industrial, commercial and public employment (Eborall *et al.*, 2010). Many vacancies in social care are termed 'hard to fill' and this is generally attributed to the existence of skills gaps (that is, there is a shortage of suitably qualified candidates), rather than to there being an overall shortage of applicants. In terms of turnover, there is evidence that most social care workers leave to work for another social care employer or the NHS ('churn'). Only a minority switch to the retail sector (Adams and Godwin, 2008; Hussein, 2010), although anecdotal reports suggest that this is a frequent occurrence. Predictions of the impact of the current recession are that there may be greater retention in the sector (King and Howarth, 2009). Within this context of staff recruitment and retention, Nelson (2006) describes a tailored approach to local recruitment in inner London Tower Hamlets to address workforce vacancies but also to increase the diversity of the staff group. We have little evidence of the effectiveness of various recruitment and retention strategies in the housing with care sector overall. It would be interesting to see if housing with care shares a general local pattern of shortages or skills deficits; or indeed that the experiences of some areas are commonly shared, in that jobs are easily filled by good quality candidates.

**2) Reliance on migrant or overseas workers:** Faced with shortages, some employers have looked to international recruitment as a way of managing staffing vacancies. While this is not a new phenomenon, the advent of the A8 EU accession states (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia) resulted in new 'sending countries' in addition to traditional sources, such as the Philippines. For people with high support needs, these staff may be valued; may possess health-related qualifications and be hardworking; however, there are concerns that supply may be unpredictable; that new immigration controls may continue to restrict entry from outside the EU; and that familiarity with local idioms, English language and care practices may be limited (Sale, 2005; Smith *et al.*, 2008) (see Hussein *et al.*, 2010). Research suggests that reliance upon migrant workers is

uneven, with providers in London and the South East in general and the private sector, in particular, being most reliant upon workers born outside the UK (Cangiano *et al.*, 2009). The reliance on migrant workers in housing with care services, their contribution and needs, have not been measured.

In addition to initiatives developed by employers, the government is seeking to improve recruitment and retention, with national media advertising campaigns aimed at improving the status of social care and attracting more people to work in the area. The government has also sought to improve retention by providing additional funds for training, including offering money to employers to enable staff to undertake National Vocational Qualifications (NVQs) and to receive induction training. Evidence suggests that NVQ initiatives have permeated the sector with some notable successes – for example, in terms of the number of managers with qualifications at least at NVQ Level 4 – but that success has been differential with larger providers being better placed to offer NVQ qualifications to all staff (Gospel 2009). Apprenticeship schemes have recently been offered to the sector for young people without employment, under the title Care First Careers (HM Treasury, 2009b).

To illustrate work on offer in this sector, Box 2 summarises a recent (March 2010) staff advertisement.

**Box 2 Job vacancy, Midlands, March 2010**

***Personal Support Assistants (Care Workers)***

Day time 16 or 24 hours per week  
£6.89 to £7.87 depending on qualifications  
Night time 18 and 27 hours per week  
£6.89 to £7.87 depending on qualifications  
+ £0.50 per hour night allowance

Friendly? Caring? Committed? Our residents need you to provide all round support, including personal care, issuing medication, cleaning and laundry. You'll actively encourage residents to get more out of life emotionally, physically and intellectually and have a can do attitude whilst performing a very demanding role.

The following sections outline four areas of particular relevance to workforce provision and performance.

## Skills and competence

The Care Quality Commission (2009) states that the health and welfare needs of people who use services 'are met by staff who are fit, appropriately qualified and are physically and mentally able to do their job' (p127) However, there are arguments that some social care employers will find it difficult to build up a workforce with this level of skill given that 'poor employment conditions are embedded in the contracting system', with some commentators asserting:

The universal right to care is based on cheap labour. Attempts to improve service quality through regulation, training and choice are undermined by the fragmented supply system. The result is a low and deteriorating quality of employment in elderly care.  
(Rubery and Urwin, 2009)

Training has been identified as an important way of improving recruitment and retention and of ensuring that workers have the skills to meet the future demands of their role, although it has been observed that the provision of training may not be enough on its own to improve skills and thus the quality of care (Wanless, 2006). The Learning and Skills Council is responsible for planning and funding vocational training in conjunction with the Sector Skills Councils. Results from the English National Employers Skills Survey (NESS) show investment in funding training for social care workers, albeit from a very low base, with Skills for Care spending an average of £2,000 per employee per annum compared with the average of £1,550 in the other sector skill councils (Learning and Skills Council, 2006, p17). This has resulted in a considerable increase in the number of care staff with NVQ Level 2 or 3 qualifications (Gospel, 2008; Rainbird *et al.*, 2009).

However, it is estimated that many direct care workers may lack some of the skills needed to learn effectively. Others may not have the fluency to follow training delivered in English so it has been suggested that estimates of the funds needed to provide vocational qualifications might need to include funding for these additional needs (support is available for those needing help with literacy).

Training is seen as the answer to almost all the problems of social care, including difficulties of the social care workforce (Manthorpe, 2008). It is cast as a way of improving recruitment and retention and of ensuring that workers have the skills to meet the demands of their role. Of course, it is not a 'magic bullet' as the provision of training may not be enough on its own to improve the quality of care (Wanless, 2006) but, for a number of reasons, training is seen to be crucial. The quality of training is less a feature of research than its quantity; thus new moves to endorse training are being developed by the National Skills Academy for Social Care and the *National Dementia Strategy* (DH 2009b) which explicitly voices its interest in improving the *quality* of training (as much as its *quantity*). These debates may be more advanced in social care than in housing sectors where management functions over buildings, resource management and marketing may be distinct from care provision.

Within this debate, there is agreement that direct care workers need a wide range of skills (Fleming and Taylor, 2007), although it is not clear whether housing with care work with people with high support needs *necessarily* differs from skill sets for care

home or home care workers. Nationally, 66 per cent are working towards a relevant qualification (Skills for Care, 2007) (as illustrated by Box 3). Regulations have substantially accelerated the pace of training (Gospel 2009) meaning that while incentives have their place, it is compulsion that has worked for many ('stick more than carrot'). The positive relationship between levels of training and outcomes is supported by evidence from some studies (for example, Godfrey, 2000; Bourgeois *et al.*, 2004; Kuske *et al.*, 2009)

Some researchers argue that there is a mismatch of staff attitudes and the capacities (meaning disabilities) of older residents in housing and care settings (here classified as sheltered/very sheltered housing and care homes) (Abbott *et al.*, 2000). However, other researchers focus more on the necessity of skills in 'building communities' that may be needed in housing with care facilities. Callaghan *et al.* (2009), for example, describe how staff in newly opened extra care schemes began to develop social activities and community engagement during the first six months, identifying and addressing facilitators and barriers to social participation.

These forms of skills and competencies may not be covered by more clinical or personal care curricula, such as NVQs. One key area for research could be to assist in the development of a consensus about the skills and competencies of housing with care staff. If NVQs are to change, then this may be an ideal opportunity to debate what training might look like and the evidence base for the choices that will need to be made. Much will depend on what people are being employed to do.

Interestingly, the Standard Occupational Classification of job roles (SOC2000) from the Office for National Statistics (ONS) makes some key distinctions between the role of Housing and welfare officers (3232) and of the role of Care assistants and home carers (6115). Skills for Care (2009) notes that there are as many as 27 different roles in social care. These roles are well worth exploring to see if hybrid roles or new ways of working are being developed in extra care.

Will there be further compulsion and greater incentives for training: providing at least minimum levels? Gospel (2009) argues that so far this has been a policy success, with perceptions that this was a burden for the sector largely dispelled (citing a Cabinet Office report that it had been a 'wake-up' call to the sector). However, we should not assume that there will be resources to fund training as much as it is needed or desired. It may be necessary to develop some priorities.

Alternatively, will there be an influx of skilled workers in the sector, if nurses, therapists and activities co-ordinators are attracted to social care and housing with care employment, bringing their specialist skills in rehabilitation, dementia and palliative care at managerial and supervisory levels, if not to frontline care. Will new investments in social care (e.g. the National Skills Academy for Social Care) promote an expansion of leadership skills among managers and senior practitioners? If yes, this might stem the flow of care workers upon the gaining of qualifications (indicated in Hussein, 2010) into the NHS and create two way traffic and exchange of skills, good practice and learning opportunities.

**Box 3 Job vacancy in housing with care complex or village, Midlands, March 2010**

***Team Leaders***

(22.5 and 30 hrs per week) £9.33 - £9.89 per hr entry level rates, depending on qualifications

We're looking for a number of experienced Team Leaders capable of taking responsibility for managing teams of Personal Support Assistants, providing the full range of support and personal care services to Village residents.

You will have a hands-on role in planning services for residents, making sure that support packages are flexible and tailored to individual needs. You'll be committed to achieving high standards and have good leadership skills. You will be responsible for recruiting, training and the ongoing development of your team members and will have previous supervisory or management experience. You should be qualified to NVQ Level 3 in Social Care or be prepared to work towards this standard.

## Resources and support, including training

In a research based document, the Institute of Public Care (IPC) (2005) identifies some ways in which housing with care staff may be supported (see Box 4). This is an unusual approach because the well-being of *staff* is not often addressed. Widespread calls for training are commonplace in housing with care services, but are not generally set within the context or culture of their employment. The IPC report also outlines a research based set of competencies which local authorities, registered social landlords, voluntary and independent sector providers may use in defining the tasks and duties of scheme managers. Such material highlights how extra care managers have much in common with care home managers, but the demands on housing with care managers may be changing and complex.

Much depends on the ways in which managerial duties are allocated, for example, if 'care' and 'housing' are under different managerial hierarchies. The former may rely heavily on the culture and practice of social care; the latter on traditions related to hospitality and leisure. Joy (2008), drawing on the experience of the housing with care provider Brunelcare, describes managerial work in extra care as including responding to the possible distressing symptoms relating to dementia though seeking support from other professionals, to permitting extra staffing when necessary, and increasing the dignity, independence and quality of life for residents, through hugely varied interventions around person-centred care, building design, educating relatives, keeping active and making the most of technology. The extent to which these are similar in other settings and among providers might be worth investigating.

Longitudinal and in-depth studies involving managers may be important to secure recruitment and leadership skills (similar to studies of social care managers and nurse managers). These would help in determining if the skill sets identified by Croucher *et al.* (2006) as part of the roles of scheme managers are unique or if they are converging with those of other managers in health or social care (NMDS-SC job role: Front line manager (M)). While managing housing with support may be different from managing other community or residential facilities, we do not have evidence about different managerial layers and the ways in which they gain support, build up their own networks or operate in business environments and corporate settings. Current work by the Personal Social Services Research Unit (PSSRU) at the University of Kent may assist in developing answers to these questions.

### **Box 4 Staff characteristics and outcomes**

#### ***A safe and facilitative working environment***

Characteristics:

1. Staff day room.
2. Staff training room.
3. Rooms and facilities for staff providing waking and sleep-in night cover.
4. The provision of a safe and attractive working environment.

Outcome:

A working environment which attracts and keeps high quality staff, and contributes to morale and team building.

### ***Trained and supported staff***

Characteristics:

1. Well paid, well trained staff with a definite career pathway.
2. Clear lines of management and financial accountability.
3. An understanding of one's own role and that of others.

Outcome:

Support for the expansion of a skilled ECH workforce committed to empowerment of older people and the provision of a high quality of life.

*Source: Institute of Public Care (2005)*

Regulation has been one of the major ways by which the government has sought to raise standards of social care as well as directing what it wants from the workforce. The passage of the Care Standards Act 2000 and the complementary legislation in Scotland, the Regulation of Care (Scotland) Act 2001, established a set of National Minimum Standards covering issues such as the level of training received by staff and the establishment of a social care register (see below), recently superseded by the Health and Social Care Act 2008 (Regulated Activities) and the 2009 Regulations.

There are strict standards for entry into social care work and similar work with 'vulnerable people', including criminal record checks. Following the passage of the Safeguarding Vulnerable Groups Act 2006, a new Independent Safeguarding Authority (ISA) has been set up to check people's suitability to work with children and vulnerable adults and prevents people deemed to be unsuitable from working in this area. The definition of a 'vulnerable adult' is broad and it is likely that many housing with care services will need to register with the ISA and will need to be aware of their responsibilities under the Act and what constitutes regulated activity. At the time of writing, the ISA is under review (August 2010).

In addition, all four UK countries have established Social Care Registers. These registers of people who work in social care, who have been assessed as trained and fit to be in the workforce, following checks on their qualifications, health and 'good character'. Currently only social workers and social work students in England are covered (and it has been announced that care workers' registration will be voluntary), but progress adding other workers to the register in other UK countries has been faster. The housing with care sector will need to be alert to the implications for staff teams if registration categories are enlarged. At the time of writing (2010), this looks unlikely.

However, in all four UK countries, Codes of Practice for Employees are used to hold social care workers to account for their conduct. There have been calls for the parallel Employers' Code of Practice to be placed on a statutory basis. Research in this area has not covered the housing with care sector or the interface of the Codes with the voluntary Code of Practice for Housing-Related Support produced by the Centre for Housing Studies.

While such matters relate mainly to 'care' provision, it should not be forgotten that housing with care may be subject to complex sets of regulations; the Care Quality

Commission (covering care and treatment), the Supporting People Quality Assurance Framework covering housing-related support and the Tenant Services Authority (TSA) covering housing management and provision (TSA, 2010). The impact of possible gaps and overlaps related to staffing might need to be investigated. At the least, the ability to manage multiple regulatory demands may be an aspect of managerial skill that could be explored to see if scheme managers find this work particularly burdensome or welcome the checks and balances entailed. One area for particular exploration might be the practical implementation and the effectiveness of the new principle of co-regulation espoused by the TSA (2010). Might this lead to better outcomes than other more formal scrutiny? Can it flourish in the context of other regulation applicable to care services?

## The role of specialism

Is there a housing with care workforce? There was no great agreement on this term in the consultation undertaken for this review. There is some suggestion that there is a 'housing support workforce' (Cameron, 2010) but this workforce is largely employed in community settings, such as 'floating support' for individuals living in their own homes or social housing, as opposed to extra care or very sheltered housing or similar. Foord and Simic (2005) argue that the changes which have taken place in supported housing over the last few years have probably been greater than in any other aspect of housing. They detect almost a new profession of 'housing carers', but this term is often used to mean that the worker is promoting 'independence' (almost the avoidance of social care support) rather than providing personal or quasi-nursing care (though the two are not mutually exclusive).

In a review of the use of the term 'support workers', Manthorpe *et al.* (2010) observe that the term is being applied to a very wide range of roles and that the addition of, say, the word 'housing' to the term 'support worker' does not necessarily mean that there is any greater clarity of role. For people with high support needs, a variety of terms such as 'care worker' or 'senior care worker' may be in use and the use of the term 'support worker' may be highly misleading.

Manthorpe *et al.* (2010) recommend far greater clarity of roles in the sector, highlighting the risks that may emerge if there is misunderstanding about a worker's level of skill and competence, or ambiguity about their role. As noted above, the Independent Safeguarding Authority (ISA), after review, may help clarify terms such as 'vulnerable people' but also the extent to which staff working in care settings contribute to their support (see, for example, the case illustrated in Box 3 where it is arguable that the person does have regular contact with vulnerable adults and would need to register and to be checked by the employer with the ISA if this is not substantially revised).

Wright and colleagues (2010, advance access) also comment on the confusion about roles that currently exists in extra care housing. They highlight the tensions that occur between some residents/tenants and staff over the specific roles of housing and care workers. In their study they observe residents and care staff disagreeing at times about the extent to which staff should promote independence among residents and residents' preference for greater amounts of reassurance and support than either the scheme or individual workers deem are necessary.

The case for specialist or generic workers in care settings, or undertaking the care of specific populations, is under discussion. In light of current policy efforts to improve the care and support of people with dementia (a group where many people may have high support needs), there are moves to make some aspects of dementia care a 'specialism' with greater consistency of approach to training and competence (in line with the National Dementia Strategy, DH 2009b) but to acknowledge that general skills in dementia care will be needed by many public service workers.

Work by the Personal Social Services Research Unit (PSSRU) at the University of Manchester (Prof David Challis) is exploring the evidence behind dementia specialisms in home care, while Darton and Callaghan (2009) observe that new

extra care housing is anticipating dementia support as integral to its provision of care – as an aspect of what might be called ‘core business’ (and therefore not a specialism). Garwood’s (2010) commissioning checklist for extra care housing and dementia covers workforce issues in section 7. She warns of the danger of mismatches between the needs of people with dementia and the numbers of staff able to support them, but also the risk of poor outcomes if workforce practice is too ‘skeletal, prescriptive and time and task based’. However, it is also important for staffing to provide continuity and consistency, and for housing and care staff, if they are separate, to have good training, leadership and support.

Likewise, better awareness of the importance of nutrition and hydration among older people with high support needs is being encouraged as part of the skill set for all staff and supporters, not just clinical or care professionals. This relates to growing attention to prevention of problems that may lead to inpatient admissions if left undetected. The ability of staff engaged in general health promotion activities to identify when precisely to call in professional or expert assistance is not known.

However, there is evidence of specialists emerging and being encouraged. Burns *et al.* (2009) provide a case example of Rowan Court’s specialist service for people with dementia in combining a social housing model with on-site specialist domiciliary care and the remodeling of sheltered housing often includes such developments (Croucher *et al.* 2008). Further clarification of what is ‘specialist’ might be warranted and whether models of provision where there is a specialist adviser ‘on site’ or ‘on tap’ may need investigating to see which is most cost-effective. There is by no means agreement over which types of specialist advisers might be needed and why. Still less, do we know about the creation and sustaining of such specialists and what might work well here?

It is possible, therefore, that while the term ‘dementia’ can cover various symptoms with degrees of severity, work in housing with care settings may involve support of people with high levels of disability, fluctuating health status and exhibiting possible challenging behaviour (some of this may relate to the levels of health need and disability when taking up tenancies/leases or may emerge later on). Commitments to providing continuity of care may entail larger numbers of registered nurses (Wild and Szczepura, 2008); access to staff willing to work flexibly, and care workers who are confident in providing palliative care, manage risk and restraint if appropriate, and reducing the distress of challenging behaviour (recent resources from the Social Care Institute for Excellence (2009) explore requirement for the safe use of restraint and the Mental Health Commission for Scotland (2007) covers ‘Safe to Wander’). This is in addition to the skill sets necessary for the evidence-based application of psychosocial interventions in dementia care (see, for example, the description of reminiscence activity in an extra care housing facility in Liverpool by Joyce (2005), which is generally underreported in contrast to the interest in end-of-life care.

There is not yet any consensus over the combination of specialisms that lead to the best outcomes, whether there should be end-of-life dementia care nurses or dementia nurses skilled in palliative care who might be called upon by housing with care services or might be employed in the care facility. However, there may be interesting comparisons that could build on recent work on medication management within care homes emerging from the PSSRU at the University of Manchester.

Medication management may be needed by a wide range of owners or tenants. It is particularly difficult to manage well in care homes; we know even less about how frontline staff and managers undertake this task in housing with care provision, if needs arise.

Several of those consulted for this review made reference to the potential for housing with care provision that takes on the support of people with high levels of disability to develop relatively insular communities within the larger facility. They described the different lifestyles and professional cultures that could emerge; with little contact or interaction between 'care' recipients and their staff teams and the wider facility. Some spoke graphically of 'walls' between different types of support. The consequences of this for staff are that they too are separated by the same 'walls', with different managerial systems, requirements, terms and conditions of employment, salary levels, and roles. Others spoke to us of the ways in which housing with care support could in some circumstances have far less to offer an older person than a good care home. Interestingly, one perceived advantage currently was the greater likelihood that housing with care schemes seemed to have better staff ratios and workforce stability, alongside the possibly higher wage levels associated with the voluntary sector in social care. These features may not be guaranteed.

In the current context, proposals to revise NVQ curricula may be informed by the blurring of tasks and skill sets that are characterising the social care and health workforces (see New Types of Worker programme, sponsored by Skills for Health and Skills for Care). However, there may be needs to work with staff whose first language is not English; to promote safeguarding as well as empowerment. Garwood (2002) and Parry (2005) are some of the few to comment on housing with care staff's needs to be alert to the risks of abuse and neglect.

If there are to be even higher levels of disability and ill-health among new residents/tenants and if there is to be a reduction of care home places and consequent delay in entry to care facilities, then there may be higher expectations that housing with care workplaces will be ready to cope. Jones (2008) notes the importance of training wider housing staff, for example, about legislation, cultural awareness, equal opportunities and anti-discriminatory practices; to this might be added disability awareness and mediation or conflict resolution if there are to be tenants/owners with very different expectations about their investment and rights.

While a focus on dementia alone may be overly limited; it has proved useful in throwing up some of the challenges affecting the workforce in housing with care services. Further work may be needed to help address some of the deficits in the evidence base, identified by Dutton (2009) as being:

- What are the benefits of integrated versus specialist-dementia models?
- How can good provision of end-of-life care be assured?
- What do we know about outcomes for different types of individuals in relation to the key variables of extra care settings, such as the design of the building and the environment, the organisation of care, medication management, delivering health care, recruiting and training staff, and the management of transitions to and from schemes?

- What are the costs and benefits of housing and service models?
- What can we learn from studies that address fundamental issues such as eating, drinking, sleeping, pain management, continence management, socialisation, and staff communication with tenants with dementia?
- What emerges from comparisons of extra care housing with available alternatives?

Debates over the variations in whether employers or providers develop highly specialised staffing teams are mirrored in the study of retirement communities and their health impacts undertaken by Kingston *et al.* (2001). This suggests that peer support, a balance between safety and security, and 'autonomy with inclusion' are key factors in maintaining tenants'/owners' health status. Staff are likely to be key influences here (but not, of course, the only ones). There is little on the patterns of support available to staff, in terms of their day-to-day practice, but also in helping them reflect on issues such as loss and bereavement. Training needs analyses may need to be undertaken more consistently and shared more widely.

To this may be added the need for staff to support tenants with sensory impairments (Croucher *et al.*, 2006), not just as specialists but as general staff. While a combination of independence and security is valued by tenants/residents, people who are very frail or who have sensory and cognitive impairments are consistently reported to be on the margins of social groups and networks. Being able to offer them opportunities for social interaction and companionship may require specialist skills and experiences; and perhaps greater confidence.

Brooker *et al.* (2009a) point to the need for mental health promotion to be part of the ethos of care housing, which broadens the debate and skills sets required beyond the need to provide support for dementia or physical care. The Enriched Opportunities initiative by Brooker and colleagues (2009b) is an extensive programme of research and development around the stimulation of activities and quality of life through investment in staff. Here individual staff were employed to act as 'locksmiths' to promote or 'unlock' the social inclusion and quality of life of residents with high support needs. While outcomes were highly positive, we know little of the long term impact of this role and the scope for such initiatives as part of workforce development. Like many initiatives, the impact of a pilot may not be the same when such a development becomes part of routine practice (if it does).

In other observations, Easterbrook and Vallely (2008) note that staff in extra care housing may be supporting people with extensive care needs. If housing care is provided in purpose built housing with 24-hour support, meals, domestic help, leisure and recreation facilities, it can offer intermediate care (hospital avoidance and early discharge care) and end-of-life care. Such services will now (from October 2010) fall under regulatory scrutiny with staffing profiles that need to be acceptable to the Care Quality Commission and to Skills for Care if employers wish to access training and other financial support. Croucher *et al.*'s (2006) review of practice around end-of-life care suggests that this area is one where staff will need not only training but also support.

## Key questions for funders and commissioners

Local analyses of the social care workforce are emerging through work on the National Minimum Data Set (NMDS) and local scrutiny of its findings (see Skills for Care's development of the InLAWS project, which takes the NMDS data and applies it to localities). These local messages may be related to the commissioning questions developed by Garwood (2006) about the planned purposes of housing with care services and specifically around dementia (Garwood 2010). From this scoping study, a set of four further questions emerge in the context of the transformation of social care – both the growth of personal budgets (personalisation) and the reprovion or closure of care homes.

First, what will be the impacts of personalisation? The roll-out of Personal Budgets means that every adult using publicly funded social care in England – or their proxy – will have control over their care budget (through various deployment routes). This will affect housing with care providers (since tenants and owners are eligible whereas care home residents as yet are not) and the workforce. There are five possible hypotheses, not all of them mutually exclusive:

- 1) If service users purchase support themselves, their support workers may leave care establishments (including housing with care), preferring to work for individuals, perhaps nearer home.
- 2) Support workers may be interested in having multiple forms of income, some from individuals and some from larger employers but may be less able to respond to housing with care managers' needs for immediate assistance or staffing (the flexibility called upon by Garwood, 2010).
- 3) People whose behaviour is extremely challenging may find it harder to recruit staff, or may find that staff are not willing to provide the support needed for the money on offer.
- 4) Highly tailored work with people with high support needs in community settings may provide care workers with beneficial experiences, the fostering of values respectful of independence and dignity, and skills in communication and personal care that can be useful in larger care settings; this may mean that the philosophy of personalisation permeates care and support practices.
- 5) If care teams become fragmented will training and skills development wither away?

Overall, increases in Direct Payment deployment options of personalisation could exacerbate recruitment and retention problems among care providers; it is estimated already that of the 76,000 individuals working as Personal Assistants for people with Direct Payments, 11,000 have left home care or nursing agencies in order to do so (Adams and Godwin, 2008).

Care providers or others may face difficulties in maintaining standards and professional boundaries whilst competing with independent Personal Assistants to provide the types of services desired by Personal Budget users or their families

(regulations permit this since November 2009). Further synthesis of the implications of personalisation is contained in the consultation, older people's discussions, staff interviews, and desk research from the *Building Choices* project co-ordinated by Housing 21 (Valleley and Manthorpe 2009; Garwood 2009). Current research funded by the new National Institute for Health Research (NIHR) School for Social Care Research being undertaken by the PSSRU at the University of Kent (Prof Ann Netten and colleagues) is exploring the impact of personalisation on people with high support needs.

Second, commissioners may need evidence that housing with care can meet desired outcomes. McCarthy (2009) observes that data from providers about staffing and training may be useful indicators of a high quality service both for public sector commissioners and self-funders. This suggests the value of good recording of these characteristics, and the NMDS-SC enables employers to bench mark themselves against others locally or against others in their sector. Housing with care providers may wish to make greater use of this data, calling on Skills for Care to refine data collection to make it more relevant if necessary. There is no other source of data that is so comprehensive about the care workforce nationally or internationally (see the *Social Care Periodical* series, Hussein, 2010).

Third, models of organising housing care and support services are various and a range of workforce deployment alternatives is supported by research (Shiple and King, 2005). Alternatives consist of:

- a) The separation of scheme management and care/support provision, since the ways schemes are commissioned affect their workforce profiles.
- b) The integration of scheme management and care/support provision.

Commissioners may need to be alerted to the extensive scope for reaching good outcomes by different routes (Box 5 illustrates the views of tenants/residents with high support needs in one evaluation (Garwood, 2008) of the contribution to their well-being made by staff). In the context of re-provisioning and service changes that are occurring through personalisation and in the current economic climate, there may be greater opportunities to outline how the skills of staff, as well as the physical environment, need to be more clearly delineated beyond simple or unspecified claims of having had training or mentioning values. Evans and Valleley (2007), for example, suggest that each tenant/owner should have a key worker, as this is likely to reduce the risk of social isolation (noted by Shiple and King, 2005).

Expectations about the role of staff to provide support for tenants/owners may vary between housing with care providers and so their role needs to be made explicit in the contract between the provider and the prospective occupant (and, of course, to staff). What is paid for and what is provided can vary between schemes and there may need to be research on the implications of current (2010) changes to Supporting People budgets for the housing with care workforce. Tinker *et al.* (2008) note that while remodelling may be expensive for commissioners to consider, it appears to have considerable advantages for many older people and support staff who are living and working in remodelled buildings.

### **Box 5 The importance of staff for end users**

Residents could not speak highly enough of the calibre of staff. One resident who had long-standing lesions on her legs when she came to Reeve Court attributed her recovery to the skill of the Reeve Court nurses. In the same way as care and general support is delivered in an integrated, seamless way, so too the nursing input. Similarly, the nursing input is flexible and responsive at Reeve Court. Residents can ring the handset and someone will go back and see them. A resident who has a minor fall and needs a dressing doesn't have to wait until the district nurse arrives for the scheduled visit or call a doctor. It can be attended to promptly by an on-site nurse. There is continuity of care with the same three nurses who know what is going on with all residents in the band.

(Garwood, 2008)

Finally, there is great interest in commissioning technology and telecare within extra care and similar provision. This may be the choice of people who have access to a personal budget rather than direct care staff. Workforce needs and capacities are underdeveloped here. Tinker *et al.* (2007) caution that all such technology needs to have able but also willing staff to operate such systems.

The Thomas Pocklington Trust (McCullagh, 2004) argues that people with sight problems are not getting access to advice or provision of technologies but sets this in a wider skills deficit:

The disciplines who would provide such advice ie Occupational Therapists and Rehabilitation Workers, are not technical experts, and in the case of the latter, have low training and status. These are national workforce issues.  
(McCullagh, 2004)

While not specific to housing with care services, this point raises the need for people with high support needs to have access to primary and secondary NHS and integrated services (that encompass dementia support, palliative care, care and treatment for depression, and so on), as well as access to support from the service's staff team. The evaluation of the Bradford Rowanberries extra care housing scheme (Bäumker *et al.*, 2008) suggests that one important role for staff is the arranging of health care consultations for residents by staff and staff encouragement of such access to health care.

## Conclusion

Behind the questions raised above are fundamental questions relevant to the workforce; in terms of its profile; composition; activities; labour costs and effectiveness. Evidence from this review suggests that while there is limited knowledge about the housing with care service workforce, then it may be helpful at this moment in time to see if the housing with care workforce closely approximates that of the care home sector and intensive home care support.

There is little evidence that housing with care providers have their own specialist workforce (but this may be emerging); and no consensus about what specialism might be prioritised. However, if current policy to reduce the reliance on care homes (DH 2009c; HM Treasury, 2009a) by English local authorities continues, then there may be opportunities that housing with care employers may wish to consider. These include; raising the quality of staff recruited (seeking specific evidence of skills, achievements and experiences); considering specific skills gaps in work units or teams; deciding upon a refresher or transfer model of training or induction to transmit values to and share learning with staff who are being recruited from other sectors. Engagement with any new NVQ curricula seems imperative.

Finally, Dutton (2009) asks these questions in relation to dementia care that could be applied more widely to people with high support needs:

- Which organisational and management characteristics and approaches foster effective staff-resident interactions and the implementation of successful practices?
- Which models of staffing and staff training, supervision and mentoring should be tested to determine how to best configure staffing for effective care for those with varying severity of dementia?

These questions might be broadened to include family members who often play a key part in care and support, even if their relative has moved home (Gaugler, 2005).

## Future research

While there are many areas where further research might be useful, this review also points to some wider research considerations.

What is the capacity of the housing with care sector to keep abreast of current workforce research being undertaken by a variety of researchers? Is there a role for a workforce grouping such as that established through the new Housing and Dementia Research Consortium? Does the Social Care Research Register reflect this area of study and is its existence known to the field? Should workforce research developments encompass training, competencies and skills or be more focused on demand and supply?

How far can studies relating to the workforce and its performance in care homes be inclusive of housing with care? And if they are, can they compare the two

approaches rather than assume them to be the same? Is there a role for the *My Home Life* initiative to play a greater part here? For example, could housing with care researchers have greater engagement with the National Care Home Research and Development Forum? What is the capacity to expand the network being established with the Housing with Care Research and Development Forum (PSSRU, University of Kent)? How can workforce studies cover the very wide range of roles and tasks in housing with support and what should be the priorities? What has been the contribution of the Housing LIN to workforce development efforts and to act as a research clearing house and how might this network look in the future?

How can research on the social care workforce (which is extensive) be of greater use to housing with care stakeholders? (without presuming that the workforces are identical or unique). Is there scope for greater attention by research or evaluation commissioners to ensuring that data collection is not repeated, or overlapping, and that anonymised data sets can be shared? Are commissioners willing to fund more than case studies or descriptions? Can case descriptions pay more attention to workforce details? Can the authors of reports and guidance be asked to provide supplementary documentation of methods, evidence and measurement tools?

### **Emerging gaps identified by this review**

There were few areas of this review where we can be confident that research provides a full or adequate picture of the housing with care workforce and its concerns and strengths. The workforce appears not to be shaping questions that are important to itself, such as its support, pay and conditions, and training needs

Current concerns among key stakeholders are the implications of commissioning decisions (at local government, private and voluntary provider and individual level) for the quality and competence of the workforce in housing for care services, for example, in the context of personal budgets, re-provision of care homes, and the housing, care and support interfaces. At national level, questions are emerging about the possible impact of new regulatory regimes in registered care settings on workforces in frontline activity and at managerial and supervisory levels. As noted, how do these relate to co-regulation?

Lastly, what do we need to know about the ancillary workforce (cooks, gardeners, cleaning staff and so on) and how its members may bring wide benefits to housing with care schemes, their tenants/owners and their colleagues? Such questions are not unique to housing with support services but there has been surprisingly little interest in this group of staff who may have considerable influence on the success of a scheme.

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## Appendix 5: Mental Capacity Act and housing with care

The Mental Capacity Act 2005 provides the framework for taking actions and decisions for someone who lacks the mental capacity to take a particular decision or action. It makes provision for people to plan in advance for a time when they may lack capacity to decide, and also provides the framework within a code of practice for those supporting someone who lacks capacity. Very importantly, mental capacity is not seen as absolute. It is time- and decision-specific.

The Act has five key principles:

- **A presumption of capacity:** every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
- **Supporting individuals to make their own decisions:** a person must be given all practicable help before anyone treats them as not being able to make their own decisions. It is good practice to help build capacity.
- **Unwise decisions:** just because an individual makes what might be seen as an unwise decision, they should not be assumed to lack capacity to make that decision.
- **Best interests:** an act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests – genuinely.
- **Least restrictive option:** anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The Act applies to all professionals and family carers working with people who may not have the capacity to do or decide particular things for themselves. (Note: The Act only applies in England and Wales.) It is relevant to HWC in a number of ways:

- Housing with care staff need to understand:
  - the meaning of capacity, the test of capacity, and the principles of the Act;
  - their own and others' powers – and the limitations on those powers – under the Act;
  - the advance decision making measures in the Act, partly so that they can advise HWC occupants, and partly so that they are aware of any such instruments being in place for a particular occupant, e.g. Lasting Power of Attorney, Advance Decision to Refuse Treatment.
- Staff need to apply the principles in their day-to-day practice.

- A landlord has no right to restrict the autonomy of someone in their own home, and depriving someone of their liberty is unlawful. The Deprivation of Liberty Safeguards introduced as part of the Act apply only to care homes and hospitals, not housing with care. This has implications for people in HWC in relation to those who are at significant risk if they go out of the scheme and assistive technology and staffing approaches are insufficient.
- Issues in relation to taking on and terminating tenancies. For a robust tenancy, an individual needs to have the capacity to understand the basics of the contract or have someone legally authorised to sign it on his/her behalf. (This is much more complex and nuanced than it is possible to outline here. The Disability Discrimination Act is also relevant in this context.)