

Gearing up

Housing Associations' responses to tenants with dementia from black and minority ethnic groups Valerie Lipman, Jill Manthorpe



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Introduction

How do social housing providers meet the needs of people with dementia who are from black and minority ethnic backgrounds?

This question is important because both the numbers of people with dementia and the numbers of older people from minority ethnic groups are predicted to rise in the United Kingdom (UK). Social housing providers have much evidence about good practice and cost-effective support. They can use this to help each other as well as offering it to other providers of care and support. Their experiences in meeting different needs in changing times are also potentially valuable to commissioning practice and policy. UK research has found that people from black and minority ethnic groups often do not access the support they need and tend to be less satisfied with care services – the implications for housing providers of this finding need to be considered proactively.

The background to demographic changes has been summarised in two Race Equality Foundation papers (Moriarty et al 2011; Truswell, 2013) and the All-Party Parliamentary Group on Dementia (2013). Personal and practice experiences throwing light on the relationships between dementia, culture and ethnicity, have been recently gathered together by Botsford and Harrison-Dening (2015). Readers may find these useful (see Box 1 for more on demographic change and its implications)

Box 1.

In the UK there are increasing numbers of studies seeking to understand and ameliorate the impact of dementia on black and minority ethnic communities and the individuals and families concerned. Some have suggested that the prevalence of dementia in Black, African-Caribbean and South Asian UK populations is greater than the white UK population, and that the age of onset is lower for Black, African-Caribbean groups than the white UK population. Others point to possible delays in help-seeking and inaccessibility of services. The All-Party Parliamentary Group on Dementia (2013) contains a useful summary of relevant research and also findings of research that talked directly to individuals and families from black and minority ethnic groups affected by dementia (see also Moriarty et al 2011; Truswell, 2013). Other insights into people's experiences are contained in a recent book edited by Botsford and Harrison-Dening (2015). This book provides examples of research, practice and personal experiences from Irish and Cypriot communities, and others. Overall, this and other research now argues that socio-demographic factors, local population profiles, and migration experiences need to inform commissioning and provision of services for people with dementia and their families.

The study's approach

This small exploratory study took an audit approach and investigated current practice and policy by interviewing respondents from 11 Housing Associations (HAs) providing sheltered housing and extra-care support that are already serving tenants or lease holders with dementia from different ethnic backgrounds and received information from 15 more. A cross-section of HAs was identified to seek views and experiences of 1) generalist HAs providing for the whole community, 2) specialist HAs established primarily to meet the needs of specific minority ethnic groups (though now providing housing for people from the whole community), and 3) differently-sized HAs in different parts of the UK. Table 1 summarises the type and range of organisations selected for interview (undertaken in Spring 2015). The HAs were identified through a search of the internet and through interviews with experts and practitioners in the three related, sometimes overlapping, fields of housing, dementia care, and care for black and minority ethnic older people.

Some generalist HAs provide specific supported living or home care schemes for minority groups adding to their portfolio of services beyond the provision of accommodation. Others offer both private (owner occupied or leasehold) and social housing (rented by tenants). The material used here relates solely to the social housing parts of their operations but could be transferable. Visits were also made to two HA sheltered units in London. We were not able to include accounts of end users' (tenants') perspectives – this would be a useful area of future study, as would the opinions of family members.

However, details of over 100 HAs were explored, using internet search of HAs and bodies representing HAs specialising in services for ethnic minority groups to inform the sample of HAs contacted. The illustrative examples provided in this report were drawn from England and Scotland.

Exploratory conversations were held with over 20 HAs, of whom ten were finally identified who met the criteria and who brought relevant comments and experiences to the study, and one further HA was included as it brought another perspective. We are grateful to all respondents for their interest and time – more than one person was spoken to in many of the HAs – at head office and service levels.

Note on terminology

In this report we use the term tenant (rather than customer or resident which are sometimes used). We refer to housing units to reflect the many forms of accommodation provided by HAs. The term 'Extra-care housing' is used to refer to accessible self-contained apartments/flats with options to rent or buy on a shared ownership basis and where social care can be provided as an 'extra' service to tenants. 'Sheltered housing' is used to mean purpose built or adapted housing, with access to an alarm or warden system. We use the term 'black and minority ethnic' to refer to people from different ethnic groups other than White British (others may use terms such as black, Asian and ethnic minorities). We use the term older people although some respondents use the term 'elder'. We did not restrict 'older people' to any specific age group but in the main respondents referred to older people as being aged over 60 years. Finally, in speaking of dementia we mean the general term referring to syndromes covering loss of abilities, such as abilities to self-care and memory problems, associated with cognitive impairment, sometimes also referred to as Alzheimer's disease.

Focus of study

We were asked to address two broad areas. First, we were asked to report on the policies in place in a HA before someone with dementia from a black and minority ethnic group moves to HA premises; the 'fitness of purpose' of the housing and care provision for people from a black and minority ethnic background who develop dementia while being tenants; and what might happen as their dementia progresses. Second, we explored how HAs were responding to such changes and what they anticipated to be these tenants' changing needs. While the focus of the review related to the physical environment, an understanding of the social environment was also sought. Areas of questioning thus covered the following:

Policies and pre-move

- Eligibility for tenancy is health status, including mental capacity or diagnosis considered at the time of the new tenancy or move by HAs that have a particular focus on one cultural, religious or ethnic group?
- How much is a new tenant permitted to do to make the home their own, in terms of dementia-related adaptations (focusing on cultural or religious matters)?
- Is accommodation designed in a way that is widely culturally/religion suitable or adaptable, e.g. with appropriate washing facilities that may be needed by a person with dementia?
- Are cultural awareness, dementia awareness and other related support and training available to staff?

Housing association (anonymised)	Tenants of all ages	Older people primary tenant group	Black and minority Led (specific tenant focus	Sheltered Housing provider	Extra Care provider	Number of Sheltered Housing & Extra Care units (rounded) 55/60/65+	Specialist Dementia Unit provided	Local/ regional/ national coverage (L,R,N)
1.	✓	×	√	√	×	150	×	L
2.	1	×	×	✓	1	Approx 3,000	×	N
3.	1	×	×	1	1	8000¹ (all ages)	✓	R
4.	1	×	×	1	1	7000 (55+)	✓	N
5.	×	√	×	1	1	19,000 (55+) (inc 2500 extra housing)	×	N
6.	×	✓	×	✓	✓	19,000 (65+)	×	N
7.	1	×	✓	1	✓	Near 200 (55+)	×	L
8.	√	×	×	1	1	Near 400 (65+)	1	R
9.	✓	×	×	1	1	300+	×	R
10.	✓	✓	1	1	1	40	×	L
11.	1	×	×	1	1	2,500 (60+)	×	N

All ages from 18 years – no breakdown available of older people households

Services for tenants

- Are 'soft' services available or adaptable for people with dementia from different cultural or religious groups, e.g. meals, specialist hairdressing and other related personal care, entertainment choices?
- How do housing managers and other staff respond to changing circumstances, if a tenant starts becoming confused or disorientated, for example, in a housing setting that is culturally specific?
- What factors affect HAs' ability to make dementia-related cultural adaptations to help individual tenants?
- How do HA staff manage related dementia-related risks in the context of cultural preferences and choices?

Findings: common experiences

The overriding finding is that while all the HAs are developing their understanding of dementia, and have policies in place relating to equalities and diversity, none have yet fully integrated the three strands of housing, dementia care and cultural or ethnicity related needs and preferences, nor the impacts of racism and disadvantage. We found many similarities in both policy and practice between the different HAs in relation to tenants with dementia and offers of housing to older people from varied backgrounds. Differences appeared to be in the degree of integrating understandings and knowledge of dementia and of cultural or ethnic diversity. However, some HAs were apprehensive about how to manage dementia if their focus had previously been on addressing needs related to ethnic or cultural identities or discrimination or disadvantages. All but one of the HAs had or were developing dementia strategies, and were training their staff to understand and recognise dementia. The challenge lies in integrating experience and good practice.

Common commitments:

- All respondents stated that their policy would be to enable tenants with dementia or without – to stay in their own home for as long as possible, but in some circumstances tenants would be moved to a new housing provider or another unit of accommodation.
- Overall, HAs try to meet individual needs the word person-centred (commonly used in social care) was not used specifically but a similar ethos was espoused.
- Most acknowledged their staff should know more about dementia and many HAs reported they had started dementia awareness training.
- Substantial adaptations to tenants' homes tend to follow professional assessment of need – but new units are increasingly designed for disability and some for dementia-related assistance. There was no general agreement about what specific adaptations might be needed to cover dementia-related needs, but a fear of expense was universally expressed.
- Specific design features related to cultural preferences and requirements may meet dementia-related needs but knowledge of how this works in practice is anecdotal.
- All HAs have policies on safeguarding and security and did not see these as needing particular modification.

In relation to the specific focus of this exploratory study, we found:

- HAs offer (and continue) tenancies or licences to people with mild dementia –
 indeed some are not aware of the presence of dementia at the time of
 someone moving in, because the dementia may not be have been diagnosed,
 or clearly identifiable. The consequences of policy encouragement of earlier
 dementia diagnosis have not been generally considered.
- Tenants are able do what they like to their homes within reason but, at times, safety considerations may mean that a modification is refused. The notion of 'reasonableness' appears to be negotiable.
- All HAs were aware of working with cultural difference as a training imperative and all had Equality & Diversity policies addressing all forms of disadvantage, including race and ethnicity.
- Levels of dementia awareness and skills among staff varied. Some HAs were at the early stages of dementia awareness; others have developed specialisms and are familiar with the resources available.
- In relation to the non-physical/building part of their services, examples were provided about changes to the common parts of Extra-care schemes, meeting different dietary preferences, celebrating different holidays/religious events, displaying diverse posters/pictures, providing access to satellite TV, and enabling tenants to access different language programmes. These were not specific to dementia but clearly were seen as transferable.

Managing changing tenant circumstances was the major challenge reported in this review. Despite commitments to help people stay at home for long as possible, cost of adapting properties is a feared or actual problem, and this affects HA willingness and abilities to meet the overall care needs of the tenant concerned, who may ultimately have to move elsewhere. The different break points for the changes and disruptions involve decisions over aids and adaptations, care provision, and the option of pursuing possible alternatives. More examples were provided of physical care challenges rather than behavioural or psychological symptoms of dementia, suggesting that these symptoms are under-recorded or classified as general depictions of 'need'.

Findings: adapting to changing tenant needs – practice and development

Policies and commitment

Many HAs have been at the forefront of developing services to meet the needs of changing communities. HA1 has developed a specialism in meeting the housing needs of black and minority ethnic local people in one region. It provides sheltered accommodation (flats) with a very small number of tenants with dementia at present. This HA is refurbishing its properties to reflect greater tenant expectations and their increased levels of disability, combined with enabling them to remain as independent as possible. Proactively, all new properties and those being refurbished are given walk-in showers although if someone doesn't want their bath removed this is not done. Tenants may decorate their own flats as they wish, and are consulted about communal areas, such as carpets, colours, curtains and furniture.

Similarly, building on a tradition of responding to population diversity, HA2 tenants are from many different cultural backgrounds and there is a strong tradition of inclusivity for different religions. This HA responds to professionals' requests for modifications arising from changes in a tenant's physical abilities. Like some other HAs, it provides sheltered housing but a different organisation provides support and care for the tenants. It has therefore separated the landlord and building side of its business from the care or 'soft' side of the business. This necessitates communication between both sides of the business. Suggestions or recommendations for aids or similar adaptations arising from a community assessment are passed to the landlord side of the business. TV satellites, for example, are a landlord matter. The costs of installing these in communal facilities are absorbed into tenants' service charges. If individual tenants want something specific, they must pay themselves. In relation to cultural considerations, the HA care side of the business offers different social activities, food, and celebrations of significant events.

In Oldham, Aksa Homes (Wood 2011) (not a respondent) has considered the possible changes in expectations and aspirations between current older black and minority ethnic groups and following cohorts. It reported that black and minority ethnic tenants and others face fewer language barriers than their parents and grandparents and predicts they will be more likely to consider a wide range of housing and support options. The implications of early diagnosis and greater social awareness of dementia need to be factored in to similar insightful studies.

Developing skills and confidence

HAs are currently providing or commissioning training related to dementia awareness but also development of specific skills (see Garwood, 2014). HA3, for example, runs dementia awareness training for its entire staff group. It considers it will be in a 'very different place' in five years in terms of its expertise and experience. This arises from its recognition that dementia is increasingly likely to affect its tenants living in general needs accommodation. It knows that some of its sheltered housing tenants have dementia, but as tenants are supposed to be independent it is unclear whether its support workers are sufficiently aware of how individuals are functioning. It is not the intention that HA staff members become expert clinicians; this HA relies on medical assessments to tell staff about possible interventions in order to assess individual abilities to stay in their own home.

Several HAs pointed to the need for dementia-related training to be offered to all their workers, such as HA10 which has started this rollout. HA2's new initiatives include a recent programme of dementia awareness training as well as information sessions for all staff to help them understand dementia and to respond to possible symptoms, e.g. if tenants are making repeat calls. Training or awareness about dementia is also being offered to their 'customers' (tenants). This has been developed with the Alzheimer's Society. HA9 provides a traditional model of sheltered accommodation but accepts tenants with dementia; and also provides Extra-care support. It runs a dementia awareness programme through its learning and development section. More broadly, HA4 provides dementia awareness training and workshops to its own staff; including contractors whose work is not traditionally concerned with tenants with dementia – this includes care and repair, and maintenance staff.

Some HAs spoke of their experiences of tenants' families in black and minority ethnic communities not always recognising or understanding when their relative has dementia. HA11, for example, offers awareness courses to all those coming into contact with older black and minority ethnic people, such as community groups, so that they can recognise if someone's behaviour is changing. The idea is that they may then contact the support worker at the sheltered housing scheme, and/or the person's family to start help-seeking, possible treatment, and information, as well as being better informed about what the later symptoms of dementia may include.

Service developments

Other HAs are developing a specialism in dementia care. HA3, for example, provides services for different groups, ranging from people who have been homeless and rough sleepers to residential care for people with complex needs, such as acquired brain injury, learning or physical disabilities, and people with dementia. It undertakes housing management, while another provider undertakes care services. It also supports older people who want to continue to live at home (home care). Further it runs a Home Improvement Agency to support older or disabled people if they need a repair or adaptation in their home.

HA3 accepts tenants with mild dementia in its sheltered accommodation scheme. It was previously commissioned to provide a round the clock resident warden service, but this is now just a support function, and this in turn has been reduced on cost grounds. Additional housing management is funded from the HA service charge, which is paid for through local authority housing benefit for those on low income. This HA runs a supported living scheme for African-Caribbean older people and comments on its experience of trying to be 'in tune' with what is needed:

'Our approach is to make sure that the community exercises its voice and has all their environmental requirements. We involve family and friends. There are different social activities, such as domino nights. In our mixed communities we celebrate a range of cultural events. We always recruit staff from local communities and related backgrounds. If we don't have this it's difficult to be in tune. The direction of travel in adult social care is that one size doesn't fit all – the aim is to build a service around an individual's needs'.

Overall HA3 acknowledges that signage (maps, direction signs and labels) in its current facilities is fairly basic and confined to things such as exit signs. This will be an area for improvement so the environment becomes more 'dementia friendly'. A specialist dementia Extra-care centre in London will open in early 2016, and HA3 has been working with the Dementia Services Development Centre at the University of Stirling to refine the building design. The aim is to take everything into consideration to manage memory problems optimally. There will be very little written down, information will be pictorial. There will be personalisation of individual's front doors, there will be walk-in showers, and the units will be wheelchair friendly. However, there is some apprehension – not always based on firm evidence – that further structural refinement to meet cultural or religious needs might incur substantial costs and challenge the business model, possibly because the tenant with dementia might move on quickly to more suitable care provision:

'If the needs are quite specialised it's costly to make substantial adaptations, especially if you don't know long the person will be resident or how their needs may change. We have to fit equipment to fit the widest possible needs over the longest period of time'.

Dementia Developments and Strategies

Many HAs are developing dementia strategies or statements of intent. HA4, for example, is currently reviewing its housing stock and support. Its main business has been sheltered housing but it is developing more Extra-care housing, mostly by re-designating some of its current stock, and creating some common facilities in recognition of changing needs and demands. On the one hand it has demands from increasing numbers of people with dementia but on the other hand there are increasing numbers of younger independent older people (55+) locally, many of whom are still working but want secure housing. Some may also have social needs. These differences in needs and expectations are giving rise to discussion about the HA's business priorities.

At national level HA5 is working towards a corporate strategy on dementia. It is using the King's Fund and University of Stirling design guides [specifically addressing cultural differences in the communal spaces]. It is committed to the ethos that 'people living with dementia are dealt with on a personal basis and on what it is that they want'. In some schemes, it has installed different toilets (that wash and dry) to meet disability needs and cultural requirements. All its new Extra-care properties are being built with walk-in showers and signage/ colour coding and so on to help tenants with dementia.

Building on a history of tenant diversity

Like HA1, HA4 has provided specialist sheltered housing for black and minority ethnic older people in diverse communities for many years. These schemes were specifically designed to meet the expressed needs of these groups, e.g. providing gas cooking facilities, rather than electric; and putting a door on the kitchen instead of the usual open-plan design. While there might be difficulty making further major changes for individuals, it declares: 'The organisation's starting point will be to make every effort to make the situation work for people'. This reflects a 'dual approach' – strategically providing purpose built units that are designed for particular groups of people (people with dementia, people from black and minority ethnic backgrounds), but also responding on an individual basis:

'(We have) recognised that no one size fits all, and design services on that basis. The organisation makes every effort to enable people to stay at home. We consult with people. There is bespoke arrangement. But the big question is always "who's going to pay?" We have flexibility in the budget and can respond to an individual.'

This individual focus might be termed 'person-centred' in a social care context. In terms of black and minority ethnic and dementia specific considerations, examples of the provision of satellite dishes for different language channels were described as likely to be acceptable within specialist sheltered housing schemes with any additional costs absorbed into the service charge. Individuals are also able to choose other adaptations if they meet the cost.

Formed over 30 years ago HA10 was established predominantly to provide quality homes and housing services for the local Chinese community. It provides bilingual services to enable Chinese speakers to access services and facilities generally available to the wider community. About half its tenants are Chinese speaking, and similar numbers of staff speak Chinese. Other tenants are mostly from other South East Asian backgrounds. Cultural awareness and accessibility are visibly expressed through the building architecture which was designed to meet particular requirements, e.g. there is a Chinese style archway into the building, dragon motifs and the colours used are mostly red, gold and green ('lucky' colours) – thus people's front doors are red and green, window frames are green. The colour black is not used because this is said to be unlucky. Such adaptations will likely be appropriate for people with dementia. Other tailored services cover a range of social and leisure events on offer, e.g. Tai Chi, films, translation services, and bilingual speakers that may be helpful to people who have lost abilities to speak or understand English

Experience with providing individualised responses

HA4 also provides an 'enhanced' care and repair service (Handyperson scheme) for small jobs (e.g. changing a tap washer) that may have become particularly difficult for older people. While these tasks would not normally be regarded as 'emergencies' in a HA, in the expectation that most tenants could probably fix or arrange to have the problem fixed quickly, it deems these to be emergencies for older people with declining abilities, which could include a dementia. Its business model, applied to both sheltered and Extra-care provision, is that the contact for care services is currently held by a local authority. One perceived advantage of this is that people with dementia are able to move from sheltered housing to Extra-care if their condition worsens and end of life care is needed that cannot be offered in sheltered housing.

HA5 is one of the largest and long-standing providers of sheltered housing and Extra-care schemes. Currently it offers two types of housing for older people – general housing with on-site staff, and Extra-care housing. Like other HAs, it reported that the management of tenants' dementia is a sometimes difficult matter and expressed uncertainty that people with dementia are best suited in their general properties or that they are best able to accommodate them. It considers cases individually but also acknowledged that what is possible often depends on the nature of the contract/agreement/service agreement with the local care commissioner or funder (local authority) and its own contract with the care provider. In terms of adaptations, HA5 has a team to assist tenants, and if someone wants to adapt or decorate someone from this team 'will go through the options with the individual. It will explore sources of funding and take the process from there'. In its Extra-care housing HA5 has made adaptations to meet the needs of people with dementia e.g. use of different colour doors, and of bold colours.

In its general retirement housing the on-site staff (Monday-Friday) are thought likely to be the first people to recognise if a tenant is becoming frail, or unable to cope. It is their role to raise concerns with the family or local authority adult services.

Experiences in Dementia Care

Some Extra-care housing schemes have substantial experience of providing services to diverse tenant groups. One HA5 scheme described itself as designed to accommodate a range of health conditions, both physical and mental, having improved the buildings' physical design with level access, grab rails, varied colour schemes, and so on. This scheme recruits staff with the relevant language and support skills for Asian older people; and there are two kitchens – halal and non-halal. Accounts relating to its older Asian tenants from Pakistani backgrounds provide some illustrations of daily practice:

'I've not come across any specific needs. Mrs X moved to nursing care because she couldn't manage her dementia. She would say things like she wanted to go home [to her son in UK]. The workers would reassure her. Or she would wake up on Sunday and want to go to the temple. It was all normal questions that anyone would ask but related to her religious beliefs and culture.'

'Mr Y, who is Asian, just moved in and has early signs of dementia. Familiar faces are reassuring. If (we were to) settle someone into a mostly white setting they may be more prone to say "I shouldn't be here". It's good to have familiar cooking smells.'

'Thinking about what people might ask for – it could be a prayer shrine or space, or a gas cooker to make the chapatti.'

Other HAs, such as HA6, have joined together over the years with other smaller HAs, such as a black and minority ethnic HA for Asian older people providing housing and care. This has enabled it to build up expertise and the arrangement provides the smaller HA with greater financial sustainability.

In other areas small HAs, such as HA7, have been offering sheltered housing and Extra-care housing for over 25 years – in its case mainly to local African-Caribbean people. It also provides care and repair and maintenance services to keep the property safe. It reports that safety is a major concern for its tenants, who are fearful of 'strange people' coming into the house. Interestingly this HA has not noticed any difference in requests for alterations between different tenant groups. In the main, its black and minority ethnic tenants speak English and do not wish to access international TV channels or have needs for interpreting or translation. As with other HAs, housing stock may be adapted to meet tenants' needs but this HA requires an occupational therapy recommendation.

Indeed, should a tenant need something substantially different or have 'extreme' dementia, it would probably suggest the tenant moves to another HA or elsewhere which could better accommodate their needs:

'We are looking at each case on a case-by-case basis. If we can be flexible on a small scale we don't have a problem. We're willing to go the extra or mile or two. We don't take people with extreme dementia and if someone required substantial adaptations we'd need to pass on'.

While not always clearly articulated, other HAs also raised the question of managing difficult symptoms of dementia and the problems this may bring to the housing community.

For some, such symptoms are managed within services if these include specialist dementia units. HA8, for example, provides sheltered housing and Extra-care schemes. Most of its Extra-care schemes house people with dementia, although one scheme is a specialist dementia unit. This is a culturally diverse unit. In its experience people of similar or same cultural background group together naturally. As with other inner city HAs, its workforce is very diverse reflecting its local community. It feels that familiarly with dementia care practice enables staff to work effectively with black and minority ethnic and other tenants through using life stories acquired from families, for example. This may include finding out what a tenant's favourite music used to be, tuning the radio to a familiar channel, or turning the TV satellite to get the relevant language programme. Outside tenants' homes staff might put photos on the front door, so tenants know where to go; and inside adding contrasting colours to fixtures and fittings, like making the toilet seat brighter; and putting prominent signage on bathroom doors in the relevant language or symbol. In terms of dementia HA10 also individualises tenants' front doors with pictures/ photos. More unusually, HA10 uses its community fund to raise awareness in the wider community about dementia.

General design modifications reflect practice wisdom in dementia care. One of HA4's Extra-care schemes, for example, created a 'dementia aware' physical environment, through colour coding of carpets on different floors, for example. Another of its schemes ran reminiscence sessions for tenants and for a short period turned its communal lounge into a 1950s living room, complete with authentic furniture and wallpaper. This HA now offers some 'reminiscence pods' designed to bring tenants with dementia back to a time they remember, potentially making them feel secure, relaxed and helping to stimulate conversation. Evaluation of such initiatives would be helpful, particularly if these could be synthesised.

Blending dementia and cultural related responses

In 2005 HA11 developed an Older People's Services Project with another HA as part a shared equalities and diversity commitment to older people. It provides, among other things, support and guidance on more general age-related issues such as dementia or coping with loneliness and isolation. Following initial activities it has attracted funding from the Big Lottery. The project continues by reaching out to disadvantaged older black and minority ethnic people in its locality. HA11 has been developing a programme for black and minority ethnic older people and housing for some time. Most recently, with grant and charitable funding, it has developed a programme of awareness training about dementia, with input from Stirling University. It works closely with older people and feels it has won trust from local communities because, 'they are not about consulting but feeding back also'. It is starting on a healthy living awareness programme with the black and minority ethnic community, working closely with the local NHS and other public bodies. Some of their tenants have developed dementia but HA11 accepts people who have a diagnosis of dementia before they move in. While much support comes from tenants' families, as a HA geared towards black and minority ethnic older people it purposively recruits staff with the requisite languages.

Some HAs thought that the housing sector lagged behind other sectors on issues relating to ethnicity, diversity and dementia, because the numbers of black and minority ethnic tenants with dementia are currently small. No-one thought that this would continue to be so. This is a sector that is aware of demographic trends. Early activity seems to be on identifying barriers to access and acceptability because of language, lack of skills and confidence, and some cultural differences or constraints.

Currently many HAs have developed policy about agreeing adaptations for individual older people with physical care needs or needing disability adjustments. There seems some lack of confidence about possible needs if dementia is present. This may lead to anxiety about possible excessive calls for expenditure and unmet expectations. Communication with local sources of expertise would seem timely, specifically over best practice in dementia design and modifications, and cost sharing and responsibilities. In relation to culture, religion and ethnicity, many social elements are addressed by housing providers, such as help with daily tasks, and access to social opportunities facilitated by use of media of different languages – and these could be transferable to the support of tenants with dementia e.g. special cutlery (or none) in schemes' restaurants or cafés, assistance with minor matters that might usually be done by the tenant, and recognition that tenants might lose abilities to speak English or have challenging symptoms such as apathy or depression.

We conclude this brief report with a set of potential self-audit questions drawing on the experiences of the study respondents.

Summary questions for self-audit

- What is the scope when undertaking HA refurbishments to consider principles of dementia design?
- Is there consistency in meeting dementia-related needs and cultural needs between the two sides of a HA business?
- Are training and skills development on Equalities reflective of dementia?
 Are dementia awareness and skills training reflective of religious and ethnicity diversity?
- How are people living in general needs HA who develop dementia able to keep close to their community (shops, temple, or similar)? What are the local supportive factors?
- Are processes for adaptations inclusive of physical but also cultural requirements?
- Are HAs recording what they are NOT able to do, as well as achievements, in order to inform local commissioning and their own business development strategies?
- What are the underlying fears about the increased costs of dementia provision? Where do they stem from and what are possible solutions?
- How do tenants with dementia feature in publicity and other materials? Is this sensitive to cultural understandings and concerns?
- Do policies and procedures addressing matters that might be seen as antisocial or discriminatory behaviour, or tenant disputes, meet the needs of schemes where some tenants may have dementia?
- Is the Board included in dementia and in Equalities initiatives do they reflect the communities they serve, including experience of dementia care and support?

References

Age UK (2012) Making it Work for Us – Residents Inquiry into Sheltered and Retirement Housing Age UK London, www.ageuk.org.uk/ Documents/EN-GB/For-professionals/Housing/Sheltered-And%20 Retirement%20Housing%20Report.pdf?dtrk=true

All-Party Parliamentary Group on Dementia (2013) Dementia does not discriminate, House of Commons, London, www.alzheimers.org.uk/site/scripts/download info.php?fileID=1857

Botsford, J. and Harrison-Dening, K. (eds) (2015) Dementia, Culture and Ethnicity, London, Jessica Kingsley.

Garwood, S. (2014) Making a Start – Dementia – Skilling The General Needs Housing Workforce, Housing LIN, www.housinglin.org.uk/Topics/browse/HousingandDementia/Practice/Workforce/?parent=5154&chi ld=9203

King's Fund (no date) Enhancing the Healing Environment dementia care tool for housing, www.kingsfund.org.uk/forms/download-our-enhancing-healing-environment-dementia-care-tool-housing

Moriarty J., Sharif, N. and Robinson J. (2011) Black and minority ethnic people with dementia and their access to support and services, London, SCIE Research briefing 35: www.scie.org.uk/publications/briefings/briefing35

Truswell, D. (2013) Black and minority ethnic communities and dementia: Where are we now? Briefing series: Better Health Briefing Paper 30 Race Equality Foundation, www.better-health.org.uk/sites/default/files/briefings/downloads/health-30.pdf

Wood, S. (2013) Developing an Evidence-Base for Housing and Related Services for Older People Product Development Workshop, Oldham, Aksa Homes.

University of Stirling (n/d) http://dementia.stir.ac.uk/housing-dsdc/design-housing

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