Appendix 2:

Decision-making and communication in housing with care

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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 Vallelly (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 Vallelly, 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 Vallelly (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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