

WHOSE RESPONSIBILITY? BOUNDARIES OF ROLES AND RESPONSIBILITIES IN HOUSING WITH CARE

Imogen Blood, Jenny Pannell and Ian Copeman

This **qualitative study** looks at how different services, providers and other key players work together in housing with care (HWC) schemes for older people and the impact this has on residents' quality of life.

HWC aims to bring the provision of housing support and care together under one roof and this can bring many benefits to older people with high support needs. However, schemes operate in a complex funding and regulatory environment. There is no single model of HWC, and in some schemes, providers are delivering different services alongside each other. This is the first UK-wide study to explore the impact of this complexity on residents' quality of life.

The report:

- examines evidence of contested boundaries, and looks at the impact which grey areas and gaps can have on older people, especially those with high support needs, their families and frontline staff;
- considers what is driving the complexity in HWC and how this impacts on the commissioning and management of schemes, and ultimately on residents' quality of life; and
- identifies a number of practical ways in which organisations can improve the way they work across boundaries to produce good outcomes for HWC residents.

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EXECUTIVE SUMMARY

This report presents the findings of qualitative research which explores the boundaries of roles and responsibilities in HWC and how the quality of life of residents (particularly those with high or increasing support needs) is affected by how these organisations and other key players work together. The focus was primarily on residents' perspectives.

There is no single model of housing with care (HWC). A range of providers and other key players are involved in commissioning and delivering this hybrid of housing, care and support. In some HWC schemes there are multiple providers, with different organisations responsible for different services.

This 18-month study was UK-wide and involved 20 schemes for rent and for sale run by private and not-for profit providers, and stakeholder meetings in each of the four nations. We interviewed 47 older tenants and leaseholders, 8 family carers and 52 professionals; including providers, scheme staff, commissioners, regulators and national organisations. We held a stakeholder conference and workshops at other HWC conferences and worked alongside a consultative group of older residents.

Rights and quality of life in HWC

Rights are intended to guide the boundaries between the older person and everyone else: family, professionals and the rest of the HWC community. We decided to use a 'rights-based approach' to explore the subject, since it views older people as citizens – and in HWC as tenants or leaseholders – with both rights and responsibilities.

Overall, the study found that older people's rights were promoted relatively well in HWC, compared to research findings on older people living in care homes or receiving domiciliary care in the community. However, contested roles can get in the way of older people's rights being promoted, such as their rights to be involved in decision-making or to remain in their home as needs increase.

Grey areas and the ringmaster

In HWC, grey areas occur where it is not clear which frontline worker should perform a task or how far their roles and responsibilities should stretch. This ambiguity sometimes leads to confusion, gaps or duplication in a number of aspects of HWC provision, including buildings and maintenance; supporting move-in and participation; and responding to increasing needs and end of life.

The majority of residents we spoke to were extremely positive about HWC: many described enormous quality of life gains from moving in and said they had not experienced problems. However, just under one-third described problems which seemed to link to issues of roles and responsibilities. Gaps seemed most likely to occur in certain situations, such as when tasks are small (in terms of time it takes to do them); when circumstances suddenly or temporarily change; or when tasks are difficult or resources are limited. They can impact more on people with high support needs and those who do not have partners or involved relatives.

Gaps are often filled by staff members over-stretching their roles, but such a discretionary approach can be inconsistent, inequitable and unsustainable. Other workers, relatives or neighbours sometimes fill the gaps. Many of the residents we spoke to were very capable of organising their own affairs. However, some (especially those with a cognitive impairment) may need a 'ringmaster' to co-ordinate ad hoc input, chase other agencies and make sure things happen for them. This might be a relative, the scheme manager, another member of staff, or an external professional.

Why is HWC so complex?

The complexity of commissioning and delivering HWC is caused by a number of factors, including:

- local authority policies – or an absence of them – in relation to planning, commissioning, procurement and contracting;
- the funding available for housing, care and support within HWC;
- the regulation and monitoring of housing, care and support services;
- the emerging thinking and application of 'personalisation' to HWC;
- the models of HWC in the social, charitable and private sectors;
- the different expectations among residents, family, staff, providers, commissioners and regulators of what HWC is and does;
- differences between the four nations of the UK in terms of the provision of HWC and the extent to which this is influenced by government, the funding of housing-related support and charging for care.

This complexity creates the potential for tensions around the boundaries between roles. This has been exacerbated by cuts in public funding; for example, there was some evidence of authorities and providers shunting costs from support to service charges – this can alter the way in which services are provided.

No single model of HWC emerged as being the best: we found examples of both multiple- and single-provider models of HWC where roles and responsibilities are managed effectively, with little evidence of negative impact for residents. In most of the schemes we visited (including both types of model), most residents reported that the boundaries between staff roles

were managed well. However, a recurring theme was that this was because residents were being shielded from the complexity of the organisational arrangements by the scheme manager and frontline staff, who were working hard to deliver a seamless service despite the complexity.

Older people, especially those with high support needs, told us it was the quality of the staff and their relationships with them that influenced their experience of HWC the most. They also placed a high value on continuity of people and place, having already experienced a significant upheaval in later life. Local authorities do not seem to pay enough attention to the potential impact on older people when making their procurement decisions. We identified negative consequences for residents from block tendering in particular; including uncertainty, lack of clarity, lack of control and a change of provider/staff. Where changes of providers seemed to have been managed well in terms of their impact on residents, these required significant time and other resources to involve residents and their families from the outset.

For residents who require input from a range of services, 'whole system' partnerships and good communication between different organisations are vital. Health is one of the key players in the day-to-day lives of many HWC residents (especially those with high support needs) but the evidence from our study is that health organisations are generally not actively involved in the commissioning or delivery of HWC services. There seemed to be mixed reports about the day-to-day partnerships with social care staff; educating them about housing rights and managing their expectations of HWC were felt to reduce boundary contests.

Practical implications

We identified a number of practical ways in which organisations can improve the way they work across boundaries to produce good outcomes for HWC residents; we present some of these in our accompanying collection of practice examples (Blood, *et al.*, 2012).

Workforce and management

Frontline staff need to be carefully selected, trained, monitored and supported with good management, pay and conditions if they are to provide the high-quality and seamless service that older residents value in a sustainable way.

Clarity between the key players

To minimise roles and responsibilities issues, there needs to be clarity from the outset about expectations of HWC; residents' rights; a shared vision; respective job roles; and mechanisms for communication with relatives and between professionals, and for user feedback.

Commissioning

Commissioners need to be flexible rather than prescriptive, focusing on what works best for older people and minimising the impact on them of organisational change within HWC schemes. They need to look at ways of implementing personalisation so that it increases self-determination, not complexity, and involve the private as well as the not-for-profit sector in strategic partnerships.

Resident involvement

Finding meaningful ways to involve residents in each of these three areas focuses joint working on the things that really matter to older people and empowers them to understand and exercise their rights and responsibilities.

Reflections

- Despite finding important differences in the policy context and provision of HWC in each of the four nations, we were struck by the similarities of the boundaries issues at a scheme level across the UK.
- Although we identified many unhelpful layers of complexity in the sector, the bringing together of housing, support and care professionals and values is a fundamental strength of the HWC model.
- People we spoke to in the course of the research tended not to use the concept and language of rights. However, promoting the idea of rights in the sector could help to involve and empower users more than a narrow financial interpretation of personalisation. Rights-based approaches seem to be taking off in some parts of the private sector, prompted perhaps by more demanding leaseholders and self-funders.
- Many participants describe their move to HWC as one of managing risk, yet HWC is independent living and expectations about what can and cannot be provided must be made clear. The schemes where we found the best practice (and this was true across nations, sectors and type of model) were those where there seemed to be clarity about what they are (and are not) trying to do, and for whom. However tight the protocols and however clear the boundaries, there will always be the risk of gaps: what matters is that all the key players understand this from the outset.
- A key message from older people was that it is the scheme staff who 'make HWC'. Yet in some areas and schemes we found evidence of complexity putting pressure on scheme managers and staff as they try to smooth over the potential fault lines and make the partnerships work.

1 INTRODUCTION

Whose responsibility? is one of three research projects on aspects of housing with care (HWC). The Joseph Rowntree Foundation's A Better Life programme has identified the key role of HWC in supporting and sustaining older people with high or increasing support and care needs.

Within the A Better Life programme, older people with high support needs are defined as

Older people of any age who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, etc. Some of the very oldest people may never come into this category.

This report complements other JRF research and practice-oriented work by members of the same research team; links are made where relevant:

- *Findings from housing with care research: Practice examples* (Blood, et al., 2012), referred to as *Practice Examples*;
- *Affordability, choices and quality of life in housing with care* (Pannell, et al., 2012, and *Findings(b)*), referred to subsequently as the *HWC Affordability study*;
- *Can self-funders afford housing with care? A guide for providers and commissioners* (Copeman and Pannell, 2012).

Previous research on HWC has highlighted the importance of strong partnerships (Croucher and Bevan, 2010) and joint commissioning approaches (Garwood, 2008) if these complex, multi-disciplinary projects are to succeed. Where there are tensions between agencies, or contested and wide-ranging job roles, researchers have identified the potential impact on residents' quality of life (see, for example, Netten, et al., 2011; Evans and Vallely, 2007). However, no previous study had focused in detail on these issues of boundaries, roles and responsibilities and how they impact on both

residents and staff in the unique context of HWC. *Whose responsibility?* also set out to address some specific gaps in the evidence base by:

- exploring roles and responsibilities issues from the perspective of older people (especially those with high or increasing support needs) and their relatives;
- building a greater understanding of whether and how these issues play out in private sector as well as not-for-profit HWC;
- undertaking a consideration of these issues across the four nations of the UK.

Introduction to HWC

There are approximately 1,300 housing developments across the UK that offer care services (see Table 1).

Table 1: HWC across the UK, 2012

Country	Number of dwellings	No. of schemes	Main providers	Sources
England	Over 56,000 (40,000+ for social rent; 15,000+ for sale)	1,100+	HA: 770+ LA: 150+ Other charities: 60 Private companies: 200+	EAC (2012a) and Housing LIN/EAC (2012)
Northern Ireland	700	21	HA only	Housing LIN/EAC (2012)
Scotland	3,800	92	HA: 72 LA: 12 Private companies: 7	Housing LIN/EAC (2012) and Scottish Government (2012)
Wales	2,500 (including 300 private leasehold)	49	HA: 42 LA: 2 Private companies: 5	Housing LIN/EAC (2012)
Total	Over 63,000	Over 1,200		

Abbreviations: EAC = Elderly Accommodation Counsel; HA = housing association; LA = local authority; LIN = Learning and Improvement Network

There is no single model of HWC. Both individual dwellings and schemes vary enormously in size and scale, location, services and cost (rent level, purchase price, charges). There are significant variations in provision and policy context between the four nations of the UK. Schemes include:

- extra care or very sheltered housing;
- retirement villages;
- assisted living and close care models;
- housing for social rent, market rent, full and shared ownership and leasehold tenure;
- private, housing association and charitable providers.

HWC aims to combine the best of both worlds for older people by offering both the privacy and independence of their own front door and their own

home, within a safe and secure setting with a range of facilities; and the availability of help and support, personal care, companionship and social activities, as and when they are needed (with staff usually available round the clock).

Because of the extent of facilities and on-site support and care, HWC is quite distinct from other forms of housing (including sheltered housing) but it is also different from residential care. HWC is 'housing first'. Older people have legal rights as tenants or owners. Housing rights give tenants and owners security of tenure (within the terms of their tenancy agreement or lease) and the right to control who enters their property. The concept of 'home' is especially important to older people (see Benjamin, *et al.*, 1995; Heywood, *et al.*, 2002; Sherman and Dacher, 2005): going into care can mean a loss of that sense of home (NHF, 2010a); HWC offers an attractive alternative.

Terms used in this report

HWC is used instead of 'housing with care' throughout. We decided to select schemes for this study which had:

- an on-site care team;
- 24/7 staff cover (i.e. more than community alarm service);
- availability of some meals, usually in an on-site restaurant;
- social and leisure activities and facilities.

It is important to distinguish between 'care' and 'support', since there are significant differences in regulation and funding. Broadly speaking, care is 'doing for' and support is 'doing with' someone.

Care activities (regulated by the Care Quality Commission (CQC)) include direct help provided to the older person, such as assistance to get up, get dressed and wash; minor medical matters that do not require a qualified nurse; and prompts and reminders (only where the person does not have capacity to make decisions; otherwise this is classed as 'support'). **Care staff/care worker** means paid staff providing care (although in some schemes, they will also provide some support). Where interviewees talk about 'carers' we have not changed this.

Support covers practical help with a wide range of tasks, which can include accompanying the older person, dealing with post and bills, meal preparation and shopping. It also includes reminders/prompts (but not direct help) for an older person (who still has decision-making capacity) to manage their own personal care. It may also include social support, such as befriending or support to participate. Where support is being provided separately from care, we describe the paid workers doing this as **support workers**, although we recognise that different terms may be in use in different HWC models, such as 'concierge staff', 'porters' or 'stewards'.

We interchangeably describe the people we interviewed as **participants**, **interviewees**, or simply as the **older people/professionals/relatives/commissioners we spoke to**. We talk about **residents** to report our general observations, stories told to us by professionals or neighbours, or when making reflections or drawing conclusions. **Residents** includes HWC tenants, owners and shared owners; where relevant, we specify the housing tenure.

Where family members provide informal unpaid care and support, they are described as **family member**, **relative** or more precisely by their degree of relationship, such as **daughter**.

We use the term **housing provider** in general across both social and private HWC. Where it is necessary to distinguish, we use the term **landlord** to describe organisations providing social housing for rent (and mixed tenure), and **freeholder** for the organisation that owns the site and buildings for private leasehold HWC for sale.

We use the term **adult social services** to refer to local authorities with adult social services responsibilities in England, Scotland and Wales, and the Health and Social Care Board in Northern Ireland; these have accountability for assessing local needs and ensuring availability and delivery of a full range of adult social services.

A HWC scheme is both a community in itself, and sits within the wider community of its locality. We use **community** for relationships within the HWC scheme (although we recognise, as discussed by Evans and Means (2007) that this is a contested concept), and **local/wider community** for relationships with the locality.

Introduction to boundaries, roles and responsibilities in HWC

Commissioning and delivering this hybrid of housing, support and care can be complex. Often there are different organisations providing a range of services: housing (management and maintenance), support, care, leisure, meals and other services. External agencies (local authority housing, social care and other departments; health services; other regulatory authorities) also have different roles, including strategic, commissioning, safeguarding and inspecting functions. Older people and the residents' committees that may represent them are also key players, along with their families, advocates, GPs and any social care professionals who are involved. For all parties, clarity over boundaries, roles and responsibilities is crucial.

Residents' quality of life can be affected for better or worse by the way in which these diverse organisations work between themselves and with residents and their support networks. The impact on people with high support needs is likely to be even greater than for other residents. Where needs are complex and boundaries unclear, people may fall into the gaps between services, have to repeat their story to many different professionals or risk a sudden, undesired move out of HWC. People with cognitive or sensory impairments or those with learning difficulties can also face additional barriers to complaining.

In our *Viewpoint* we identified a number of areas around which roles and responsibilities between the key players tend to be contested in HWC. These were:

- decisions to move in (residents and families), nominations and allocations (professionals);
- different expectations of HWC (residents, families, different professionals);
- buildings and facilities provision, management and maintenance, health and safety;
- promoting well-being, preventing exclusion of frailer residents;
- safeguarding and duty of care;

Where needs are complex and boundaries unclear, people may fall into the gaps between services, have to repeat their story to many different professionals or risk a sudden, undesired move out of HWC.

- managing increasing care and support needs;
- moving on and end of life – is HWC a ‘home for life’?

We also argued that there were many variables which might affect boundaries and the impact of them. These can relate to:

- the national external context (such as national policies on charging for care);
- the local external context (such as local authority commissioning strategy and practice);
- the internal management context for HWC providers and their partners (such as the sector and mission of provider organisations);
- the characteristics of the residents (such as the profile of health, care and support needs).

Understanding different models of HWC

To understand better the complexities of boundaries, roles and responsibilities and how they might impact on residents, we introduce a real, anonymised example in this section.

Example HWC scheme

A number of different providers have been involved at different stages of this medium-sized English HWC scheme’s operation (see Table 2).

Table 2: Service providers during three stages of an HWC scheme

	Housing provider	Housing management	Support	Catering	Care	24/7 cover
Stage 1	Charity	Housing Association A	Housing Association A	Housing Association A	Local authority domiciliary care team	Housing Association A
Stage 2	Charity	Housing Association B	Housing Association C	Housing Association C	Housing Association C	Housing Association C
Stage 3	Charity	Charity	Housing Association C	Housing Association C	Housing Association C	Housing Association C

Scheme set-up: stage 1

The housing provider is a charity, which owns the building. The new-build scheme was developed with a mix of public and private capital funding, in partnership with the local authority, which provides funding for care and support and nominates new residents for the 50 units.

The charity worked closely with Housing Association A to develop and manage the scheme, initially contracting them to provide housing management, support and catering and the 24/7 cover. The local authority had responsibility for commissioning and providing care through their in-house domiciliary care team.

The scheme manager, employed by Housing Association A, was responsible for everything except care. The charity had only two organisations to liaise with: Housing Association A and the local authority. There were clear and detailed protocols and partnership arrangements.

Changes to housing, care and support providers: stage 2

After a few years, Housing Association A experienced structural and staff changes and it was agreed mutually that they should no longer manage the HWC scheme. The charity instead contracted with local Housing Association B for housing management (including employment of the scheme manager). However, Housing Association B did not have the experience to provide support and catering services within HWC.

The local authority was also changing its contracting arrangements and tendering care and other services to outside agencies. So it was agreed that the scheme's support, care, 24/7 cover and catering services should be put out to tender by the local authority. Housing Association C won the contract. Some existing staff were transferred (TUPEed¹): the scheme manager to Housing Association B, and catering, care and support staff to Housing Association C. This left the charity with contractual responsibility for housing management only.

Resident dissatisfaction

With all these changes, the original protocols no longer worked and nobody knew who was responsible for what. Although the providers knew there were problems, they hoped that they were managing to hide these from residents. However, matters came to a head when most residents signed a petition to the housing provider, which focused mainly on their perception that too many people with high support needs were moving in and that the scheme felt 'like a care home'.

The housing provider called in independent consultants, who spoke to residents and staff. In their report, the consultants explained that, from the residents' perspective:

They see a lot of people in the office they don't know, people coming into the scheme they don't know; the scheme manager is no longer able to do for them things which she used to; something is different, and out of their control. Also, residents don't see a single service but are very aware of (and confused by) the fact that different organisations are in charge of different aspects of the scheme. This all contributes to a loss of confidence in management and a sense of [HWC scheme name] feeling more like an institution, and less like their own home, than it used to. This may contribute to a withdrawal from activities.

Changes to housing, care and support providers: stage 3

The charity acted on recommendations from the external consultants to address resident concerns. Some time later, there were changes at Housing Association B. The charity decided to regain control of housing management and take it back in-house, rather than find another external partner. So the final result was that there were only two organisations involved: the charity and Housing Association C.

Role conflict and ambiguity were impacting on a number of the contested areas we highlighted earlier, such as nominations and allocations; access to the building, catering and other facilities; and the provision of care and support as needs change. In turn, this was having a significant impact on residents' quality of life: their sense of control, their feelings about the place they live, their relationships with staff, and their social lives.

Diversity of models

There are many different ways of organising HWC. In some schemes all the key services are provided by the landlord or freeholder, but often – as in our example – some or all the key services are contracted to other providers. Service providers include private companies, not-for-profit organisations (especially housing associations) and social enterprises. There can be a mix of providers, regardless of whether the HWC scheme is publicly funded or private sector, for social rent, owner-occupation or mixed tenure. Local voluntary organisations are often involved in running social activities which may be available to older people living in the vicinity, and other external providers may come in to provide services (such as hairdressing in the scheme salon).

To add to the complexity, providers can change for a number of reasons, including local authority commissioning decisions and organisational change or failure. As in our example, this can have a significant effect on residents' quality of life. Residents may have little or no control over such changes, as explored in Chapter 4.

The complexity of HWC is reflected in many previous studies (see, for example, Croucher, *et al.*, 2007; Netten, *et al.*, 2011; ADASS and Housing LIN, 2011) and the Housing Learning and Improvement Network (LIN) (www.housinglin.org.uk) has many publications on this subject. In Chapter 6 we consider the evidence from our study and reflect on how and why the national and local external context creates such complexity.

To add to the complexity, providers can change for a number of reasons, including local authority commissioning decisions and organisational change or failure.

Differences in the four nations of the UK

This research was UK-wide. At an early stage in the project, we identified significant differences in provision of HWC, funding of housing support and charging for care services across the four nations and were keen to explore whether and how such variables affected boundaries, contested areas and resident experience. We presented a table setting out some of the specific national differences in our *Viewpoint* and we reflect further on these differences in Chapter 4. However, in our fieldwork and stakeholder meetings, we were struck by the similarities of issues and experience across the four nations, perhaps because complexity itself is a consistent feature of HWC across the UK.

We highlight relevant national differences where we encounter them in the main body of the report and have attempted to include quotations and examples from each of the four nations to present as balanced a picture as possible.

Introduction to this study

In this section we provide an overview of the study, including our research questions, data collection and some headlines regarding the profile of our sample. We include a short discussion of our research methods and consider how equality and diversity impacts on this study, before setting out the structure of this report.

Overview of the study

The study focuses on the following research questions:

- What are the boundaries/fault lines of roles and responsibilities in HWC?
- What are the impacts on quality of life for older people (already living in HWC) whether they have high or increasing support needs, or no support needs?

- How far can clarity over boundaries ensure that for every resident, HWC remains 'my home' and not a 'care home'? What else is needed? What works, and what does not?
- Can a rights-based approach empower residents? Does this still work for those who have high support needs (and perhaps mental capacity issues) and how does it link to safeguarding issues?
- How do these issues change across different models/providers of HWC?
- How is quality of life affected by different expectations among residents, family, staff, providers, commissioners, regulators, and so on?

The research took place between January 2011 and August 2012 across the UK. This was primarily a qualitative study. We were also keen for it to be led by older people as far as possible, within the limitations of budget and resources, and we included:

- a consultative group with 8–10 older residents in one HWC scheme;
- four consultative groups with commissioners, providers and other stakeholders in England, Northern Ireland, Scotland and Wales;
- a limited and focused literature review, which included relevant documents from schemes as well as national studies, reviews and policy documents;
- visits to a case study example and a further 19 schemes in all four nations, including interviews with 47 residents (of whom 3 were caring for partners), 5 family members and usually the scheme manager or equivalent – we included schemes from both rural and urban areas, most of the English regions and a cross-section of providers (two schemes were aimed at black and ethnic minority older people – one exclusively, the other in an ethnically mixed community – and one scheme also had housing specifically designed for people with learning difficulties);
- 52 interviews with providers, statutory organisations, experts and other relevant organisations;
- two workshops at the December 2011 Housing LIN conference, a conference with residents, providers and other stakeholders to test findings in March 2012, and a workshop at the Older People & Ageing Research & Development Network (OPAN Cymru) HWC conference in March 2012.

Profile headlines

Of the 47 older people we interviewed:

- two-thirds were women;
- 11% were from black or minority ethnic communities;
- 22 (47%) were 85 years and over – the average age was 80 years;
- 85% were social renting, 15% were leaseholders, 47% had previously been either council or housing association tenants and 34% had previously been owner-occupiers;
- 64% were receiving Housing Benefit, 47% were receiving Attendance Allowance;
- 47% were paying something towards their care or support;
- 7 people had been living in the scheme for less than six months, 8 for more than five years.

We did not use formal tools to identify residents with high or increasing support needs but rather relied on respondents (or relatives/HWC staff where they had difficulty with this) to tell us about their own health

conditions and care/support provision. They had, on average, two health conditions each; 3 people had five health conditions. Just under half were receiving personal care (in addition to the basic package of support) at least once a day and/or regular night time assistance

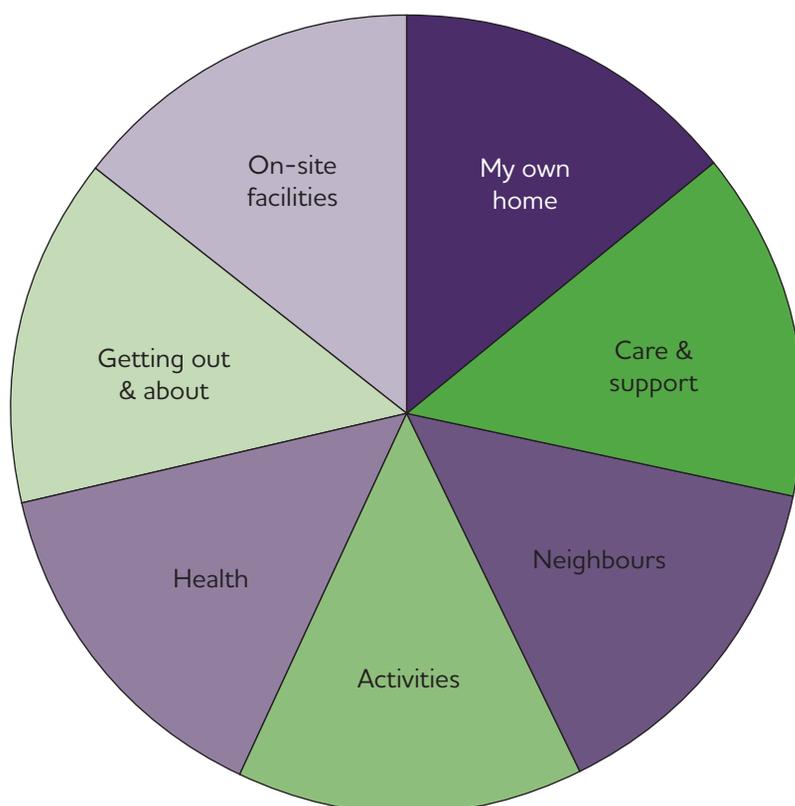
We met a number of residents who had high support needs (such as those linked to learning difficulty, mental health or cognitive impairment) but did not need personal care. We also met people who had received significant care packages in the community but needed no or little additional personal care now they were in HWC. Reasons for this included living in a more accessible home; the support included in the HWC package; and using the restaurant rather than needing help to prepare food at home.

Research methods

It was a challenge to work out how best to raise the research questions with residents in a face-to-face interview. Some residents might quickly grasp the issues (especially if they had experienced a problem/solution in their HWC scheme), but others (especially those with any cognitive impairment) might find this more difficult and we were also anxious not to steer participants in a particular direction or leave them feeling unsettled or confused.

To help with this, the research team devised a wheel, based on one used by Katz, *et al.* (2011) in their conversations with older people (see Figure 1). This showed different areas in HWC where there could be boundaries issues. To this were added a selection of name cards for all the people who could be involved in different issues, including family and staff from HWC and outside agencies.

Figure 1: Aspects of life in HWC wheel



This tool acted as a prompt for people to pick one or two aspects of their life and talk about the roles and responsibilities of key players (from the cards) and about how decisions and complaints were made. For example, a woman who has a learning difficulty opted to talk about how her care and support are provided; she used the key players to identify the ongoing input of a previous support worker and the support she receives from a friend, alongside that provided within the scheme.

In conversations with professionals, and in the analysis and reflection, the wheel has also helped to keep the focus on the older person's perspective and their quality of life.

The team sought advice and guidance on research ethics. It was agreed that the research could address the key research questions by including all residents who could be supported both to take part and to give informed consent.

We analysed the qualitative data using QSR NVivo software. This helped us to organise the data into over a hundred themes and cross-reference what participants said with information about them (such as age/ethnicity/health and HWC scheme type). Close communication within the project team and involvement of the consultative groups enabled us to identify unanticipated themes and to generate and test different hypotheses.

Equality and diversity

Equality and diversity issues run through this study in a number of different ways and are discussed in more depth in King and Pannell (2010) and in Blood and Bamford (2010). For example:

- An individual's support needs are shaped by a number of what the Equality Act 2010 terms their 'protected characteristics'; for example, disability, ethnicity, gender, marital status, and so on.
- The impact of contested areas on people from some protected characteristic groups is likely to be greater.
- Those who share protected characteristics may encounter greater or different barriers as they seek to complain or enforce their housing rights, and may need support to participate in the life of the HWC community or in decision-making about their own lives.
- There can be particular issues for residents who represent a minority within a scheme, whether on account of their gender, race, religion, sexual orientation or social class, and this can be intensified by decisions around allocations.

Our approach is based on the social model of disability, recognising that the support people need results from the environmental and social barriers they face as much as the medical conditions they have. Central to this model is the notion of rights – and accompanying responsibilities – and the fact that older people make choices, which will sometimes include taking risks. We present our rights-based approach in more detail in Chapter 2.

How the report is structured

There are effectively two units of reference in this study: we are interested both in the individual older person and their experience; and in the scheme and how it operates (and, of course, how this impacts on the older people living within it).

In Chapter 2 we develop our conceptual framework for the research, looking at rights and quality of life within HWC.

In Chapter 3 we consider how frontline staff work together within the scheme to support the older person; where grey areas occur in the

boundaries between their roles and responsibilities; and whether and how these impact or are overcome.

In Chapter 4 we ask why HWC is so complex, considering funding, regulation, commissioning practice and policy, personalisation and differences between the four nations of the UK, and how this complexity can drive contests at a local, scheme or individual level.

In Chapter 5 we reflect on the key messages from the study, suggest some practical implications, which we will be exploring in the *Practice Examples*, and draw some overall conclusions.

2 RIGHTS AND QUALITY OF LIFE IN HWC

Our focus in this study was on the impact ambiguous and contested roles and responsibilities in HWC can have on the quality of life of residents, particularly those with high or increasing support needs.

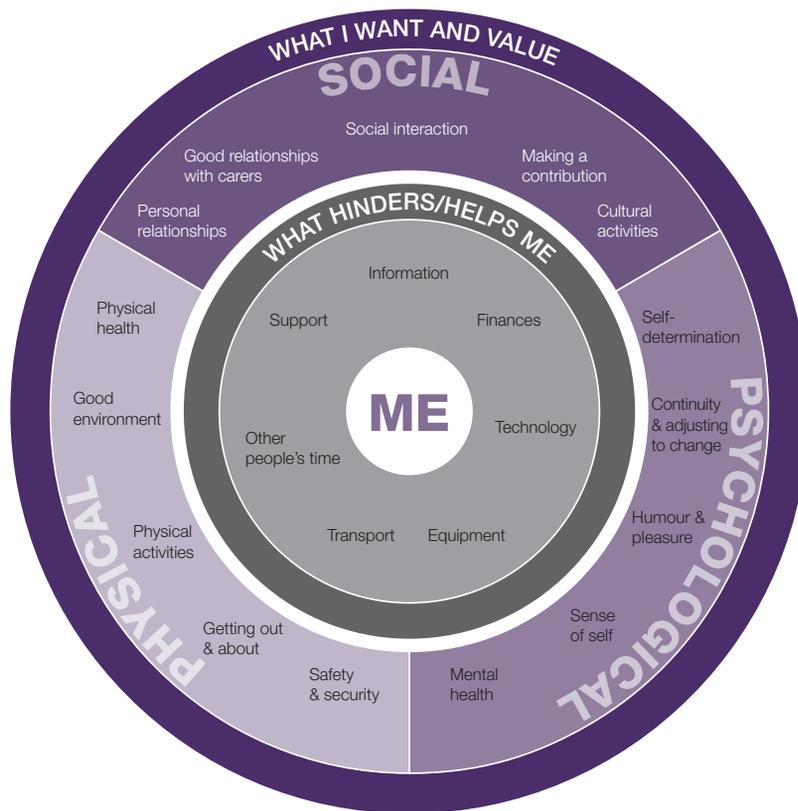
Our conceptual framework

We used the model developed by Katz, *et al.* (2011) (see Figure 2) to explore how different aspects of 'quality of life' might be affected by boundary issues. This earlier study, commissioned by the Joseph Rowntree Foundation, identifies the things that older people with high support needs value most in their lives, along with enablers and barriers that can help or hinder them to achieve these things.

In keeping with the values of the A Better Life programme, we were also particularly interested in the concept of a 'rights-based approach' to the housing, care and support of older people with high support needs, and in how HWC can further this. Such an approach promises voice, choice and control to older people (Macadam and Bowers, 2008): they are not the passive recipients of care but citizens with rights (rather than needs) in relation to services.

Stakeholders at one of our project meetings pointed out that, because tenants and leaseholders have housing rights, HWC is an inherently 'rights-based' model. Rights are intended to guide the boundaries between the older person and everyone else – family, professionals and the rest of the HWC community – so they formed a key part of our conceptual underpinning as we explored the boundaries of roles and responsibilities between the key players in HWC.

Figure 2: What older people with high support needs value



Some of the rights which apply in HWC

- Housing rights, as set out in the tenancy agreement or lease – including the Right to Manage for private leaseholders – and more general housing rights from the civil and criminal legal systems, including protection from eviction, harassment and disrepair (Arden and Dymond, 2012) apply to HWC schemes.
- Residents have the right to an assessment for social care services.
- The Human Rights Act 1998 applies, although it does not cover care for self-funders in HWC, and is unlikely to cover private/charitable providers of HWC. Of particular relevance to HWC may be:
 - the right to participate in decision-making which affects you;
 - the right to be free from discrimination;
 - the right to be treated with dignity and respect;
 - the right to respect for your private family life, home and correspondence.
- Anyone using or receiving a service has the right to complain (Hasler and Davis, 2010).
- The Equality Act 2010 gives protection from discrimination around age, disability and other 'protected characteristics'.
- Various standards, guides and codes of practice set out what service users can expect from HWC providers, such as the right to be consulted and involved in decision-making (although these are not legally enforceable). These include:
 - *The regulatory framework for social housing in England* (Tenant Services Authority, 2010);

- *Guidance about compliance: essential standards of quality and safety* (CQC, 2010);
- Association of Retirement Housing Managers (ARHM) codes of practice for England, Wales and Scotland (ARHM, 2005; 2009; 2010);
- guidance on sheltered housing, such as on support, complaints and tenant involvement (CHS, undated; Hasler and Davis, 2010; Hasler, *et al.*, 2010).

We recognise there may be limitations to a rights-based approach: whether or not rights actually make a difference to quality of life depends on the key players being aware of them, understanding them and being able to access mechanisms which can effectively enforce them. Most of the specific and legally enforceable rights that apply to those living in HWC (outlined above) set out the *minimum* standard for services – the bottom line. For example, tenants/leaseholders have the right to live in the property peaceably and without interference or disturbance from others; they have the right to be assessed for social care; and formal procedures are available (such as those within codes of practice) so that they can complain about any of the services they are receiving. Although they can provide a useful framework during contests between service users and professionals or between individuals in a communal setting, rights do not cover all the things that matter to older people. For example, Katz, *et al.* (2011) found that social interaction, cultural and physical activities, and making a contribution are also of key importance to older people with high support needs.

The Human Rights Act 1998 covers broader areas of well-being, such as the right to be treated with dignity and respect, and the right to participate in decision-making which affects you. Ife (2001) has argued that human rights aspire to go beyond the bare minimum: 'The right to realise one's full humanity is at the core of an idea of human rights' (p. 9). However, older people do not have specific enforceable rights to many of the things – such as social, cultural and physical activity – which may be central to 'realising their full humanity'. Moreover, although the Human Rights Act 1998 applies where housing associations are allocating and providing publicly funded social housing on behalf of local authorities, it does not yet cover care for self-funders in HWC, and is unlikely to cover private/charitable providers of HWC (EHRC, 2011).

The concept of 'self-determination' is critical to a rights-based approach (Macadam and Bowers, 2008) and also emerged as one of the categories in the Katz, *et al.* (2011) study. Our research, like the Katz, *et al.* study, found that 'independence' meant different things to different people, but it might include being able to shape how care is provided; deciding how you want to spend your time; and receiving support to plan ahead in life, including end of life. Self-determination implies that people feel they have a choice and that they are able to take risks (Faulkner, 2012); it also inevitably means they must accept some responsibility for their choices and actions. As Macadam and Bowers (2008, p. 38) argue, it 'includes balancing assumed and legally enshrined rights with both explicit and implied responsibilities'.

HWC promoting rights and quality of life: our findings

We got the impression that the language of ‘rights’ and ‘empowerment’ was not particularly understood or welcomed by older people, frontline staff or senior people in housing organisations. At times, rights seemed to be used as an excuse for not doing things; for example, not telling a resident that their neighbour had gone into hospital because of the neighbour’s right to confidentiality. We found barely a mention of the word ‘rights’ in all of our interviews.

Nevertheless, we found many examples in which the rights of older people with high support needs were being promoted effectively in HWC. This seems to compare favourably with the alternatives: recent studies of older people’s human rights in care homes (Bowers, *et al.*, 2009) and domiciliary care in the community (EHRC, 2011; Speed, 2011; Sykes and Groom, 2011) have found significant shortcomings.

Our fieldwork suggested that HWC scores particularly well around promoting the right to a family life/sexual relationship; the right to privacy/quiet enjoyment of home (although there were delicate balances to be found between the rights of individuals and the community here); and the opportunity to raise a formal complaint (although there was some evidence of role confusion around who to complain to and who was responsible). The right to confidentiality was being upheld (although at times rather too rigidly) and we found evidence of people’s right to be treated with dignity and respect being promoted well. However, we identified some organisational threats to the latter, as a result of the impact of the factors we discuss in Chapter 4 on workforce and regulation.

We heard examples in which people had been supported to stay in HWC until the end of their lives, although residents and their families may benefit from clearer information about their right to a home for life to facilitate future planning. In general, the right to participate in collective decision-making was an area for development and one which, as our example in Chapter 1 demonstrates, could make a real difference to how change is managed.

Many of the residents we spoke to told us that staff had worked far beyond the legal minimum, effectively closing the gap between what people are entitled to (their rights) and what they want (in the Katz, *et al.* model). For example, we met a couple with very high support needs who had been helped to move into HWC where they could continue living together and were supported to do more for themselves and each other, assisted by equipment and basic adaptations. Fulfilling their human right to ‘private family life’ for them was not just a question of being left alone; it involved a range of staff working in partnership with them and each other and with clear shared values about independent living (see Blood and Pannell (2013, forthcoming) for further discussion of this).

Contested boundaries affecting rights and quality of life

As in our example of the couple above, good partnership working and clarity about professional and personal boundaries can promote both the rights and the quality of life of older people with high support needs living in HWC. Conversely, we found examples in which roles and responsibilities issues were getting in the way of rights being promoted. Themes here included:

- staff not having enough time, clarity of remit, management support or skills (for example, in striking a balance between respecting individual rights to privacy and encouraging participation);
- residents and staff not being clear who is responsible for something (for example, for supporting a tenant whose challenging behaviour is impacting on neighbours' rights to quiet enjoyment of their homes) – in some cases, this lack of clarity meant that people were not sure who to complain to;
- older people, relatives, social workers and health professionals having different expectations of HWC (for example, not understanding people's housing rights and what the basic support package in HWC consists of when planning hospital discharge or end of life).

Complex funding arrangements and re-tendering – leading in some cases to high turnover and sickness absence – or roles being removed or changed seemed to be exacerbating (although not necessarily creating) these fault lines, as we will explore in Chapter 4.

Although boundary issues can work against rights being promoted, the very fact that HWC brings together different providers and different perspectives was felt by many of those we interviewed to be beneficial to older people. One provider explained that housing can counter the 'doing to' approach of social care: where care workers tend to focus on the needs of the individual, housing staff must also balance these against the needs of the community if they are to uphold the housing rights of their tenants and leaseholders. Another professional participant felt that partnerships with housing associations or private organisations can galvanise the public sector. We found some evidence to suggest that, in terms of rights, leaseholders who have paid to move to HWC may be more confident around exerting their rights, which now include the Right to Manage. Our conversation with the resident chair of a Right to Manage board felt in sharp contrast to the lack of meaningful resident involvement we were told of in many – although not all, as our guide shows – of the other schemes we visited.

If different professionals are to work effectively with each other there needs to be clarity about how roles fit together and what the overall objectives are. Older people and their relatives need to understand what they can expect from HWC and their own responsibilities – towards neighbours, property and themselves – if they are to understand and accept the risks that are entailed in living independently. It is interesting to note that, for many, the move to HWC was about reducing risks: 'dangerous' was a term used by several people when describing their previous home (both their own view and sometimes the verdict of a social worker), including risks of domestic violence, falling, physical and mental ill-health, or the risk of a care worker not turning up.

It's essential to be clear with applicants about what they are moving into and their individual responsibility as a resident within extra care housing; people do need to know fully what they are signing up to when they move in to extra care housing.

– Commissioner

We develop these themes in the next chapter as we explore the risks arising for those with high support needs from the grey areas between the boundaries of frontline services.

Although boundary issues can work against rights being promoted, the very fact that HWC brings together different providers and different perspectives was felt by many of those we interviewed to be beneficial to older people.

3 GREY AREAS AND THE RINGMASTER

In this chapter we consider the relationships and boundaries between the frontline staff in HWC; how these impact on the older person; and how these are, in some cases, mediated by the older person's family.

In the first part we consider the grey areas between the roles and responsibilities of staff members within the scheme. We discuss our findings regarding whether and how these grey areas lead to gaps and role confusion and, if they do, how they impact on residents' quality of life. A key finding here was that potential gaps are often filled by staff stretching beyond their job descriptions or by others – fellow residents, private helps, or even hairdressers – shielding residents from the impact.

In the second part we introduce the idea of the 'ringmaster'. This is usually a scheme, care or support manager, a key worker or a relative who 'holds it all together', co-ordinating the input of health and other external agencies for an HWC resident who is unable to do this for themselves.

Grey areas and gaps

A 'grey area' is an area that is not well defined: 'a situation in which the rules are not clear' (*Macmillan Dictionary*). In HWC, grey areas occur where it is not clear who should do a task or how far their roles and responsibilities should stretch. Unless this ambiguity is identified and a mutual solution agreed, grey areas can result in one or more of the following:

- confusion, which can lead to stress and uncertainty;
- duplication, often accompanied by poor communication about what each person has done;
- gaps where there is no service – it does not get done;
- staff going beyond the call of duty and filling in the gaps – this can have implications for work–life balance, mental and physical health, insurance and accountability (for example, if you change a fuse for someone and this

falls outside of your job description and formal training, who is liable if the appliance breaks, someone gets an electric shock or it starts a fire?).

As staff time is limited and such gap-filling is discretionary, this results in an inconsistent service – some service users get the service because they ask, because they are liked, or are seen as being ‘vulnerable’ (perhaps as a result of disability, illness or limited family involvement); others do not. Some care workers provide the service because they are particularly conscientious; others do not because it is not in the care plan and they do not have to. Since this happens in an ad hoc manner, some of those who experience gaps will suffer a negative impact on their quality of life. There may also be accusations of favouritism, which can affect the atmosphere and relationships in the scheme. Discretionary services also risk having a negative impact on equality; in other words, there may be patterns of advantage and disadvantage around who gets the service and who does not. Staff may (unconsciously) be more likely to ‘go the extra mile’ for residents who are more demanding (who may be those from richer, professional backgrounds), whose ‘face fits’ or who are not ‘too difficult’ (which may be linked to disability, language, gender, and so on).

Where are the grey areas and gaps?

If you look at it from a resident’s point of view, all they want and need is ‘help’. There is a danger that a rigid definition of roles and responsibilities constrains a provider’s ability to deliver that bit of help.

- Professional from a national organisation, England

In this section, we discuss our findings on some of the key contested areas confirmed by our fieldwork.

Move-in support

The majority of residents will need extra practical support during the first weeks or months after moving into HWC. This need is likely to be greater where people are confused, have a sensory impairment or have moved from long-stay residential care, or for those who have been particularly isolated or have experienced recent bereavement, abuse or sudden health crises. Although some interviewees felt they had received plenty of support to settle in, we did also hear of a number of significant gaps. One relative told us that her mother, who has a cognitive impairment: “spent the first six months lost in the building”. Another relative told us that her mother had been promised a ‘buddy’ but that this did not happen in the early months and that she was, as a result, very isolated in a large scheme and missed out on most of the Christmas activities. These gaps seem to fall on the fault lines between housing management, housing support and care.

Where gaps occur following move-in, we heard examples of them being filled by a range of people. One resident told us that her key worker helped her to settle in by taking her to social events (presumably outside of her working hours since she pointed out that she was not paid to do this and that the worker’s partner came along as well). In the case of the woman whose buddy had failed to materialise, it was the hairdresser who eventually put her in touch with another isolated resident and they became close friends, supporting each other. A couple of professionals pointed out that there is a risk in these early months that family withdraw the support they were previously providing. If this gap is not recognised quickly (or if there is a delay

while social services set up additional care), there is a risk of the tenancy breaking down.

Lack of resources may well be a factor in these cases, but the gaps are also the result of a lack of clarity about roles and the key players' (especially relatives' and social workers') differing expectations of what is provided as *standard* within a scheme.

Supporting participation

We found examples in which individuals with high support needs had been supported to participate or even get involved in running communal activities by scheme staff. However, in some schemes there were questions and ambiguities around whose responsibility it was both to organise the social life of the scheme and to support individuals to access it (see also Evans and Vallely, 2007; Callaghan, *et al.*, 2009). Sometimes, reductions in Supporting People funding (we discuss this in more detail in Chapter 4) have led to the withdrawal of the activity co-ordinator or similar post; sometimes older people had been told that *they* need to organise activities themselves. Some residents said they did not feel willing and able to take on this responsibility without support; others had tried but had been demoralised by low levels of participation by neighbours. Competing priorities in allocation policies were blamed by several for tipping the balance between 'fit and frail' and thus reducing the numbers who could attend.

Buildings and facilities

The maintenance of the building is clearly the responsibility of the housing provider/freeholder; however, there are still grey areas here between the landlord/freeholder's and tenant/leaseholder's responsibilities. In general needs housing it would be the tenant's responsibility to do very minor things like changing light bulbs, but in HWC, where someone is unable to do such tasks due to disability or age, will maintenance staff help out or is this the role of support workers? Some schemes do have handymen or porters; in other schemes this may be a gap, which is filled by support staff (perhaps going beyond the call of duty), relatives or neighbours:

One of the things that would be beneficial here is having their own handyman. We tend to get flyers put through our door for those types of services but I am reluctant to seek outside help for something like changing light bulbs – there's a bit of a 'no man's land' where it's not anybody's job to do these little things – they need to be done but it's no one's job. What I find is that [support manager] will do things for me even if he is not supposed to.

– Resident

Out-of-hours problems with the building can raise particular issues in schemes where only care staff are on site at these times. One housing provider told us how important it had been to clarify the service standards of their maintenance contractor's call centre and the job descriptions of care staff. Care staff could reasonably be expected to report an out-of-hours problem with the lift, but it was unreasonable to expect them to keep chasing the problem or provide access to contractors when they were busy providing care. We heard that in one scheme where there were several different providers, everyone had assumed that someone else was testing the fire alarm until someone realised that no one was.

Some issues also arose from the research around the use of the building and facilities – who decides, who needs to know, and what is the impact on residents or other staff members where there are changes to the way the building is used? One provider told us that the care agency had tried to set up and register a profit-making business using the scheme as a base, without negotiation with landlord or tenants. One of the questions that arose in the example we introduced in Chapter 1 concerned who is responsible for building bridges between tenants and outside groups using the scheme facilities so that tenants did not resent these groups and feel they were intruding on their homes. Ensuring there is clarity about ‘payment’ for use of external facilities can help here – ‘payment’ might mean that residents can attend activities for free or that a small donation is made to the resident committee fund.

Increasing care and support needs

The boundaries between care, support and other provision can be tested where needs increase, especially if this happens suddenly or temporarily. The serving of meals seemed to be a particular issue, perhaps because there are potentially three organisations (or parts of the same organisation) involved here: caterers, support staff and, where individuals are ill or have high care needs, care staff. In the words of one provider:

I guess the biggest grey area between us and the care providers at this scheme has been over who is responsible for assisting tenants to get down to the café when they are not feeling so good.

– Provider

Another provider told us that they had experienced problems when a woman was too ill to come down to the dining room and the care staff had agreed that they would bring a meal to her, but not to her husband. Support staff had ended up making a separate trip with his meal so that the couple could still eat together.

There seemed to be recurring grey areas when residents who do not have existing care plans need temporary or one-off assistance, especially where this occurs out of hours in models where there are only staff from the care provider available at these times. Examples included:

- pressing the buzzer out of hours – it was not always clear how calls from those not in receipt of care plans should be prioritised (we heard examples where they were not responded to at all) and how involved care staff should get in providing support;
- welfare checks over a weekend where people are ill or have just come out of hospital;
- help putting in eye drops, putting on a plaster, and so on.

However, even residents with existing care plans felt that it was difficult to get little bits of practical support, like help putting out the milk bottles, or occasional assistance, such as getting a cup of tea made for you when you are ill. As one resident explained:

The care plan is agreed with your social worker and the care organisations but little odd things crop up ... some care staff will help and some won't; with things like that it's difficult to find out who can help.

Planning for end of life and safeguarding

Providers and partners told us of cases in which scheme staff had ‘helped enormously’ to support people to die in the scheme, as they wished. We also heard of cases in which decisions to move on to settings with higher levels of care had been jointly made by the older person, their relatives, scheme staff and health or social care professionals.

However, several providers described contests around these decisions between themselves, older people and their families, and social services. Usually the contest arose because social workers were pushing for a move to residential care, for reasons linked to safeguarding and/or funding issues.

We heard, for example, of one case in which a resident who had choking risk and swallowing problems needed PEG (percutaneous endoscopic gastrostomy) feeding, and HWC staff received training for this. However, the situation deteriorated, the resident was admitted to hospital and regular suctioning was needed. The family wanted the resident to return to HWC and would have paid privately for nursing care; the scheme staff were happy with this but social services decided it was a safeguarding issue, so he had to leave. As the provider pointed out, social services do not tend to understand tenancy rights. In this instance, there also seemed to be a lack of clarity and trust about what HWC could and should offer, and conflict over how the different professionals prioritised the man’s right to self-determination (supported by his tenancy rights) and his right to life.

Some of the older people we spoke to were adamant that they did not want to leave HWC and expressed fears that they would end up having to move into a care home. Our findings suggest that, in some cases, more could be done to clarify how and why decisions to move on may be taken so that older people and their families can plan ahead. However, we found examples of this potentially difficult task falling between the boundaries of professional responsibilities:

A lady I know who had been living here for about 6–7 years became very unwell and she moved to another place, a nursing home I think, and then she died soon afterwards. I’m not saying that she could have stayed here or that she died because she had to move, but I wouldn’t like that to happen to me – that is my main concern. I have tried to discuss this with the care staff here but I was told ‘this is not my department’ by one of the staff. In my experience the care staff don’t want to talk about it, staying here for the rest of your life if you become very ill, I don’t think anybody [staff] wants to talk about it.
– Resident

The impact of grey areas and gaps on older people

The majority of people we spoke to were extremely positive about HWC: many said they had not experienced any problems. Many described enormous quality of life gains from moving in – for example, at least one person told us they did not think they would still be alive had they not moved; others said they had ‘got their lives back’ in terms of social interaction, or because they had not been able to move around or go out independently due to inaccessibility of their previous home.

Just under one-third of the older people we spoke to described problems which seemed to link to roles and responsibilities issues. Some of these issues were very serious, some relatively minor, and one or two people

reported a lot of little but related problems. However, for most people these concerns did not detract too much from their overall quality of life in HWC. One couple summed up this view:

In summary, we do think it is really quite good here and although there are hiccups, if we could get back to a better community feel – which needs better management – it would be a fantastic place to live. The concept is great: if there is an emergency there is always staff available, but there is room for improvement.

Where gaps and grey areas did impact on older people and their families, they sometimes led to residents:

- going without a service or experiencing delays and interruptions;
- not being sure who to ask for help;
- not being sure who to complain to, or who is accountable;
- having to ask others to do things as favours – family, neighbours, friends;
- experiencing uncertainty and stress;
- paying someone privately;
- finding that damaging rumours can develop if no one communicates clearly and takes responsibility;
- having an impact on other residents' quality of life if dementia is not properly managed;
- experiencing anti-social behaviour or tension between neighbours where there has been insufficient mediation or intervention;
- feeling the lack of a sense of community if social activities stop;
- experiencing poor relationships with staff and reduced self-esteem where staff are very task-focused and take the attitude that 'it's not my job';
- having to move out when they would rather live in HWC until the end of life.

In some cases, the older people we spoke to did not seem to be aware of some of the roles and responsibilities issues which staff, relatives or neighbours told us about – perhaps because staff or relatives were doing such a good job of filling them. This might also be explained by the fact that some of these people were quite confused. In addition, a few had not been living at the scheme for long and, of course, it is possible that people did not want to seem to be complaining to us, especially about relatively minor concerns when they were basically happy with most aspects of their lives in HWC.

Where gaps were being filled by other people, this tended to happen in an ad hoc way: the hairdresser introducing two isolated neighbours, or a support worker dropping someone's glasses off to them in hospital on her way home. This may not be a problem where the tasks are relatively small, staff are not too overstretched and older people are able to identify any problematic gaps and ask for help. However, such gaps can have a greater impact on those who have higher support needs, particularly where someone has dementia or another condition that reduces their capacity to co-ordinate, remember, communicate and chase. As the daughter of an HWC resident with a cognitive impairment asked, who at the scheme has "any ownership of Mum's well-being, especially on the health side"?

Where gaps were being filled by other people, this tended to happen in an ad hoc way: the hairdresser introducing two isolated neighbours, or a support worker dropping someone's glasses off to them in hospital on her way home.

Who acts as the ringmaster?

Over the course of the study, we coined the term 'ringmaster' to describe someone who plays a co-ordinating role, advocating, liaising, and making sure things happen for someone who can no longer do this consistently for themselves (and who does not have a partner who can do this for them). This type of support has been identified by Bradford Dementia Group (2009) as being particularly beneficial for HWC residents with dementia in terms of quality of life, relationships with neighbours and tenancy sustainment. Sometimes this might just involve making sure that information is shared; sometimes it is as serious as a safeguarding issue. But without someone taking this responsibility, some older HWC residents (especially those with cognitive, learning, mental health or multiple sensory disabilities) will be at risk of sudden and unplanned moves to residential care.

We found examples of different people playing this role or sometimes different parts of it: the scheme manager (or equivalent), family members, other HWC staff (including key workers), and social workers or other professionals based outside of the scheme.

Scheme manager

As sheltered housing developed from a 'good neighbour' model to an 'enabling' (scheme manager) model, this typically helped to fill the ringmaster role for those residents who needed someone to co-ordinate and advocate on their behalf, although many sheltered housing schemes have since lost their scheme manager (NHF, 2010b; King, *et al.*, 2009). We found many examples in which the scheme manager also played this role in HWC. The scheme manager (if there is one – we will come to this shortly) is in an ideal position to play the ringmaster, since they have an overview of the scheme and can also act as a central point of contact for external agencies. A selection of the ringmaster-type tasks that scheme managers were reported to have helped our interviewees with includes:

- advising on/organising/accessing (more) care and support;
- setting up chiropodist, hairdresser and similar appointments;
- empowering residents to do more for themselves (for example, following a stroke);
- explaining how everything works and who does what, and co-ordinating on-site input;
- mediating between residents;
- acting as a single point of contact for complaints/repairs/feedback;
- general 'keeping an eye' on someone;
- liaising with family and friends;
- controlling access to the building – liaising with (external) care workers;
- chasing and advocating with health and social services (such as over aids and adaptations, care packages, assessments, and so on).

This role is particularly important where there is a range of different professionals and providers involved and boundaries between them may become blurred or even contested. One older person felt that the scheme manager acted as the 'glue in the scheme', holding everything together. There were instances where residents thought agencies were working well together, but the scheme manager told us otherwise. We developed an image of the scheme manager holding back an oil slick of roles and responsibilities contests from a blissfully ignorant resident sunbathing on the beach!

A further challenge for this model is that HWC schemes do not always have a single scheme manager. Often the support manager (or sometimes, though less frequently, the care manager) took on the role of the ringmaster, although sometimes this seemed to require them to overstep their formal job roles. One older person told us that the support manager “will do things for me even if he is not supposed to” and another said: “from my perspective it is the support manager who is in charge and she runs the place, although I don’t really know if that is actually her job”. One commissioner told us of a support manager who is doing a very good job of ‘covering for the fact’ that there is no scheme manager.

Perhaps unsurprisingly, given this overstretching of roles (also discussed in previous reports on HWC, such as Croucher and Bevan, 2010; Netten, *et al.*, 2011), there seemed to be a significant number of managers who were or had been off sick. In one scheme we visited, the scheme manager had resigned just a few days before our visit. One resident, who was very upset about this, told us she thought it was too much for one person to run the scheme and all the care. This is also risky for organisations: as one commissioner explained, if one or two key staff are holding together the boundaries, long-term sick leave can result in a “wobble’ in the partnership arrangements”.

However, we did find examples of organisations trying to find more positive solutions to this problem. In at least four different organisations we were told that the scheme manager is *now* (i.e. following lessons learnt) responsible for care and everything else that happens at the scheme. One approach had been to give them line management responsibility for the ‘other’ (usually care) team so that they have sufficient autonomy to make decisions at scheme level, although they need to be able to delegate effectively if this role is to be sustainable. In addition to these changes in organisational structure, it also seems to be vital to manage the different expectations around how much of the ringmaster role can be taken on by the scheme manager or other staff, such as key workers. What does ‘keeping an eye’ on someone really mean in practice? Is it sustainable for a member of scheme staff to act as ringmaster for a single person with dementia if there is minimal family involvement?

In order to protect the well-being of the scheme manager, providers need to find ways to share the ringmaster role with family and other workers, yet communication must be excellent and there needs to be clarity about where responsibilities begin and end in order to protect the well-being of the older person too. As we pointed out at the end of Chapter 3, clarity at the outset is vital, but so too is flexibility at the edges, with regular reviews of roles and responsibilities, especially where an individual’s needs are increasing.

Relatives

In addition to both regular and ad hoc social, practical and emotional support, relatives often seemed to be fulfilling at least some aspects of the ringmaster role. Most commonly, this included:

- arranging and accompanying to health appointments;
- liaising with professionals (in one case the older person used a nephew as the ‘go-between’, even when dealing with the scheme manager);
- managing correspondence and finances (we talk more about the role that family can play in financial management in our *HWC Affordability* study report);

-
- sorting out problems – one relative, who had herself been very ill for a while, explained how you needed to have “the energy to pursue things”.

This brings us to a key question: what happens if family members are temporarily unable to act as ringmaster or provide the practical support they usually offer? In some cases, there seemed to be a clear contingency plan. For example, one older person told us: “My daughter takes me shopping but we have a support plan which says that the support staff will do this if she can’t for any reason.”

In other situations, there seemed to be less clarity on this. One relative told us: “I imagine they would step in if I wasn’t very well”, although this seemed to her to be based on the status of ‘repaying a favour’, since she helps out at the scheme. Another told us that she had been called in to sit with her mother and wait for a call-back from NHS Direct late on a Saturday night. She was glad to have been contacted and was happy to wait, but she said: “I did just wonder what would have happened if I hadn’t been here or available.”

There is clearly a continuum of family support: some family members live close by and visit very regularly, and some are involved but at a distance (including families now living abroad); at the other end of the spectrum, one provider told us that the son of a resident with dementia will not answer the phone if the scheme contacts him. Social class, national differences and ethnicity may play a part alongside individual characteristics in shaping family involvement. For example, our Northern Ireland stakeholders pointed out that substantial out-migration over the past couple of generations has meant that many Irish older people do not have family in the same country. Elsewhere, we met one woman whose daughter was a care worker working locally (and, in fact, now in the same scheme that her mother lived in); we also met more affluent leaseholders whose children worked in professions that involved considerable international travel.

A private HWC provider pointed out that the families of their relatively wealthy leaseholders are busy professionals, living at a distance or travelling for work; this can make it difficult for them to play the ringmaster role effectively. They “don’t really get the feel for the situation in the same way that our house manager will”, yet it can be difficult for the house manager to arrange additional support without their input. Playing the ringmaster role in the absence of close family involvement seemed to be more difficult for some private providers, especially those who are not directly providing care. These providers often do not have the relationships with social services (since their leaseholders will all be self-funders) and there tends to be more of a culture of privacy for leaseholders.

Other ringmasters

For those we interviewed who have learning difficulties or long-standing mental health conditions, a social worker or, in one case, a support worker from a previous housing association was acting as the ringmaster.

It’s the best thing that ever happened, moving in here – the [name of previous housing association] support worker has been brilliant – I’ve got more confidence in myself now. They asked me to have a support worker from here but I asked if I could keep [name of worker]. She comes every week and helps me with forms, money, health ... that’s been much better since [name of worker] got involved, she comes with me to the hospital and to the doctor’s appointments.

– Resident

The social services case manager role is effectively one of ringmaster. However, it is unlikely that many, if any, HWC residents would receive this intensity of involvement for very long. Self-funders are unlikely to receive input from social services at all (except perhaps immediately following hospital discharge) and, as one of our Scottish commentators pointed out, even where HWC residents are receiving publicly funded care, the care management role is increasingly being handed back to the scheme manager.

Some of the schemes we visited operate a key worker system and these staff members generally provide support to move in and a point of contact for review, feedback, repairs reporting or complaints.

Role of the wider staff team in supporting the ringmaster and filling gaps

Although the scheme manager has a key role in protecting residents from complexity and contested roles and in providing further support to some residents by acting as a ringmaster, it is the input of the wider staff team which has perhaps the greatest impact on older people's quality of life. A provider told us that frontline staff generally find ways to work around 'artificial' boundaries and deliver a seamless service. They can also protect residents from boundary disputes (or not) by being discreet and professional and being as flexible as possible.

We don't really know whether the staff from the care agency or housing association have any problems working with each other but they never seem to complain, or not to the residents.

The staff here bend over backwards to help residents, they are really involved. They do a lot for us and we don't have to pay extra.

– Residents

All staff – catering, gardening or cleaning as well as care and support staff – have a role to play in connecting with and supporting individuals. One private provider, who has insisted on keeping all contracts in-house, told us that because everyone is working for the same relatively small organisation, cooks and gardeners will share their observations and concerns about an individual.

While working for the same organisation may help here, it is neither necessary nor sufficient. What does, however, seem to make a difference (and these points were highlighted by older people, not just providers and commissioners) are:

- management;
- pay and conditions;
- turnover/use of agency staff;
- training;
- monitoring/performance management;
- recruitment and selection;
- organisational change and how this is managed, bearing in mind that a change of provider through a block contract tender can also cause a change of ringmaster.

We will return to some of these themes in subsequent chapters and in the practice guide. The next chapter explores what is driving the complexity of HWC and provides vital context in trying to understand the *external pressures* on frontline staff and how these are shaping workforce issues in HWC.

4 WHY IS HWC SO COMPLEX?

In this chapter we consider what is driving the complexity of HWC, how this in turn influences the boundaries of roles and responsibilities, and how this impacts on the quality of life of older people and their families.

Our *Viewpoint* identified that commissioning and delivering HWC is complex. Our *HWC Affordability* study and Copeman and Pannell (2012) explore commissioning and funding issues in more detail. From our research it is apparent that complexity in HWC is influenced by a range of factors including:

- local authority policies – or an absence of them – in relation to planning, commissioning, procurement and contracting;
- the funding available within HWC for housing, care and support;
- the ways in which housing, care and support services are regulated and monitored;
- the emerging thinking and application of ‘personalisation’ to HWC;
- the models of HWC in the social, charitable and private sectors;
- the different expectations among residents, family, staff, providers, commissioners and regulators of what HWC is and does.

Dimensions of complexity and differing expectations of HWC

The sheer complexity of the way HWC is planned, commissioned, funded and operated has a tendency to foster roles and responsibilities tensions rather than minimise them. Contested roles and conflict can occur due to the potential for fracture between the different functions and roles in the complex HWC model. However, they do not always: we found examples of both multiple- and single-provider models of HWC where roles and responsibilities are managed effectively with little evidence of a negative impact for residents.

In this section we consider how key 'dimensions' of HWC – funding, local authority policy, regulation and personalisation – and the differing expectations of the model are driving its complexity.

Funding for care and support

The knitting together of different public and private funding streams is a core feature of the complexity of HWC; costs and affordability in HWC are also complex (Institute of Public Care, 2010). For schemes that are dependent on public funding, the shifting nature of funding for *support* in particular has created both complexity and uncertainty. The funding for support, as distinct from personal care, has been subject to substantial change over recent years. For example, the removal of the 'ring-fencing' of Supporting People (SP) funding in England and Scotland, but the retention of ring-fencing in Wales, means there is now huge variation in the way that support for older people in HWC is paid for: 'housing support' and 'care' often still come from different funding 'pots' and may be overseen by different commissioning teams.

Even now the SP ring-fencing has been removed in England, the funding is still divided – you tend to have two separate commissioning teams trying to funnel the available funds into their area of work.

- Consultant working for a local authority

In other local authority areas in England the boundary between funding for care and for support has been removed. Although this appears to remove a level of complexity, many professional participants expressed concerns that funding for support will end up – or is already – subsidising the critical end of social care needs. This situation has been further intensified by cuts to public funding; we came across examples of cuts in funding for support leading to attempts to cost-shunt elsewhere. One provider told us that social care commissioners expected them to redefine support costs as service charges that would be eligible for Housing Benefit.

Support and, crucially, the funding of support is unravelling across the country. Now that SP has been absorbed into social services' budgets, social services won't pay for support but are focusing their resources on acute services. In a significant number of areas, housing providers are re-classifying support as 'intensive housing management' and putting it back into Housing Benefit claims.

- Professional from a national organisation, England

Linked to these changes, many professional participants identified insufficient understanding and joint planning between housing, health and social care agencies. Many providers reported working to promote residents' quality of life holistically, despite the complexities of funding arrangements.

Local authority policies

Local authority policies play a significant role in shaping the complexity of HWC. Planning issues were a major concern for most of the private sector HWC developers we spoke to, typically in relation to type of scheme, the range of facilities provided and affordable housing contributions. However, there were examples of good practice: one private provider described the strategic approach taken by one authority in researching local needs and involving planners from the outset in tendering for a private/social housing partnership HWC development.

We heard that some authorities had neither a housing strategy that set out their approach to HWC nor a specific extra care housing strategy, so complexity seemed more a result of accident than planning. Where authorities had taken the time to develop an extra care strategy properly, this was felt to have focused service development and delivery on what older people value.

When we reviewed the way that our existing extra care schemes functioned as part of developing our extra care strategy, we tried to look at the service from the residents' perspective and we also spoke to quite a large number of residents about their experiences.

– Commissioner

We found very different local authority commissioning and procurement policies regarding HWC. The input of different organisations should be determined by contracts and funding (Miller, *et al.*, 2007) but in practice it also depends on relationships between staff within different organisations.

Regulation of HWC

The regulatory landscape is complex and varies across the four nations of the UK. Housing regulation is, at best, separate from the regulation of health and social care; at worst (for example, in England following the demise of the Tenant Services Authority) practically non-existent.

While HWC is unique as a model, it is not a legal entity. Regulation of HWC generally follows the distinction between 'care' and 'housing'/support; commissioners and providers have often configured HWC schemes with separate care and housing/support functions to avoid any challenge for them to be registered as a care home. Some of the regulators we interviewed recognised that they should ideally be supporting providers to deliver flexible services for older people:

The danger is that we get hung up on structures and become systemised and mechanised rather than looking at what needs doing.

... Providers shouldn't have to ask, 'Whose responsibility is it?' – they should just be enabled to do it!

– Regulator

The interaction of changes to public funding for HWC, variation in commissioning practice by local authorities and a complex regulatory framework are creating changes to HWC which are not driven by the needs of older people and may even have a negative impact on them. For example, in an attempt to reduce administration, monitoring and costs, providers may configure services so as to avoid being registered with the CQC or to fund housing support through service charges. This may impact negatively on residents; for example, by reducing external monitoring or increasing charges (see our *HWC Affordability* study; Copeman and Pannell 2012; Aldridge, *et al.*, 2012 and *Findings* (a)).

Some housing providers are making more of a link between housing management and support, and by providing both services are blurring the boundary between the two. ... Commissioners are increasingly linking support and care in contracts, separating it from the housing management function ... what both these models have in common is that they are being driven by function, not by the needs of the individual resident.

– Professional from a national organisation, England

We heard that some authorities had neither a housing strategy that set out their approach to HWC nor a specific extra care housing strategy, so complexity seemed more a result of accident than planning.

Personalisation

Personalisation in HWC was felt to be in its infancy, yet practice is already different both within and across the four nations. While most would agree that the ethos of self-directed support is to be welcomed, there is a distinction to be drawn between this and the mechanism of personal budgets. One of the risks for HWC is that the latter might result in a critical mass of HWC residents opting to 'micro-commission' their care, bringing more providers and workers into a scheme and creating additional boundary problems and quality issues. This simplistic approach to personalisation could threaten the financial viability of the HWC model:

The big challenge is trying to get a sense from local authorities of where they want to be with HWC in ten years' time. It's about trying to ensure the sustainability and deliverability of care services within this and personalisation is something of a risk to this.
– Provider

Nevertheless, we found one or two examples of good practice: in our *Practice Examples* we describe one council's approach to commissioning 'flexicare', in which the council contracts HWC providers to provide a basic 'well-being' service, with individuals free to select their care provider.

The challenge will be to commission and provide HWC that encourages and responds to the personal preferences of older people with high support needs without creating additional complexity. Although some providers stressed the fact that provision needs to be *large* to be sustainable in the context of personalisation, others felt it would be more important to be *good* in order to remain popular with residents.

Health services: the HWC interface

Health is one of the key players in the day-to-day lives of many HWC residents (especially those with high support needs) but the evidence from our study is that health organisations are generally not actively involved in the commissioning or delivery of HWC services.

At scheme level, a recurring theme was that GPs and other frontline health workers are often not aware of or do not understand HWC. Several providers spoke about the day-to-day challenges in relation to roles and responsibilities in their interface with health services – for example, prescriptions getting left at the front desk; ambulance staff criticising HWC staff for not helping someone up after a fall; GPs not wishing to discuss HWC provider's concerns about a patient due to confidentiality. However, many providers and older people described positive relationships with district nurses.

Older participants gave us lots of examples of HWC staff making GP appointments, setting them up with chiropodists, making sure all residents are registered with a GP, calling ambulances (and waiting with them until they arrived), arranging transport or support to attend hospital appointments, and noticing when people were unwell and referring them for help. However, to return to our idea of the ringmaster, there was sometimes a lack of clarity about whose responsibility it was to access and co-ordinate health input and how this responsibility was shared with relatives where older people were unable to do this for themselves.

In all of the four nations professionals reported problems developing effective strategic partnerships with health agencies and convincing them of the preventative benefits and potential cost savings from HWC. Health commissioning and funding were often felt to be 'disconnected' from HWC

and difficulties accessing NHS Continuing Health Care funding for individual residents was identified in England and Wales, with negative impacts on choice and affordability at the end of life. A commissioner in Wales told us that, despite recent attempts to align local health boards with the planning and delivery of housing, there is still a need for:

- improved clarity between housing and health as to their respective roles in ensuring that extra care housing is a genuine lifelong option for older people and people with long term conditions.
- Commissioner

However, we heard of a number of good partnership initiatives in HWC to reduce hospital admission and delayed discharge; for example, the development of on-site intermediate care, 'step-up/step-down' or 'pathway' flats.

Variation between the nations of the UK

The provision of HWC varies significantly across the four nations. In England there is a wide mix of HWC in all sectors, but with significant regional variations. In Scotland there are very few private sector or retirement village models. Similarly, in Wales the majority of HWC is in the social sector; however, there are private HWC schemes, generally in traditional retirement areas like the north coast. In Northern Ireland there are very few HWC schemes at all and no private sector provision.

We have already noted the differences in SP funding across the UK and the implications of this for HWC. National variations in care funding and charging also create a different environment for those paying for care in each of the four nations (for more detail, see our *HWC Affordability* study; Copeman and Pannell, 2012; Aldridge, *et al.*, 2012). In England and Northern Ireland local-authority-funded personal care provision is subject to means testing. In Scotland personal care is free, subject to certain provisos. In Wales there is a cap on individual contributions to the cost of personal care (up to a maximum of £50 per week).

Governments across the four nations vary in the extent to which they have explicit strategies and policies in relation to HWC, and this was reflected in our four national stakeholder group discussions. In England there is no national policy in relation to HWC: 'localism' leaves local authorities to decide whether or not they develop their own strategies and, as we have seen, practice here varies. Similarly, in Northern Ireland there is no national policy in relation to HWC. The Scottish Government (2012) has recently published a strategy on older people's housing and support, and the Welsh Government (2006) has published a national policy regarding extra care housing. However, we did not find evidence from our study that these 'high level' policy variations between the four nations led to a greater or lesser propensity for boundaries issues to arise at scheme level.

Models of HWC

As we saw in Chapter 1, there is no single model or even a consensus definition of HWC. We have introduced the different 'dimensions' of complexity – funding, local authority policy, regulation and personalisation – and we argue that these, combined with differing expectations of HWC, have tended to result in the different HWC structures. In this section we look

at the mix of organisations involved in different models of HWC and how tenure and market sector influence boundaries issues.

The mix of organisations

Local authority policies in relation to commissioning, funding and procurement of care and support services are a key factor in determining the structure of publicly funded HWC. Models where care and support are separated from housing management, or where care is separated from housing management and support, are typically the result of deliberate local authority policies.

Separation of these functions has been promoted for a mixture of reasons, including a need to maintain separate funding streams; a view that it spreads risk; and a belief that a service user's housing should not be linked to the provision of their care and support. However, some local authorities that we spoke to had a preference for a single-provider model. Either way, there can be implications at scheme level:

In our experience commissioners and funders insisting on a boundary between care and support almost inevitably create a situation where the quality of service for tenants reduces.

– Provider

Some authorities specify the separation of housing management/support/care roles:

I really do like the split between the two organisations where you have a different housing and care provider: I think they offer good checks and balances to each other, even though there may also be conflict at times.

– Commissioner

Some providers argued that checks and balances could be built into a sole provider model:

In our own schemes (where we are also the provider), we have two managers and two teams for housing and care provision. Even though both teams/managers are from the same organisation, they still challenge each other. And the commissioners also challenge both, particularly where they take feedback from residents.

– Provider

In the private sector, where most residents self-fund, variation in models is driven by other factors. Some private providers have established arms-length or joint venture organisations to provide care, support and other services, separate from the housing provision; and in some cases residents have to purchase care privately from local domiciliary care agencies.

The provision of catering (and other) services within HWC can be problematic for providers and commissioners; it is a key feature of HWC but rarely covers its costs. How catering services are provided and by whom is often a pragmatic decision between providers and commissioners, with approaches ranging from in-house provision to fully outsourced, and from 'pay-as-you-go' restaurants to core meals service models.

Where different organisations were providing care and support our participants identified both advantages and disadvantages. Some relatives were concerned about which organisation in this arrangement had the

lead responsibility for their family member's well-being. Some providers said this model was workable provided there was just one organisation providing care. A model involving multiple domiciliary care providers (such as might occur with widespread personal budget take-up) raised challenges for communication, accountability, safeguarding and practicalities such as car parking – all of which can impact negatively on residents' quality of life. Where we visited schemes in which different organisations were providing care and support, almost all of the older people's direct comments about these arrangements were positive or neutral:

I find everything works here smoothly and it's mainly down to the personalities of the staff, from all the different organisations, with everybody trying their hardest to make it a good place to live.
– Tenant

Most of the resident participants in these schemes were able to describe the roles of different providers, despite one of them observing that the organisational structures “can seem a bit confusing”. They identified the following as being helpful:

- the role of the scheme/support manager, which is pivotal in these circumstances – this is the person who is seen to be in charge and the person to go to if there is a problem;
- the importance of all the staff having shared aims as well as having the ‘right personality’;
- the roles of different staff being explained fully at the point of moving in;
- staff being professional – if there are tensions between them, they do not give this impression to residents.

For residents, then, quality of life seems to hinge more on the ethos and the relationships with carers (which links back to the Katz, *et al.* findings) than on the structure in place.

I don't really know who does what but I know what I need to know.
– Tenant

Most housing providers and at least one commissioner felt that the same provider model was “easier” and “simpler”. A small number of providers were adamant that they would not want to work with a different care provider for reasons which included retaining management control, simpler communication, consistent organisational culture and seamlessness of service for users.

We heard many different views about preferred models of HWC. While there may be different implications for roles and responsibilities from each, the evidence from our research does not identify a particular model as being the best at minimising boundaries impacts for residents. What matters most is how the different components of HWC function as a whole and what works best for each individual scheme.

Tenure

We found a number of ways in which tenure can affect the experience of residents in relation to boundaries issues, particularly in leasehold and mixed-tenure HWC.

Providers seem to have less of a mandate to get involved in the lives of leaseholders; perhaps because they are private customers. However, this

seemed to vary with the model in use: private sector providers that also provided care tended to be more involved with leaseholders and the health and social care professionals working with them.

There was evidence that scheme tenure affects the health profile of residents, with leaseholders more likely than social renting tenants to move in with low care and support needs that increase over time as they 'age in place'. One mixed-tenure private provider observed:

The current resident balance is that most of the leaseholders are able and therefore do not use the care service provided by [on-site care provider]. Most of the tenants, on the other hand, are more frail.
– Provider

Some HWC providers felt that leaseholders were generally more demanding than tenants in their expectations of HWC. The respective responsibilities of leaseholders and the landlord/freeholder are set out in the lease. We encountered various models (discussed in Blood and Pannell, 2012; Kneale, 2011; and our *Practice Guide*) which aim to increase the control leaseholders have over the operation of the scheme.

It's happening now more and more that private sector retirement housing developers retain the landlord [freeholder] role and appoint a management company to manage the leasehold. A lot of owners in retirement housing are becoming dissatisfied with the managing agent: they are not accountable to them, only to the landlord [freeholder] – it's a very top-down model, which focuses on the landlord [freeholder]'s needs, not the tenants.
– Provider

Market sector

We found evidence of a perception among some local authorities that private providers are less interested in promoting the quality of life of residents. One private provider described the mindset of "public sector good, voluntary sector a bit dodgy, private sector bad". Some local authorities have been less interested in the private sector, as they have assumed that those living in private HWC would not require public funding for care; a point we question in our *HWC Affordability* study. However, some of our interviewees indicated that other local authorities are taking a more proactive interest in delivering a mixed HWC economy, and have developed strategies or invited tenders to this end.

We're also looking at leasehold extra care housing although we recognise this is much harder for us to influence the service model in the private sector; however, we are keen to work with private sector organisations to look at how they try to avoid any confusion or disputes between organisations affecting service quality for residents.
– Commissioner

The evidence from our research is that the differences between the HWC sectors can be complex. As one commentator – speaking specifically about dementia care in residential and nursing homes as an example of sector variation – explained:

I think the private sector seems to be typified by extremes – some of the best examples of dementia provision are in the private sector

and some of the worst. The public sector is generally more prone to mediocrity.

– Independent expert

We found evidence of private sector HWC providers that had developed innovative models of provision and partnerships (explored further in Copeman and Pannell, 2012). They were clear that there is a business case for promoting the quality of life of their customers and developing in partnership with not-for-profit and public sector organisations. One private provider pointed out that they make most of their profits from selling the leasehold units, rather than providing care. There seemed to be a clear distinction in ethos between those private companies that develop, sell and pull out and those that build and continue to provide:

We are a family-owned company and we retain our role as landlord [freeholder]; i.e. we don't just invest to sell then pull out, we work to build and develop the scheme, its services and its reputation.

– Private provider

The impact of complexity in HWC on older people

We have already identified some of the ways in which complexity in HWC can impact on its residents. In Chapter 2 we saw how good partnership working can promote people's rights and allow them to live independently while managing risks; and that a lack of clarity, flexibility, ownership and resources can mean that staff do not promote residents' rights as much as they might. In Chapter 3 we identified some of the grey areas between roles and responsibilities and the gaps that can result. In this section, we highlight other key consequences of this complexity, focusing in particular on the impact of changes on residents.

The external context

It can be difficult for older people and their families to make informed choices about HWC, given the variety of models on offer and the possibility that these might change over time.

If we are trying to get people to look at and consider this as a housing option (especially where they are considering a move to a different geographical area), we really need some national consistency on what HWC is.

– Professional from a national organisation, England

Cuts in public sector funding affect all sectors. Professionals expressed concern that changes to funding for support could change the boundaries of roles or even lead to the withdrawal of core services in future. Already we heard that in some areas local authorities will no longer fund activity co-ordinator roles, which leaves a gap in terms of who is responsible for organising activities and supporting participation. Although previously eligible for help through Pension Credit, private leaseholders are now unlikely to receive financial support from local authorities for the support element of their service charges (see our HWC Affordability study; also Copeman and Pannell, 2012; Aldridge, *et al.*, 2012). In some areas we heard that there is insufficient local authority capacity to monitor contracts and investigate resident complaints about issues concerning roles and responsibilities.

Local authorities do not seem to pay enough attention to the potential impact on older people when making their procurement decisions, and we identified negative consequences from block tendering in particular, including uncertainty, lack of clarity, lack of control, and a change of provider and/or staff:

We [the residents] recently went to a meeting where we were asked for our opinions [the care provider was changing due to a different organisation being awarded the care contract] and I was scared that all the staff would change if the care provider changed – I wouldn't have been too happy about that – but the existing staff all transferred to the new care organisation so we are keeping the same staff.
– Resident

We heard examples of changeovers managed well in terms of their impact on residents, but it is clear that these require significant time and other resources to involve residents and their families from the outset. A resident with dementia is likely to find it more difficult to adjust to complex and changing structures and to work out who to ask for what, or who to complain to.

The regulatory system is important and relates both to complaints and to where responsibility lies when problems arise; this was a problem for residents living in sheltered housing in *'Nobody's Listening'* (King, *et al.*, 2009). The current regulatory system for care is complex. This can make it difficult to know who to complain to when problems arise. As we have seen, it can also lead to providers changing their model in order to avoid registration rather than because they think it will improve the service:

If a HWC provider wishes to provide care, they have to register with CQC, but CQC doesn't understand HWC and it is causing chaos for the housing providers. So housing providers are trying to get round the bureaucracy, either by not providing care at all, or by ensuring that each resident employs his or her own carer, which means the care provision doesn't have to be registered.
– Professional from a national organisation, England

Several professional participants raised concerns about the impact of complexity on safeguarding. Situations where different care workers are coming in and out of the building, where there are contested areas and where there is no ringmaster can all have a much greater impact on those with higher care and support needs, especially those without involved and local family. Even in single-provider models there can be a lack of clarity about responsibilities. For example, one provider told us that some of their own staff had not intervened when they observed a resident with dementia starting to climb over a fence by a busy road as they did not feel it was their job to stop her. The provider has had to clarify that safeguarding issues are the responsibility of all employees.

Impact at scheme level

In most of the schemes we visited (including both single- and multiple-provider models), the majority of residents felt that the boundaries between staff roles were managed well. However, a recurring theme was that this was because residents were being shielded from the complexity of the organisational arrangements by the hard work and flexibility of the frontline staff.

I think it's down to everybody who works here having a good attitude and being willing to work together, and they always seem to have time for residents. I'm not sure how the procedures between them work but it's not something that I ever notice.

– Resident

I think what we're seeing is staff trying to mitigate the effects of multiple organisations involved in managing some of the schemes in our area.

– Commissioner

However, another key finding was that some of the issues that may seem relatively minor to commissioners and providers were often very important to older people. The level of social interaction and 'mix' of residents' needs within a scheme was a key concern for some participants, as in the example in Chapter 1. As shown in previous research (Raynes, *et al.*, 2006), simple practical support mattered a lot to the older people we spoke to, yet many were confused about who – if anyone – could provide it, or had been impacted by changes to provision or charging policies. Some providers also suggested that this type of support can get 'squeezed' out by care.

Residents who receive care experience an additional set of roles and boundaries. Those with the highest care and support needs will be affected the most by high staff turnover, change and poor morale among staff, since workers provide not only their intimate care but also much of their day-to-day social interaction.

I've got eight or ten or twelve different carers here, and I know them very well and they know me, I class them as friends so I wouldn't want another bunch of strangers coming in.

– Resident

For those who require input from a range of services, such as community nursing, occupational therapy, adult services care management or palliative care, 'whole system' partnerships and good communication between different organisations are vital and can make the difference between good quality of life and a sudden unplanned move to a care home.

Another key finding was that some of the issues that may seem relatively minor to commissioners and providers were often very important to older people.

5 IMPLICATIONS AND REFLECTIONS

We have seen how commissioning, funding, regulation and differences in local and national policies create an extremely complex environment for HWC, with many different models operating across the UK. This creates the conditions for contested boundaries and the evidence suggests that commissioners and funders give insufficient consideration to the consequences of their policies and decisions on older people.

Summary of key messages from the study

This complexity has led to multiple providers operating in many models, posts being funded from different sources, and group structures being set up by private and not-for-profit providers.

There does not seem to be one HWC model that works better than all the others, but where multiple providers are operating – and especially where there is a *change* in providers and roles – a lot of time and energy need to be put into making this work and ‘shielding’ residents from the potentially negative impact of boundary disputes and grey areas. In cases where these ‘shields’ have broken down, we found instances where roles and responsibilities issues and complexity behind the scenes have had a clear negative impact on residents, their relatives and frontline staff, such as in our original example in Chapter 1.

Most of the people we spoke to were extremely positive about their quality of life in HWC, although around one-third of them were concerned about grey areas and gaps. Grey areas at the boundaries of roles and responsibilities seemed most likely to turn into gaps in the following situations:

- where there is a huge variety of need (for example, around move-in support: some people will need a lot of support, including befriending,

-
- confidence building and physical orientation to settle, while others will need little more than an information pack and a courtesy call);
- where things are small (in terms of time it takes to do them, although they are often far from unimportant to older people) such as light bulbs, gate catches, plasters, cups of tea for ill residents or eye drops – the mechanisms to get things done (care plans which need reassessing by social workers, complex repair reporting structures between several agencies) are disproportionately unwieldy, and small tasks therefore do not get prioritised: they cannot easily be spelt out and costed up on a care plan, and organisations tend not to spend time and energy developing shared protocols around them;
 - when circumstances suddenly and/or temporarily change (for example, due to illness, hospitalisation or a relative not being able to provide support);
 - when resources are limited (for example, where funding for roles such as activity co-ordinator or handyman is scarce, and where social services are less willing to fund preventative input or continue funding care above a certain level);
 - when things are important or seemingly obvious and everyone assumes someone else is doing them (such as fire alarm testing or stopping a resident with dementia from climbing over a fence to a main road);
 - when things are difficult and everyone would rather avoid doing them (especially where they lack the skills or confidence – for example, talking about end-of-life/home-for-life issues);
 - where they involve advocacy with external agencies (such as accessing aids and adaptations, making and chasing up health referrals, and so on – this can be unpredictable, ongoing, time-consuming, and can depend on contacts and knowledge);
 - where perspectives on risks/safeguarding and gains to quality of life differ (as in our PEG feeding example in Chapter 3).

Gaps are often filled by the scheme manager (or support/care manager), another staff member, a relative, a neighbour or someone else, such as the hairdresser. The dangers here are that this is ad hoc and discretionary and that some people who need it will not get the service, or that staff end up constantly doing more than they are trained, insured and paid to do. Without someone to act as the ringmaster – co-ordinating input and identifying any gaps – some residents with high support needs (especially those who have reduced capacity and/or no regular family input) may not be able to continue living independently and with good quality of life in HWC.

A clear message from the older people we spoke to was that continuity – of place and of relationships – is extremely important to them. This echoes the Katz, *et al.* (2011) headings of 'continuity and adjusting to change' and 'meaningful relationships (personal and with paid carers)'. Most HWC residents have already made significant upheavals in later life to move home; many have had a series of losses and traumatic experiences prior to moving in. The fear of having to move to a care home which many expressed seems partly to be a fear of the loss of independence and rights, but also the fear of having to make another transition, especially during crisis or at the end of life.

Practical implications

We identified a number of practical ways in which organisations can improve the way they work across boundaries to produce good outcomes for HWC residents and we present some of the practical examples we encountered in our accompanying *Practice Examples*. Finding ways of involving residents (including those with high support needs) meaningfully in each of these areas should be a priority; for example, through identifying the qualities they value in staff, or gathering feedback from them about what they want from services.

Workforce and management

A carefully selected, well-trained and well-managed workforce is essential if older people are to receive a person-centred and seamless service, yet as identified in the recent National Audit Office reports (National Audit Office, 2011; Ipsos MORI, 2011), we too heard of ‘zero-hours’ contracts, unsettling TUPE transfers and care staff not being effectively monitored. We found that high staff turnover and use of agency staff to fill the gaps can have an extremely negative impact on older people’s day-to-day experience; however, the majority of people we interviewed were generally happy with their staff and praised their flexibility and dedication.

In the *Practice Examples* we consider what some providers are doing to recruit and train staff who can form good relationships with residents; to ensure one person has overview at scheme level; and to make sure that staff are clear about the boundaries between their roles and about when and how they might need to overstep them.

Clarity between the key players

To minimise roles and responsibilities issues there needs to be clarity from the outset about:

- the HWC model (generally and for each specific scheme) and the expectations of all parties at the outset;
- residents’ rights (and responsibilities);
- the shared vision and ethos of different providers and commissioners;
- the input and responsibilities of relatives and others – what contingencies need to be in place and how this will be regularly reviewed;
- what everyone does and who is responsible for what;
- how service users can complain and provide feedback and what mechanisms are in place to resolve conflicts between different agencies/ different workers;
- communication and liaison arrangements both between providers at the scheme and with key external agencies such as social services (at all relevant levels within the organisations).

Commissioning

Commissioners need to:

- adopt flexible approaches to service delivery, rather than prescribing one model;
- focus on what works best for older people through effective consultation, involvement and allocation processes;
- look at ways of implementing personalisation so it increases self-determination and choice without adding complexity;

-
- change providers and models only when it is clear that current arrangements are not working and/or cannot continue;
 - anticipate the impact of such changes on older people and their families – consult with them, plan ahead and allocate sufficient resources to reduce this;
 - think strategically about the role of the private sector and promote the partnerships needed to make HWC work for leaseholders as well as tenants.

Resident involvement

Finding meaningful ways to involve residents in each of these three areas focuses joint working on the things that really matter to older people and empowers them to understand and exercise their rights and responsibilities.

Reflections

It would seem that the principles of good practice in managing boundaries apply across the various operating environments for HWC.

There are significant variations across the four nations of the UK in relation to the provision, funding and regulation of HWC and the presence or absence of strategic approaches to HWC. However, from the evidence of our study, these variations do not necessarily result in significantly different boundaries issues within HWC schemes. Our discussions with older people and frontline staff and managers suggest that the issues and experiences may be common across all UK nations. As the amounts of public funding available to develop new HWC schemes reduce, most new schemes in future will either be wholly private or mixed tenure, and the proportion of people living in HWC who are leaseholders or shared owners will grow. This is relevant because in the private sector, although some of the rights differ, the confidence to exercise them may be greater and these providers have very different relationships with local authorities.

National and local policies bring often unhelpful layers of complexity to the HWC model; yet, even if we can scrape away some of these layers, HWC is inevitably based on a marriage between housing and social care. As we saw in Chapter 2, several of the professionals we spoke to argued that therein lies its strength. One respondent, who was talking in particular about working with people who have a dementia diagnosis, argued that:

Where social care dominates or works alone, we tend to end up with a really institutional model, so the collaboration with housing seems to be critical here and the strength of HWC for people with dementia lies in this collaboration.

We have highlighted the risk that personalisation may bring further complexity. A narrow focus solely on personal budgets seems to bring little in terms of meaningful choice to older people in HWC. Instead, rights may be the missing part of the jigsaw needed to ensure that innovative person-centred approaches (such as, for example, those proposed by Bowers, *et al.*, 2007) are promoted. However, we were told by housing providers and commissioners that social workers often do not understand housing rights (viewing HWC more as ‘a placement’).

Rights seem to have developed something of an image problem among housing professionals and HWC residents, and not without reason. We heard examples of them being used as an excuse for not doing something (such

as supporting tenant participation, or challenging a centenarian to be ‘more independent’ and do her own laundry) or as a blanket policy (such as not, under any circumstances, talking to a neighbour about someone’s admission to hospital). Providers at our Bristol conference talked about rights-based approaches as though they were restricting and working against person-centred approaches – quite contrary to the Equality and Human Rights Commission’s vision (EHRC, 2011) that rights can provide a ‘framework for person-centred decision-making’.

In HWC, older people with high support needs can enjoy self-determination: privacy, independence and control over how they live their day-to-day lives in their own homes, within a supported community setting where many risks will be much lower than they might be living in the wider community. However, this model still entails risks and responsibilities: it is community living; you are responsible for your own tenancy/lease; and, as one provider explained to residents at a new scheme who were pressing their buzzers to request extra pillows or remote controls to be passed to them, HWC is not a hotel.

The main recommendation of the consultants involved in our example in Chapter 1 was that all partners needed to develop and agree a strategic vision for the scheme, including clarity about allocations and resident mix, and to convey this to frontline staff. The schemes where we found the best practice (and this was true across nations, sectors and type of model) were those where there seemed to be clarity about what they are (and are not) trying to do and for whom. However tight the protocols and however clear the boundaries, there will perhaps always be the risk of gaps: what matters is that all the key players understand this from the outset. It is also vital that where there is a high or increasing risk that a gap will have a serious impact on someone – perhaps due to disability, marital status, support network or language – there are systems in place to identify and respond to this before the tenancy breaks down or safeguarding issues develop. On a day-to-day level the overarching message from our research was that it is the scheme staff who shape the experience of HWC for older people, and it is their flexibility and determination which (mostly) results in a seamless service. However, in some areas and schemes we found evidence of complexity leading to increasing and at times unsustainable pressure on scheme managers and staff as they try to smooth over the potential fault lines and make the marriage between housing and care work.

It is the scheme staff who shape the experience of HWC for older people, and it is their flexibility and determination which (mostly) results in a seamless service.

NOTE

- 1 The 2006 TUPE Regulations (Transfer of Undertakings (Protection of Employment)) apply when a 'service provision change' takes place (for example, when a contractor takes on a contract to provide a service for a client from another contractor). When the transfer takes effect, the previous contractor's employees automatically become employees of the new employer on the same terms and conditions. (For more details, see Department for Business, Innovation and Skills, 2009.)

REFERENCES

- ADASS and Housing LIN (2011) *Strategic housing for older people: planning, designing and delivering housing that older people want: a resource pack*. London: Housing LIN
- Aldridge, H., Kenway, P. and Pannell, J. (2012) *Affordability of retirement housing in the UK*. Available at: <http://www.npi.org.uk>
- Arden, A. and Dymond, A. (2012) *Manual of housing law* (9th revised edn). London: Sweet & Maxwell
- ARHM (2005) *ARHM Code of Practice for England* (revised version). Available at: <http://www.arhm.org>
- ARHM (2009) *ARHM Code of Practice for Scotland*. Available at: <http://www.arhm.org>
- ARHM (2010) *ARHM Code of Practice for Wales*. Available at: <http://www.arhm.org>
- Benjamin, D., Stea, D. and Aren, E. (eds) (1995) *The home: words, interpretation, meanings and environment*. Aldershot: Avebury
- Blood, I. and Bamford, S-M. (2010) *Equality and diversity and older people with high support needs*. York: Joseph Rowntree Foundation
- Blood, I. and Pannell, J. (2012) *Building mutual support and social capital in retirement communities: Viewpoint no. 23*. London: Housing LIN
- Blood, I. and Pannell, J. (2013, forthcoming) *Putting rights at the heart of housing with care: Viewpoint*. London: Housing LIN
- Blood, I., Pannell, J., and Copeman, I. (2012) *Findings from housing with care research: Practice examples*. York: Joseph Rowntree Foundation
- Bowers, H., Bailey, G., Sanderson, H., Easterbrook, L. and Macadam, A. (2007) *Person centred thinking with older people: practicalities and possibilities*. Stockport: HSA Press
- Bowers, H., Clark, A., Sanderson, H., Easterbrook, L., Macadam, A., MacDonald, R., Macfarlane, R., Maclean, M., Patel, M., Runnicles, D., Oshinaike, T. and Smith, C. (2009) *Older people's vision for long term care*. York: Joseph Rowntree Foundation
- Bradford Dementia Group (2009) *The Enriched Opportunities Programme: a cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages*. Bradford: Bradford Dementia Group
- Callaghan, L., Netten, A. and Darton, R. (2009) *The Development of Social Well-Being in New Extra Care Housing Schemes*. York: Joseph Rowntree Foundation
- CHS (undated) *Centre for Housing and Support code of practice for housing-related support: brochure 1: introducing the code of practice*. Available at: http://www.cornwall.ac.uk/downloads/chs/Brochure_1_Introducing_the_Code.pdf
- Copeman, I. and Pannell, J. (2012) *Can self-funders afford housing with care? A guide for providers and commissioners*. London: Housing LIN
- CQC (2010) *Guidance about compliance: essential standards of quality and safety*. Available at: http://www.cqc.org.uk/sites/default/files/media/documents/gac_-_dec_2011_update.pdf

-
- Croucher, K., Hicks, L., Bevan, B. & Sanderson, D. (2007) *Comparative evaluation of models of housing with care for later life*. University of York/Joseph Rowntree Foundation
- Croucher, K. and Bevan, M. (2010) *Telling the story of Hartfields: a new retirement village for the twenty-first century*. York: Joseph Rowntree Foundation
- Department for Business, Innovation and Skills (2009) *Employment Rights on the Transfer of an Undertaking: A guide to the 2006 TUPE Regulations for employees, employers and representatives*. Available at: <http://www.bis.gov.uk/files/file20761.pdf>
- EAC (2012) *Statistics on specialist housing provision for older people in England*. Available at: <http://www.housingcare.org/eac-services.aspx>
- EHRC (2011) *Close to home: an inquiry into human rights and older people in home care*. Manchester: Equality and Human Rights Commission
- Evans, S. and Means, R. (2007) *Balanced retirement communities? A case study of Westbury Fields*. Bristol: University of the West of England
- Evans, S. and Vallely, S. (2007) *Social well-being in extra care housing*. York: Joseph Rowntree Foundation
- Faulkner, A. (2012) *The right to take risks: service users' views of risk in adult social care*. York: Joseph Rowntree Foundation
- Findings (a): 'Who can afford retirement housing?', JRF Findings (September 2012, Ref: 2830)
- Findings (b): 'Affordability, choices and quality of life in housing with care', JRF Findings (December 2012, Ref: 2840)
- Garwood, S. (2008) *Evaluation of Reeve Court Extra Care Retirement Village, St Helens: an extract*. Available at: <http://www.suegarwood.co.uk>
- Hasler, J. and Davis, S. (2010) *Making your voice heard – a guide to complaints*. Coventry: Chartered Institute of Housing
- Hasler, J., Haynes, M. and Long, N. (2010) *Effective resident involvement and consultation in sheltered housing: a good practice guide for housing providers and local authorities*. Available at: <http://www.housingcare.org>
- Heywood, F., Oldman, C. and Means, R. (2002), *Housing and home in later life*. Buckingham: Open University Press
- Housing LIN/EAC (2012) *Housing with care locator* [Online] (Updated 27 March 2012) Available at: <http://www.housinglin.org.uk/Topics/HousingCareLocator/> [Accessed 16 October 2012]
- Ife, J. (2001) *Human rights and social work: towards rights-based practice*. Cambridge: Cambridge University Press
- Institute of Public Care (2010) *Charging in extra care housing*. London: Housing LIN
- Ipsos MORI (2011) *Users of social care personal budgets: Ipsos MORI report for the National Audit Office study on the Department of Health's regulatory oversight of care markets*. London: National Audit Office.
- Katz, J., Holland, C., Peace, S. and Taylor, E. (ed Blood, I.) (2011) *A Better Life: what older people with high support needs value*. York: Joseph Rowntree Foundation
- King, N. and Pannell, J. (2010) *Access and diversity in housing with care*. York: Joseph Rowntree Foundation
- King, N., Pannell, J. and Copeman, I. (2009) *'Nobody's Listening': the impact of floating support on older people living in sheltered housing*. London: Help the Aged
- Kneale, D. (2011) *Establishing the extra in Extra Care: perspectives from three Extra Care providers*. London: International Longevity Centre
- Macadam, A. and Bowers, H. (2008) 'A rights-based approach to improving the life chances of older people' in Churchill, N. (ed) (2008) *Advancing opportunity: older people and social care*. London: The Smith Institute

-
- Miller, L., Murphy, W. and Brady, S. (2007) *Contracting arrangements for extra care housing: Factsheet no. 21*. London: Housing LIN
- National Audit Office (2011) *Oversight of user choice and provider competition in care markets: Department of Health, and local authority adult social services*. London: The Stationery Office
- Netten, A., Darton, R., Baumker, T. and Callaghan, L. (2011) *Improving housing with care choices for older people: an evaluation of extra care housing*. Canterbury: University of Kent
- NHF (2010a) *Breaking the mould: re-visioning older people's housing*. London: National Housing Federation
- NHF (2010b) *Literature review – breaking the mould: re-visioning older people's housing*. London: National Housing Federation
- Pannell, J., Blood, I. and Copeman, I. (2012) *Affordability, choices and quality of life in housing with care*. York: Joseph Rowntree Foundation
- Raynes, N., Clark, H. and Beecham, J. (eds) (2006) *The report of the Older Persons' Inquiry into 'That Bit of Help'*. York: Joseph Rowntree Foundation
- Scottish Government (2012) *Age, home and community: a strategy for housing Scotland's older people: 2012–2022*. Edinburgh: The Scottish Government
- Scottish Government website (2012) *Housing Statistics for Scotland – Housing for Older People, those with Disabilities and those with Supported Tenancies* [Online] (Updated 30 August 2012) Available at: <http://www.scotland.gov.uk/Topics/Statistics/Browse/Housing-Regeneration/HSFs/SpecialNeedsHousing> [Accessed 19 October 2012]
- Sherman, E. and Dacher, J. (2005) 'Cherished objects and the home: their meaning and roles in late life', in Rowles, G. D. and Chaudhury, H. (eds) *Home and identity in late life: international perspectives*. New York: Springer Publishing Company, Inc.
- Speed, L. (2011) *Older people and human rights in home care: a report of two surveys: Equality and Human Rights Report 80*. Manchester: Equality and Human Rights Commission
- Sykes, W. and Groom, C. (2011) *Older people's experiences of home care in England: Equality and Human Rights Report 79*. Manchester: Equality and Human Rights Commission
- Tenant Services Authority (2010) *The regulatory framework for social housing in England from April 2010*. London: Tenant Services Authority
- Viewpoint: 'Boundaries of roles and responsibilities in housing with care schemes'. Jenny Pannell and Imogen Blood (October 2011, Ref: 2691)
- Welsh Government (2006) *Guidelines for developing extra care housing in Wales*. Cardiff: Welsh Government

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ABOUT THE AUTHORS

Imogen Blood is a freelance consultant working across the public and not-for-profit sectors to improve effectiveness and promote equality, with a particular interest in older people. Her background is in social work, research and evaluation, and equality and diversity training and consultancy.

Jenny Pannell is an independent researcher working with Housing & Support Partnership, New Policy Institute and other colleagues. Her research interests focus on older people's housing, care and support, and especially on resident perspectives and choice. Jenny was previously a senior housing manager and Visiting Research Fellow at the University of the West of England, Bristol.

Ian Copeman is Director of Housing & Support Partnership, a firm that specialises in housing, care and support consultancy and research projects particularly in relation to older people and disabled people. Ian has worked previously as a local authority senior commissioning manager, for housing associations and voluntary sector organisations.

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