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PROMOTING SUPPORTIVE RELATIONSHIPS IN HOUSING WITH CARE

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This report explores how to promote positive and supportive relationships between older people with and without high support needs who are living in housing with care schemes.

Evidence has consistently shown that older people with high support needs, particularly those who have cognitive and sensory impairments, can be marginalised within housing with care schemes. The report identifies a number of approaches which have demonstrated how housing with care can be made more supportive and inclusive, either through initiatives driven by provider organisations, by the efforts of residents themselves, or by external organisations.

The report highlights how organisations can:
- promote a culture of tolerance and respect within housing with care schemes;
- raise awareness of the nature of specific conditions or aspects of a person's identity to foster greater understanding and tolerance of individuals;
- provide an underlying environment where individuals, whatever their circumstances, can flourish; and
- broker opportunities for residents to take part in the life of their communities, and provide guidance and support to those residents who are willing to reach out to others.

INSPIRING SOCIAL CHANGE

CONTENTS

EXECUTIVE SUMMARY

The Living Together, Getting Along programme described in this report explores how positive and supportive relationships between older people, with and without high support needs, living in housing with care schemes can be promoted. The report identifies a number of approaches, located in England and Wales, which have demonstrated how housing with care can be made more supportive – either through initiatives driven by provider organisations, by the efforts of residents themselves or by external groups.

The overarching intention was to develop an understanding of a range of approaches with a potential to enhance the quality of life of older people with high support needs through enabling meaningful, supportive relationships and full, active participation in these communities.

Methods

The first stage of the research was to identify potential approaches, drawing on interviews with key informants, including practitioners working within a number of different housing organisations. A stakeholder event was held with a diverse group of older people with high support needs, which assisted with identifying those to be followed up with case studies. In the second stage, 15 approaches were investigated. These investigations drew upon published material as well as interviews and discussions with relevant stakeholders, including project workers, staff and residents. A total of 101 individuals took part in the study. The third stage involved discussing with residents how far the key themes to emerge from the approaches reflected the concerns and issues that were important to them.

Approaches that support inclusive communities

The focus for this study was on approaches that were located in housing with care or could be transferred to housing with care settings, but it also addressed what older people with high support needs want and value in their lives (see Katz, *et al.*, 2011). The examples identified in the report illustrate a range of approaches that either facilitate environments that are more inclusive and empowering of people with high support needs or highlight examples where residents, providers and other organisations are making this happen. A key focus was on what organisations can do to promote greater inclusion. Some of these approaches were unique to one organisation or scheme but others were more widespread.

Organisationally driven examples

Previous studies have highlighted how the social well-being of frail residents in housing with care can be promoted. Our study focused more on the ways that organisations have tried to provide an underlying organisational ethos and culture within schemes to enable any resident to feel included in the life of the scheme and in the wider community if they so choose. Table 1 provides examples of organisationally driven schemes.

Table 1: Organisationally driven schemes

Example	How it works
Enriched Opportunities Programme – ExtraCare Charitable Trust	Based in ExtraCare Charitable Trust schemes, the Enriched Opportunities Programme (EOP) is multi-level intervention that has been shown to improve the quality of life of people with dementia or other significant mental-health challenges. A key element is a dedicated key worker or 'locksmith', who works with people with dementia to unlock their potential and to enable individuals to enjoy an enriched life through increased activity and occupation.
A life worth living – extra care for people with dementia (Accord Housing Association)	Accord has undertaken a number of approaches to make its extra care schemes more inclusive and supportive of people who live with dementia. This includes retrofitting design features to assist with personal safety and orientation around schemes; introducing dementia awareness training with all members of staff within schemes (this is also open to residents), and establishing the post of dementia care manager to lead across the organisation.
Moor Allerton Care Centre (MHA)	The Care Centre is an extra care scheme that has apartments for general needs, apartments for people who live with dementia and a dementia day-care centre. The scheme promotes the active inclusion of all residents via activities coordinators, and also participation with local communities, including a local community centre for all ages.
Linc-Cymru	This provider uses a mixture of approaches tailored to the needs of specific groups, such as people who live with dementia and also people with sight loss. It gained Platinum status under the 'Visibly Better' accreditation scheme and has also undertaken dementia awareness raising within schemes, as well as person-centred approaches to promoting active inclusion within schemes.
Local agreements, Hanover	Local agreements are written agreements between the organisation and the residents of each particular estate, covering the services provided, and setting out which services can and cannot be provided. The aim is to give residents as much choice as possible in determining local service levels.
Older LGBT group (Anchor)	A support group open to tenants and staff drawn from across the organisation's sheltered housing that aims to make the organisation a safe and welcoming environment for LGBT tenants and staff.
Bradley Court Methodist Homes Housing Association (MHA)	Purpose-built extra care development that offers culturally appropriate facilities in response to a need for housing with care for minority ethnic groups within the locality.
Plaxton Court, Joseph Rowntree Housing Trust (JRHT)	A mixed tenure extra care housing development that was designed to offer resources – a restaurant, a small shop, and a healthy living and fitness suite – to the wider community. The scheme offers opportunities to explore how links with the wider community can be developed through the use of shared facilities.

Resident-led approaches

As well as approaches driven by organisations, it was also important to explore resident-led approaches to offering support to each other, regardless of individual background or circumstances. Even though not a specific approach, good neighbourliness is a key foundation for supportive communities. The majority of housing with care schemes will have a number of individuals who are recognised to be the 'informal' driving force behind resident-led activities, be they social activities, volunteering, or representing the views of residents through resident committees and so forth, as illustrated in Table 2.

Table 2: Informal, resident-led approaches

Example	Description
Sunshine Club	Resident-led group organising social activities and low-level support in their sheltered housing scheme.
Resident Volunteer Group	Group of resident volunteers, informally coordinated by the scheme managers, offering low-level support and social activities to other residents within their sheltered housing scheme.
Resident Champions	Particular individuals who have taken on a role to support or provide particular opportunities for other residents within housing with care.

Approaches taken forward by external organisations

Increasingly, it is recognised that housing with care schemes do not exist in isolation but can gain much from links with the wider community (including the community where schemes are located) and also with organisations that can provide additional support and assistance to scheme residents, and that help to promote and develop a supportive, inclusive, physical and social environment within housing with care schemes. Table 3 gives examples of some of these.

Table 3: Organisations that support residents of housing with care schemes

Example	Description
'Hear to Help' and 'Hear to Meet' (Action on Hearing Loss)	Support programme for people experiencing hearing loss, delivered in the community (including housing with care schemes) by volunteers, and coordinated and supported by Action on Hearing Loss working with local audiology services.
Visibly Better (Royal National Institute for the Blind Cymru)	An accreditation scheme developed by RNIB Cymru aimed at sheltered housing and extra care homes for clients who have a sight loss.
Opening Doors London	A checklist for social-care providers to develop the groundwork for a safe and welcoming environment for LGBT residents.
Older Lesbian, Gay, Bisexual and Trans Association Community Network	Provides training for *all* staff in an organisation to raise awareness of LGBT issues and to badge organisations to give confidence that lesbian and gay people will be welcomed and respected.

Key themes in developing supportive communities

In terms of drawing out wider learning and transferability of the examples, the emphasis in this report is on what organisations can do to promote greater inclusion.

Promoting tolerance and respect

A crucial role for provider organisations that emerges from the case examples is fostering tolerance of and respect for individuals in order to help communities – residents, staff and visitors – to see beyond an impairment or condition or facets of an individual's identity. Many of the examples highlight techniques and approaches that promote equality and diversity with this objective in mind.

Awareness raising – staff and residents

A significant way of setting the tone of schemes in relation to enabling inclusive communities is by raising awareness of the nature of conditions or aspects of a person's identity so as to foster greater understanding and tolerance of individuals. One theme that links a number of approaches involves the recognition of the role that *all* staff play in determining how communities work within schemes. A further shared theme is the inclusion of residents in awareness raising.

Background enabling

The examples in the report also illustrate a range of other approaches that organisations could take in order to create an underlying environment which helps residents to take advantage of opportunities to participate. These approaches include:

- attention to the design of indoor and outdoor spaces;
- providing support as part of care packages to enable individuals to take part in activities and events;
- ensuring that hearing aids and glasses work effectively;
- specific opportunities for people with higher support needs to have a greater voice within schemes and organisations;
- information, positive language and images to make housing with care a welcoming place for people from diverse identities and backgrounds.

Brokerage

A further dimension to many of the examples is the brokering of opportunities for individuals. This may include staff making sure that individuals with higher support needs are able to take advantage of activities within schemes. A number of examples also highlight the positive outcomes arising from person-centred approaches (such as attention to the specific needs of individuals with a sight loss) that enable people not to be stymied by the experience of their condition or illness. An important aspect of facilitating this brokering role comes back to the training and skill sets of staff, and a recognition that all staff have a valuable role to play in setting the tone and ethos of a scheme.

Linking with wider communities

While it may require some negotiation with residents regarding how their privacy is protected, it would appear that embedding housing with care schemes within the local community or partnering with other schemes or

organisations to share resources offers financial as well as social advantages to individual residents and provider organisations.

Respecting autonomy, privacy, choice and dignity

Organisations and staff within housing with care schemes have a crucial role to play in developing supportive communities, but residents themselves are key players too. The research demonstrates that for many people living within housing with care settings, autonomy, privacy and choice are key aspects to how they want to live their lives in such schemes, and that opportunities for activities, companionship, friendliness and neighbourliness may be valued and often welcomed as part of this. Active participation, or not, in the community life of the schemes is seen very much as the individual's choice.

Taking forwards inclusive and supportive communities

As the case studies clearly demonstrate, there is much work already being undertaken to ensure that older people with high support needs living in housing with care are able to enjoy a better quality of life. It is also clear that communities within housing with care settings are unique, diverse, complex and constantly evolving, reflecting the changing lives and different experiences and expectations of both residents and staff.

It appears that in order to reflect that diversity and complexity, 'light touch' responses are required by staff and provider organisations. Creating an ethos of respect and tolerance provides the foundation for achieving the things people as individuals want and value. It can be argued that the development of positive opportunities to enable inclusive communities, and the choices that individual residents can make – whatever their circumstances – flow most readily where this central ethos has been specifically fostered within schemes.

1 INTRODUCTION

The Living Together, Getting Along programme explores how positive and supportive relationships between older people with and without high support needs living in housing with care schemes can be promoted.

The main aims of the research were to:

- explore current approaches that promote supportive communities and help to minimise frictions and tensions between groups of people and individuals with and without high support needs living in housing with care schemes;
- examine which approaches are the best in delivering what older people with high support needs want and value in life.

The report identifies a number of case studies which have demonstrated how housing with care can be made more supportive – through initiatives driven by provider organisations, by the efforts of residents themselves or by external groups or factors. The overarching intention was to develop an understanding of a range of possible approaches that can enhance the quality of life of older people with high support needs through enabling meaningful, supportive relationships and full, active participation in these communities.

A Better Life programme

Living Together, Getting Along is part of a wider programme of work, A Better Life, being undertaken by the Joseph Rowntree Foundation (JRF). This five-year programme focuses on how to ensure a better quality of life for the growing group of older people with high support needs, defined by the JRF as:

> older people of any age who need a lot of support due to physical frailty, chronic conditions 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 or lifestyle.

A key aspect of this overarching programme was the development of a model that sets out what older people with high support needs want and value in their lives (Katz, *et al.*, 2011).[1] This model informed our decision-making about the nature and type of approaches to include in our study (see Chapter 2). Living Together, Getting Along covers examples from England and Wales, although the underlying principles set out in the conclusions are applicable to any of the countries in the UK.

Background: housing with care

What is housing with care?

In the last two decades, a growing number of housing schemes have been developed for older people that allow independent living to be combined with relatively high levels of care. Some schemes are entirely new-build; others have been created by remodelling existing sheltered housing. In England there has been considerable investment, notably from the Department of Health's Extra Care Housing Fund, which committed £227 million towards such developments between 2004 and 2010. Terms used to describe such provision include 'very sheltered housing', 'assisted living', 'Flexicare' and 'close care', although 'extra care' housing is the most common term (see Croucher, *et al.*, 2006). For convenience we use the term 'housing with care' throughout this report. Flexible provision of care allows people to remain in their homes even if their needs increase, reducing the need for a move to residential care and facilitating the maintenance of independence. Communal facilities within schemes also help to reduce social isolation, and improve the quality of life for residents. However, schemes and practice are evolving, and there is no one single model. Provision varies in size, type and mix of tenure, the range of facilities offered, and entry criteria applied (see for example, Wright, *et al.*, 2010; Croucher, *et al.*, 2006; Croucher, *et al.*, 2007; Burholt, *et al.*, 2011).

What do we need to understand about housing with care communities?

The Living Together, Getting Along project is rooted in the recognition that those with high support needs are consistently reported to be marginalised within housing care schemes, and as a consequence their quality of life is diminished (Croucher, *et al.*, 2006; Callaghan, *et al.*, 2009; Percival, 2010). While the project is not intended to explore the reasons for such marginalisation, it is perhaps useful to reflect briefly on the nature of the communities within housing with care schemes and on the barriers for those with high support needs to taking a full and active part in those communities.

Diversity of provision
Key informant practitioners, interviewed in the early stages of the project, highlighted their concerns that the project should consider the particular policy and practice contexts of housing with care schemes, and, as outlined above, noted that there is considerable diversity of provision, different mixes of residents and particular challenges for provider organisations. For example, it was felt that many local authorities saw housing with care simply as an alternative to residential care, rather than as a more distinctive model to accommodate the 'fit and the frail', resulting in some schemes where the majority of residents had high levels of complex needs. All respondents were concerned about the current and future availability of resources to

fully support the model. For example, cuts to the Supporting People budget meant reductions in the housing support element of the schemes.

In earlier work (Croucher, *et al.*, 2007), we also noted how schemes could be very different depending on the:

- ethos of the provider organisation and commissioning organisation;
- location of the scheme (for example, schemes in busy urban locations were very different from schemes that were more geographically isolated);
- resident community (which might be drawn primarily from a small local catchment area, or from much further afield);
- entry and eligibility criteria and their impact on resident mix and levels of needs, and the age of a scheme (many are very new).

There is, therefore, a general 'messiness' about what housing with care is, and what is being offered. No single scheme is quite like another. Below, we highlight some of the issues in housing with care that might offer some partial explanation for the marginalisation of those with high support needs.

Moving into housing with care – mixed motivations
Ideas of community are complex, often relating to shared interests, shared places, and shared identities (Evans, 2009; Liddle, *et al.*, 2012). People move to housing with care at a particular point in the life course. For some it may be a positive choice, for others the move may be a consequence of crisis or loss. Yet others may be directed to housing with care by social services – thus the choice will be 'made for them' (see for example, Croucher, *et al.*, 2003; Baumker, *et al.*, 2011). The mix of residents and residents' motivations will be unique to each scheme, and play out in different ways in terms of how communities develop, and how supportive they are towards people with high support needs.

Expectations and adjustments
Some promotional material for housing with care draws heavily on the language and images of successful and positive ageing, and the promotion of independence. However, evidence suggests that fitter and more active residents within housing with care schemes have been surprised and often felt uncomfortable to find so many people with high support needs living in communities that they feel have been 'sold' or presented to them as being 'vibrant communities' and places for active retirement and independent living (Croucher and Bevan, 2010; Croucher, *et al.*, 2003; Bernard, *et al.*, 2004).

Blood and Bamford (2010) have highlighted the increasing diversity of older people with high support needs across several domains. Reports have highlighted the significant health problems that older LGBT people may experience, combined with lower levels of informal support available (Guasp, 2011; Musingarimi, 2008). On paper, therefore, housing with care potentially offers a good option for people from LGBT communities. However, research with older LGBT people has highlighted the fear that many people have about the housing options that are available for older people who may need care in later life. Concerns include the fear of homophobic and transphobic reactions by other residents and staff (Guasp, 2011; Gold, 2005; Croucher, 2008). Reports of very negative experiences in sheltered accommodation and also in care settings support these concerns (Addis, *et al.*, 2009).

Research has also highlighted the extent to which people from minority ethnic communities are under-represented in housing with care schemes (Jones, 2006). Such research has also noted the importance of culturally

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appropriate services as a key component of the choices available to minority ethnic communities within a variety of schemes (Jones, 2006).

Learning to live in a community
Most residents will have little or no experience of living in a community that is defined and shaped by age, where all the residents are usually above a certain age (although there may be several decades' age difference between the youngest and oldest residents), and where younger people are staff or visitors. People may also not be familiar with the expectation that residents will share some facilities and services (which means that they will spend some time together, probably quite regularly). Evidence suggests that 'living in a community' is not the primary motivation for the majority of those who move to housing with care (Callaghan, 2008). Some people may indeed be seeking community, but for others the imperative is a safe place to live as they grow older and face the personal challenges and uncertainties that come with age – ideas of sanctuary rather than community often emerge when residents speak about their reasons for moving to housing with care (see Croucher, *et al.*, 2007). Further, earlier work highlighted how residents described living in such communities as 'a different way of life' (see Croucher, *et al.*, 2007).

For many people the move to housing with care is likely to be the last house move they will make before they die. In our earlier work at Hartrigg Oaks, some residents acknowledged this (Croucher, *et al.*, 2003). However, evidence from other studies suggests that end of life care, and how communities in housing with care cope with death and dying, remain poorly understood (Croucher, *et al.*, 2006; Croucher, 2009). We understand less about the effects of bereavement on older people in comparison with other age groups generally (Seymour, *et al.*, 2005). In addition, part of learning to live in a community may include handling not only personal bereavement and how this may impact upon other relationships, but also how to deal with collective grief over the loss of friends and neighbours within schemes.

In summary, perhaps we have underestimated the adjustments that some people have to make to live comfortably in a community that is defined by location and shared space, and the shared experience of ageing and end of life – and the particular challenges that this presents.

Costs and resources
Housing with care can be expensive – typically residents will pay rent (or purchase a property), additional service charges to cover the costs of shared spaces and communal facilities, housing management and support costs, which often include a contribution to 24-hour staff cover, and any charges for the care an individual needs. A frequently reported source of tension and resentment among residents is often between those who pay for the care and support they receive and those who receive state assistance (Croucher, *et al.*, 2007; Croucher and Bevan, 2010).

Social engagement in housing with care
Understanding the complex social lives of people in housing with care schemes is crucial to our understanding of how and why initiatives to make schemes more supportive might work. As Oldman (2000) noted, housing with care schemes combine aspects of living 'at home', with aspects of 'living in a home'. Residents echo this view in their consistent reports that the combination of independence and security offered by housing with care is the most valued and attractive feature. Burholt, *et al.* (2011) conclude that a

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key feature of living in housing with care that sets it apart from simply being cared for in your own home, is the opportunity for a more active and self-determined social life. Making new friends, having the choice to take part in resident-led and other social events, acquiring new interests, residents offering and receiving mutual support from each other — all these are ways in which schemes are thought to help combat social isolation and loneliness, and their consequent negative impacts on physical and mental health, well-being, and quality of life. Many people who move to housing with care report that the companionship of other residents and social life within scheme were unexpected bonuses (see, for example, Croucher, *et al.*, 2006; Callaghan, 2008).

The literature suggests that the most supportive and valued relationships in later life are often those that are long-standing (Croucher, *et al.*, 2006). For residents moving to housing with care schemes, nurturing and maintaining these existing and valued relationships may be more important than making new friends. One recent study suggests that social contacts within retirement communities are more likely to be seen as superficial, an exchange of pleasantries or a conversation in passing, a welcome alternative to loneliness but not necessarily meaningful, supportive relationships (Burholt, 2011).

The maintenance of privacy is often a concern for residents, alongside concerns that social participation should not be enforced (Croucher, *et al.*, 2006; Croucher, *et al.*, 2003). Gossip and cliques of residents are recognised features of housing with care, and almost every other housing setting (see for example, Bernard, *et al.*, 2004; Percival, 2000; Liddle, *et al.*, 2012). As already mentioned, there can be resentment between those who 'self fund' their care and accommodation, and those who receive state support (Evans and Means, 2007; Croucher and Bevan, 2010). A recurrent theme in the literature is the potential for isolation among frail older people, especially those experiencing significant hearing loss or cognitive impairments. It has been reported that those with cognitive impairments are a particular focus for hostility, abuse or discrimination by other residents (Reed, 1999; Streib and Metsch, 2002; Brooks, *et al.*, 2003; Garwood, 2008; Callaghan, *et al.*, 2009, Mahoney and Goc, 2009).

A reluctance to engage with people who are obviously poorly might be simply because of the recognition that such relationships will inevitably be short-lived. Further, engagement can be possibly unrewarding if other participants' capacity to take part in a conversation or activities or to be 'good company' is constrained (Percival, 2006). We understand little about people's needs for social contact when they are not feeling well. It may be that pain and discomfort, or indeed cognitive impairment, make social engagement burdensome, or it may be that company and social activity is a welcome diversion. It seems most likely that individuals will have different preferences and capacities for social engagement, although work undertaken as part of the programme A Better Life (Katz, *et al.*, 2011) does highlight the value older people with high support needs place on personal relationships and social interaction.

In the spirit of promoting independence, many organisations have left social arrangements within housing with care schemes to be organised by residents themselves. It has been suggested that 'resident-led' activities tend to be dominated and organised by fitter, more able residents, leaving those who are not so able to participate, or less able to organise activities themselves, on the margins (Croucher, *et al.*, 2006). However, evidence suggests that even when there was a designated activities organiser, over time this made little difference to the proportion of residents who were not

actively engaged in their communities, particularly to those whose care and support needs were increasing (Callaghan, 2010).

Reflecting on the literature (most notably, Percival, 2010) that sets out the nature of tensions and reasons why some people in housing with care may feel marginalised and excluded, Garwood (2010) suggested a number of themes that indicate the kind of approaches that might offer solutions, including:

- attention to the balance between proportions of 'fit and frail' in setting eligibility criteria and maintaining a mixed community;
- focus on individual residents' preferences for offering support (for example, some residents appear more willing to engage on an individual basis with other residents with cognitive impairments than in an organised social setting);
- making schemes 'outward facing' with strong links with neighbouring communities, and also volunteers;
- attention to the design of schemes: both the provision of spaces to allow informal and formal social interaction and the design of environments that take account of a range of impairments, not just mobility problems;
- staff training;
- person-centred care;
- achieving a balance between fostering social interaction and respecting privacy/a desire for personal space.

These themes helped to shape the kind of approaches we selected for further investigation, even though not all of them had been explored in detail.

Methods

The project was conducted in three stages.

Stage 1
The first stage was to identify approaches to developing supportive communities which minimise or manage frictions and tensions in housing with care. This stage comprised:

- a review of academic and grey literature;
- searching of relevant organisational websites (for example, housing organisations, Age UK, Mental Health Foundation);
- contact with fellow academics from within the housing with care network;
- interviews with key informants, including practitioners working within housing organisations, some of whom were involved with specific initiatives around dementia, visual impairment, tenant mediation and participation;
- placing a short article describing the intentions of the project and calling for information in the Housing Learning and Improvement Network e-news.

There are many examples of ongoing initiatives that broadly aim to reduce social isolation among older people and enable them to take a more active role in their communities through a variety of means.[2] In this project, the focus had to be on approaches that were located in housing with care, or could be transferred to housing with care settings, but which also addressed

what older people with high support needs want and value in their lives, as outlined in an earlier study (Katz, *et al.*, 2011) undertaken as part of the A Better Life programme. This work identified a number of themes, and proposed a model – 'What I Want and Value' – with the individual placed at the centre, and three domains that are of key importance:

- The psychological domain includes: self-determination, continuity and adjusting to change, humour and pleasure, sense of self and mental health.
- The physical domain includes: getting out and about, physical activities, physical health, a good environment, and safety and security.
- The social domain includes: meaningful personal relationships, good relationships with carers, social interaction, making a contribution, and cultural activities.

The Katz, *et al.* (2011) study identified a number of barriers or enabling features that affect the ability of older people to achieve what they want and value. These included: information, finances, technology, transport, other people's time, and support.

Potential case studies were short-listed for their capacity to address at least one or more of these themes. In addition, priority was given to approaches that specifically addressed the needs of groups of older people who have been identified as being marginalised on the basis of ethnicity, sexuality, or cognitive, physical and sensory impairment. A further consideration was to ensure that the case studies included both formal and informal approaches, as well as resident-led approaches, and approaches taken forward by housing-provider organisations and by external organisations. In addition, the examples were to be located in housing with care settings provided by a range of organisations – including large organisations operating nationally, and others that were more locally focused – and different locations serving diverse communities.

A consultation event with a diverse group of older people with high support needs living in an extra care community was used to ensure that the case studies were focusing on their priorities. Participants considered five themes:

- meeting people and making friends;
- getting out and about;
- joining in with social events and activities;
- having a voice;
- promoting tolerance and respect.

Of the range of themes that were discussed, how to promote tolerance and respect clearly resonated with most of the participants and generated the most interest and discussion. Getting out and about, and generally being sociable, were also of concern. It is of interest to note that as the case studies progressed, the themes of respect and tolerance often emerged in discussion with residents and staff, regardless of the nature or particular focus of the case-study example.

The examples included a variety of approaches that will be familiar to many organisations and residents. In this respect the study did not only seek new or innovative practice but also intended to spotlight practice that would seem to have the greatest potential to address the issues identified as key to older people with high support needs.

Stage 2

In the second stage, 15 approaches were investigated. These investigations drew upon published and unpublished written material as well as interviews and discussions with relevant stakeholders, including project workers, staff and residents. All the case-study examples were distinctive; however, while some of them were unique, others were illustrative of a particular approach. Our key informants varied depending on the nature of the approach being explored, but usually included scheme-based staff, residents and managers from within the provider organisation, as well as managers and volunteers from external organisations. The number of key informants could vary depending on the nature of the case study. Some staff interviews were undertaken on the telephone, but the interviews and discussions with residents took place in the schemes where they lived. At interview and in discussion groups, the following topics were covered:

- where the idea for the approach originated;
- how it was developed;
- how success was understood and measured;
- resources required;
- barriers and constraints;
- key lessons that could be taken forward.

A total of 101 individuals took part in the study.[3] Of these participants, 72 were residents living in one of nine different housing with care (*n*=7) or sheltered housing (*n*=2) schemes and 29 were members of staff either of provider or of external organisations. Six housing with care provider organisations took part in the study.

Stage 3

The third stage involved discussing the range of approaches with residents, describing the key themes to emerge from them; 21 residents in three different schemes took part in individual or group discussions. The aim of these discussions was to explore how far the themes coincided with things that residents felt were important to them and that addressed their concerns.

Note that we have not given individuals their real names for the purpose of preserving anonymity.

Report outline

Chapter 2 provides a more detailed explanation of what we were looking for in the case-study examples, and why the case studies were selected, with a concise description and analysis. Chapter 3 analyses what makes the examples work in terms of developing supportive and inclusive communities for people with high support needs. The final chapter discusses the conclusions.

2 IDENTIFYING AND EXPLORING APPROACHES TO DEVELOPING SUPPORTIVE COMMUNITIES

As outlined in the introduction, the broad aims of the Living Together, Getting Along project were to identify and explore approaches to promoting supportive communities in housing with care settings, and develop an understanding of how approaches can be developed that enhance the quality of life of older people with high support needs. The selected case-study approaches are clustered below according to whether they are primarily driven by organisations, by residents themselves, or by agencies and individuals that are external to housing with care schemes and based in the wider community.

Organisational approaches

Ways in which the social well-being of frail residents in housing with care can be promoted have previously been highlighted (see, for example, Evans and Vallelly, 2007; Callaghan, 2008). While this is important, in this study we were more interested in ways that organisations have tried to provide an underlying environment, ethos and culture within schemes that enable

any resident to feel included in the life of the scheme, and in the wider community if they so choose. The following examples set out scheme-based organisational approaches.

Enriched Opportunities Programme – ExtraCare Charitable Trust

Based in ExtraCare Charitable Trust (ECCT) schemes, the Enriched Opportunities Programme (EOP) is a multi-level intervention that has been shown to improve the quality of life of people with dementia or other significant mental-health challenges within integrated schemes (Brooker, *et al.*, 2009). There are five key elements to the programme including:

- Specialist expertise: a dedicated key worker or 'locksmith 'works with people with dementia to unlock their potential and enable individuals to enjoy an enriched life through increased activity and occupation.
- Individualised assessment and casework: based on an enriched care planning approach, including active liaison with housing with care staff, and primary and secondary health-care teams. The locksmiths work with individuals to identify interventions and activities that are most likely to enhance their potential for well-being.
- Activity and occupation: EOP locksmiths work with staff to ensure that a programme of activities is in place both within the community of the scheme and in the wider local community.
- Staff training: all staff in schemes receive training in person-centred care and mental-health awareness, and skills are mentored by the EOP locksmith in practice.
- Management and leadership: site managers work with the locksmiths to provide EOP activities and ensure that these are embedded into the schemes. All EOP locksmiths also receive support and guidance from a regional manager who has overall responsibility for EOP across ECCT.

The formal evaluation reported that residents taking part in the EOP reported greater feelings of social support and inclusion, including opportunities to be active, greater use of community facilities and also a greater variety of things to do than they had prior to taking part in the programme (see Brooker, *et al.*, 2009). The evaluation also reported that, in comparison with a control group, participants were less likely to have to move on to other settings, and spent less time in hospital. Thus, they were able to sustain their established social links with peers in surroundings they were familiar with.

An emerging additional impact is that people who don't have dementia in ECCT schemes are specifically coming forward to volunteer in activities linked with EOP.

Brooker, *et al.* (2009) noted a range of upfront costs associated with setting up EOP. A guideline average cost was about £2,600 per month per scheme. This figure was accurate at the point at which the evaluation of EOP was undertaken, but it is reported that this cost has subsequently decreased. The National Audit Office (2010) has also demonstrated broader cost savings arising from EOP. The cost of running EOP has thus far been met by ECCT's charitable works.

'A Life Worth Living' – extra care for people living with dementia in integrated schemes: Accord Housing Association

The impetus for action stemmed from Accord Housing Association recognising tensions between residents following an organisational shift from sheltered to very sheltered accommodation around the turn of the

millennium. Some of the additional challenges included older schemes that were poorly designed for people with dementia and other support needs, with implications for safety within both the home and wider community. Accord Housing Association put in place a number of changes, including:

- Retrofitting design features to assist with personal safety and orientation around schemes.
- Introducing dementia awareness training with all members of staff within schemes.
- Awareness raising with residents: this could include groups and one-to-one discussions with individuals (but could also include family and friends of residents).
- Accord established the post of dementia care manager to lead across the organisation. Each scheme also has a 'dementia champion', who can be either a member of staff or a resident. The organisation would like to move towards residents delivering awareness raising to other residents.
- Revising the organisation's anti-social behaviour policy to reflect the circumstances of people who live with dementia and to create more tolerant and supportive communities.

The changes aimed to facilitate social interaction between residents, as well as between staff and residents, by developing a tolerant and welcoming environment. Staff respondents report that people's level of understanding of dementia has increased, and this has led to a change in attitudes (including a complete turnaround for some). They also report an increased amount of socialising between residents with a range of support needs:

> … really good friendships have sparked between people with dementia and people without dementia. The persons without dementia won't take on caring, but [will] be a good neighbour. Pop in and make a cup of tea. They'll be companions to one another. We find that works really well.
> – Practitioner respondent

Moor Allerton Care Centre (MHA)

The example illustrates approaches to facilitate the inclusion of people with high support needs in events and activities through activities coordinators, as well as opportunities for greater inclusion in the surrounding neighbourhood.

Moor Allerton is a purpose-built extra care scheme which comprises:

- Yew Tree Court: 50 apartments for general needs;
- Rosewood Court: 20 apartments for older people living with dementia;
- Bay Tree Resource Centre: a 20-place dementia day-care centre, offering care, support and therapeutic services to older people living with dementia.

Although people who live with dementia may live in Rosewood Court, their participation in the overall life of the centre is encouraged. The centre promotes the active inclusion of all residents as well as participation in the life of local communities. Two activities coordinators (one full-time equivalent post) ensure that residents with a range of support needs can discuss potential activities and how they can participate. The coordinators also make sure that people with high support needs, including people who

live with dementia, can subsequently take part in activities such as swimming and line dancing.

The scheme also includes intermediate care flats (as part of Yew Tree Court) to facilitate hospital discharge for people too unwell to return to their own home. One focus for the centre is to enable these short-stay residents to be able to participate in the social life of the scheme if they so wish. A number of these individuals have subsequently decided to move to the care centre as permanent residents.

The centre also has strong links with the community in the immediate neighbourhood. A local community centre for all age groups makes use of the care centre café, and there are reciprocal arrangements for care centre residents to participate in activities run by the community centre. People who live with dementia can take part in regular organised trips to a city-centre shopping mall, as well as attend local lunch clubs.

Linc-Cymru

The example draws attention to the use of a mix of approaches to meet the needs of people with a *range* of conditions such as sight loss or dementia (including people who experience both). Linc-Cymru provides a range of sheltered housing and housing with care schemes in South Wales. Part of the work that Linc-Cymru has undertaken focuses specifically on the needs of people with a sight loss. Linc-Cymru was the first organisation in the UK to achieve Platinum status in three of their schemes under the Visibly Better accreditation scheme (see also externally led case-study example on the Visibly Better scheme below, page 26).

As part of this approach there has been a focus on the design and layout of indoor and outdoor spaces in and around schemes. Person-centred work has led to a detailed understanding of the specific needs of individuals within schemes that can help to promote their independence. For example, staff have an understanding that an individual with sight loss may need their plate to be positioned to their left or right at mealtimes.

A further aspect has been to develop an inclusive and tolerant sense of community within schemes. Awareness raising has been undertaken with staff and residents regarding the particular experiences and needs of residents who live with dementia and/or sight loss. Discussions include how best to communicate with people, as well as treating people with dignity and respect. Linc-Cymru has developed an information leaflet as part of the welcome pack for incoming residents so as to set out clearly the expectation that accommodation provided by Linc-Cymru is intended for people with a diverse range of needs.

Case studies of individual residents undertaken by Linc-Cymru illustrate the positive changes that can take place in the well-being and experience of people within their schemes.[4]

Local agreements – Hanover

Local agreements, introduced by Hanover, are an example of how residents of retirement housing and housing with care, through collective and inclusive discussion, can be enabled to have more autonomy (and responsibility).

Hanover is one of the UK's largest providers of retirement housing, with more than 600 mixed-tenure retirement schemes or 'estates', including more than 50 housing with care schemes. From 2010 onwards, Hanover introduced a local agreement in each of the estates, including housing with care schemes. The local agreement is part of a wider Choices framework that sets out those choices and decisions that can be made by individual residents, those that can be made by residents together (through the vehicle

of the local agreement) and those that are made by Hanover and apply to all estates and residents. Decisions that are 'non-negotiable' include the setting of rents, the amount of staff training and the values of the organisation.

A local agreement is made by all residents and records their decisions around aspects of communal living, particularly areas where there is disagreement or dispute, as well as issues relating to change. The intention is to 'listen to the silent majority' and ensure that all residents have the opportunity to take part in discussions. A range of methods – one-to-one sessions and small-group meetings – are used to ensure that the views of those residents who may not be able to engage in large meetings and discussions, are included. Making a local agreement is a consensus-building process, which may involve some compromise, but once consensus is reached all residents must agree to abide by it.

The development of local agreements reflects a strategic organisational decision to devolve responsibility down to the local level, and to acknowledge the individuality and independence of residents. Hanover recognised that many of the complaints being brought to estate managers were around common pressure points that generate tensions among resident groups: for example, pets, use of communal facilities and parking. As each estate is different, such issues needed to be resolved locally, rather than taken further up the organisational management structure. Local agreements also allow residents to decide which contractors should be used in each scheme (for example, for gardening, maintenance, and in the case of housing with care, catering), and for discussion about possible changes and transitions that affect all residents. Facilitation skills training and guidance on consensus development was given to all housing managers to help them to support the development of local agreements (housing managers usually manage ten estates and their estate managers). Each agreement is revisited every year, or sooner if an issue triggers the need for review.

The year following the introduction of local agreements across the organisation, Hanover's Residents' Council visited various schemes. It was clear that although residents knew they had choices and were being asked for their views, they did not fully understand the local agreement or the process. Consequently, further refinements were made to the process, and to the Choices framework.

The resources required to put together a local agreement were 'front loaded'; for example, time was required for staff training, and to set up meetings and discussions with residents in all schemes, particularly to put together the first Agreement. A perceived barrier was that the process was time consuming.

From the organisational perspective, local agreements have allowed a cultural shift within the organisation, with residents having more choice and control over the schemes where they live. Key informants felt that the introduction of local agreements were a useful and effective tool for resolving tensions and disagreements, as well as for engaging with all residents. It was felt there had been a reduction in complaints to estate managers, and cost savings were achieved across the organisation around maintenance and repairs. With regard to benefits for residents, discussion with residents at one extra care scheme demonstrated that in that particular scheme the catering arrangements had been improved.

As part of this case study we visited a housing with care scheme where there were many elders from the South Asian community, as well as the African Caribbean and White British community. Our interest in this scheme was to explore how the process of developing a local agreement had been taken forward in the housing with care setting, where more than 50 per

cent of residents had high levels of needs. The example showed that a key requirement in processes of resident consultation was for additional time to enable people with high support needs to take part in consultations, and usually on a one-to-one basis with a member of staff (staff in the scheme were fluent in a number of languages) rather than in meetings or groups. Many of those whose first language was not English were not literate in their first language, thus printed material was not that helpful to them (although it could be handed to other family members for their reference).

Anchor Older LGBT tenant group

This group illustrates an approach used to develop a welcoming and supportive environment for LGBT people. The central feature of the approach is an LGBT support group, which the Anchor tenant participation manager established in October 2007, working with LGBT tenants. The impetus for the group stemmed from a talk by a tenant to the Anchor national tenants' forum about her experiences of living as a lesbian in sheltered accommodation, and her fear of rejection by neighbours. The support group in 2012 is about 50 strong and is continuing to grow. The group is open to both tenants and staff (the latter comprise about two-fifths of the total) and meets quarterly in various locations around the country.

At the core of the approach is awareness raising to develop a tolerant and welcoming scheme for LGBT residents with high support needs – providing an environment that encourages social interaction.

The existence of the group helps Anchor to make a clear statement about its ethos: that it has come out as an organisation and will support and stand up for LGBT customers and staff.

The group has a number of roles:

- providing a voice for LGBT people within Anchor;
- providing support to vulnerable and isolated tenants;
- helping make Anchor a safe and welcoming environment for LGBT tenants and staff;
- benchmarking activities and sharing best practice with other associations;
- being involved in developing further equalities and diversity training and online guidance to staff, and also advising on how Anchor can help to meet the needs of LGBT people in care homes.

In terms of staff costs, the tenant participation manager devotes part of their time as a facilitator for the group (although this is seen as integral to the role). Anchor provides funding to cover the tenants' costs of attending the meetings, and also venue hire (Anchor will also cover the cost of carers to support attendance as required for people with higher support needs). The total cost of the support group is about £5,000 per year.

A key lesson from the support group is the importance of confidentiality. The group is very careful to ensure that anyone can participate, or make contact, in confidence if they want to. The quarterly meetings are all held away from Anchor schemes in LGBT-friendly locations. Another lesson was to enable anyone who wanted to make contact with the group to speak to another tenant, rather than the tenant participation manager; it was found that people felt reassured about coming forward if they had spoken with another tenant. A recent development is the idea of outreach work, to make stronger links with people with high support needs who may not always be able to get along to meetings. There is also a secure online space for LGBT members as part of Anchor's website for customers.

Bradley Court (Methodist Homes Housing Association)

The focus of the example is on establishing and maintaining a mixed and culturally inclusive community. Bradley Court has 46 flats and was originally developed to help meet the needs of older people from minority ethnic communities in the local area (see also Patel and Traynor, 2006). The development was intended to include a mix of African-Caribbean and white older people (approximately 50 per cent of tenants from each group). The scheme offers a range of culturally appropriate facilities:

- dining room – a choice of African-Caribbean and non-African-Caribbean dishes is available;
- hairdressing – this includes African-Caribbean hair care;
- worship – four denominations of church visit the scheme.

The research showed that residents with high support needs valued the availability of these facilities, and the opportunity to attend social events – especially faith-based ones – both within the scheme and in the surrounding area.

Social events and outings are organised by staff and volunteers at Bradley Court as well as a diverse range of activities. Staff noted that an important context is maintaining a balance in the scheme between people with and without care and support needs, which can encourage peer support between neighbours. Further, people who live in the scheme tend to be drawn from the surrounding area, and often have prior social links with other residents. The allocation policy of the scheme supports these links, which enables and encourages greater independence through mutual support.

An additional development is that the scheme is exploring the opportunity for residents with high support needs to participate as volunteer befrienders in an emerging telephone befriending service for the local area.

Plaxton Court, Joseph Rowntree Housing Trust

This scheme was of interest to the project as it placed emphasis on linking with the wider community, opportunities for people to make new friends, and also – given that restaurants and dining rooms are often the spaces where tensions and hostilities play out between residents – it was an opportunity to explore aspects of design and service.

Plaxton Court is an extra care housing development, with 69 units of mixed tenure accommodation. The scheme opened in 2008. From the beginning, it was designed to offer resources – including a restaurant, small shop and a healthy living and fitness suite – to the wider community. The scheme's marketing material is also clear that the facilities are open to the wider public.

Previous learning from JRHT schemes was applied to the design and operation of the restaurant and other shared facilities. The restaurant, although open plan, allows areas to be screened off for privacy. It is designed to be accessible, with generous space standards and good acoustics, and to have the feel of a commercial restaurant with a lounge area at one end, large windows with spectacular views and an exit to the garden. The restaurant is open every day, serving meals and light refreshments to residents and the public. However, unlike many housing with care schemes where the daily meal is paid for as part of a package of services, residents can choose whether to eat in the restaurant or not.

The restaurant has become the hub of the scheme. It is seen by residents as the place to meet other people, particularly when residents first move in. The residents we met liked to bring guests into the scheme, and indeed

some had used the facilities there, which had led to them making applications to move in. Others welcomed the opportunity to "hear different voices" in the restaurant, and felt that they would become "very insular if we didn't have outsiders".

There have been some tensions around the restaurant being used by the wider public – for example, the residents' first choice of meal is not always available if the restaurant has been busy. However, as one resident remarked, without the income generated the food would be more expensive for residents. A further tension has arisen around residents wanting to use the kitchen facilities out of hours (which for reasons of health and safety is not possible) to do their own catering for resident-organised events.

The quality of the food has been crucial to the success of the restaurant, and customer satisfaction surveys demonstrate good levels of satisfaction. Residents also remarked on the discreet support and kindness of the catering staff; for example, in bringing trays for those who cannot carry them or serving small portions of food for those who do not have large appetites. The main challenge for the restaurant is to be financially viable, given that the resident group is relatively small, and to maintain the quality of the food.

Resident-led approaches

Studies have consistently highlighted how groups of residents in housing with care support each other or 'keep an eye out', and how such support networks tend to develop over time (Croucher, *et al.*, 2006; Croucher, *et al.*, 2007). Even though not a specific approach, good neighbourliness is a key foundation for supportive communities. However, the majority of housing with care schemes will have a number of individuals who are recognised as being the 'informal' driving force behind resident-led activities, be that social activities, volunteering or representing the views of residents through resident committees and so forth. It was important to illustrate and explore some resident-led approaches to mutual support, and to identify how organisations may support and enable such activity.

Resident volunteer group
This is an example of how the energy and goodwill of some residents can be harnessed and coordinated in a very informal way by scheme managers to support other residents. It is an informal group of resident volunteers living in a sheltered housing scheme in a rural location, who offer low-level support and organise social activities for other residents within their sheltered housing scheme. It is important to note that this is not a 'formal' group as such.

The context is perhaps important to the development of this particular group. The scheme had been a very sheltered housing scheme, with 68 dwellings, that first opened in the 1970s and has since been refurbished. The scheme has two on-site managers, and both have been in post for a number of years. There are no other on-site staff. Many of the older residents in the scheme have aged in place, and some have intensive packages of domiciliary care. Some years ago the eligibility criteria for residents moving to the scheme were relaxed and new residents are predominantly 'younger' older people, with few support and care needs. The scheme managers (and residents) observed that there were few residents in the middle of the age range of the scheme, where the oldest resident was reported to be 103, and the youngest residents were in their fifties.

The volunteer group consists of a core group of mostly younger residents who engage in a range of activities to support their fellow residents, from providing lifts to doctor's and hospital appointments, gardening, collecting shopping and prescriptions, befriending and visiting, and organising social and leisure activities for all scheme residents. These activities are, however, carefully but informally coordinated and supported by the scheme managers. The particular skills and interests of the volunteers are harnessed depending on the tasks and the needs of other residents for help and support.

Discussion with residents and the scheme managers indicated that the scheme would be "a very different place" without the combined efforts of the volunteers and the managers. Many remarked on the general friendliness, neighbourliness and sense of community in the scheme that was not to be found in other similar schemes.

Sunshine Club

This example is entirely resident-driven: the focus of the group's activities is on social events and creating a social life within the scheme. It is therefore distinct from the Resident Volunteer Group described above.

The Sunshine Club is a group of four residents living in a small leasehold housing scheme with 38 flats, which opened in 1998. The scheme is not a housing with care scheme, although many of the residents have aged in place and have high support needs. The scheme is located close to various amenities, and has a communal lounge and gardens; thus there are shared spaces and facilities.

All the club members have been living in the scheme since it opened and have a great sense of ownership of the club, which was established by a former resident and friend (who has since died). Members of the group described a range of activities – mainly social – that they organise, inviting all residents in the housing scheme to take part. They also spoke about how difficult it was to get many residents to join in with events. However, they recognised that joining in was a personal choice and they certainly did not want to pester people to join in, or be seen as interfering or pushy. In discussion, group members said they would in principle value more help from the scheme manager, for example, linking them with residents in other retirement housing schemes nearby to enable joint events and activities, and the sharing of facilities.

This example perhaps illustrates both what can be achieved by residents, and the limitations on activities that are purely resident-led, reflecting the concerns of the group not to be 'nosy' or 'pushy' , and to reflect the privacy of their neighbours in the scheme.

Resident Champions

Particular individuals living in housing with care schemes are often formally recognised, either by housing provider organisations or by other organisations, such as Age UK, for the contribution they make to their communities. For the purpose of this project, we contacted two such individuals: Angela, who introduced residents in different schemes to the possibilities of new technologies, and Catriona, who organised outings and social events for fellow residents.

We were eager to explore with them the reasons why they were prepared to give their time and energy to supporting other residents in the schemes where they lived, their reflections on their achievements, how they were supported by organisations, and what lessons they could share that could be taken forward by others. For both 'resident champions', there was considerable personal satisfaction in assisting others. Their interest

was based on a recognition that life could be made more interesting and enjoyable for their fellow residents if there were more opportunities to connect with the outside world.

With regard to introducing new technologies to residents, Angela had a long-standing interest in computing, and regularly placed a blog on the residents' network set up by her housing provider. The housing provider had then encouraged her to visit schemes and introduce other residents to new technologies. They supported her by paying for her transport, and by organising visits.

Catriona had taken forward different activities in the various places where she had lived.

> I used to take the dog out for a walk and never saw anybody out, and thought there's more to life for these people, so I organised a jumble sale to pay for an outing, and it went from there.

Over time, Catriona built up considerable knowledge of potential sources of funding, as well as networking with other community organisations and residents' groups, sharing ideas and resources. Both Angela and Catriona recognised the value and usefulness of support from organisations – both housing providers and others – in enabling them to help other people.

With regard to those with high support needs, Catriona felt that sometimes other residents lacked insight. Staff attitudes and skills were key to promoting acceptance and encouraging people to participate, but not to take over, as it was important for residents to feel that "they're part of it, they've helped to achieve it".

Approaches taken forward by external organisations

Increasingly, it is recognised that housing with care schemes do not exist in isolation, but can gain much from links with the wider community (including interaction with the wider neighbourhood where schemes are located) and links with organisations that can provide additional support and assistance to scheme residents. The following examples illustrate approaches that can help to promote and develop a supportive and inclusive physical and social environment within housing with care schemes.

Hear to Help (Action on Hearing Loss)

This example demonstrates how social isolation among older people with hearing loss can be addressed through simply enabling them to better manage and use their hearing aids, and by linking them to services that support people with hearing loss.

Hear to Help and Hear to Meet are support programmes delivered in community settings (including housing with care settings) by volunteers across the UK, and are coordinated and supported by Action on Hearing Loss, working with local audiology services.

The programme was developed as a consequence of the recognition that as society ages, there are increasing numbers of older adults with acquired hearing loss. More than 70 per cent of people over 70, and 40 per cent of people over 50 have some level of hearing loss. In older people, hearing loss is associated with decline in cognitive function, increased levels of depression, social isolation, difficulties in close relationships and poor quality of life (see, for example, Gopinath, *et al.*, 2012). Often, however, older people do not know or understand how to use their hearing aids. Through

trained volunteers, the programme provides regular practical advice and assistance with managing hearing aids – for example, cleaning, changing batteries and maintenance – as well as information about other services and equipment to support people with hearing loss. The evidenced benefits for hearing-aid users include:

- increased use, benefit and satisfaction with their hearing aids;
- easier and speedier access to hearing-aid support in the local community;
- increased awareness of local services;
- improved confidence and communication skills, leading to reduced isolation.

In addition there are benefits for audiology services, e.g. reduced demand for routine maintenance and support tasks.

Building on the Hear to Help experience, Hear to Meet groups are also facilitated by volunteers. The groups give people with hearing loss an opportunity to meet and exchange experiences and information, again using community settings including housing with care and sheltered housing. The groups developed from the recognition that many people who were returning to the Hear to Help meetings were in fact coming for company rather than help. In using older people's housing schemes as venues for services, residents are able to access the service, but also meet with others from outside the scheme.

The services are free to users; however, they are not cost neutral. For example, volunteers – who are often (older) people with experience of hearing loss – have to be trained and supported, and their services coordinated. The challenge for the service is funding to support its continuation and, indeed, new groups. For further information about these services, see www.actiononhearingloss.org.uk/supporting-you/hear-to-help-hearing-aid-support.aspx.

Visibly Better (Royal National Institute for the Blind Cymru)

This approach highlights how housing with care schemes can draw upon the expertise of external organisations to promote the inclusion of people with high support needs who live with specific conditions.

Visibly Better is an accreditation scheme developed by RNIB Cymru aimed at sheltered housing and housing with care schemes, and it focuses on improving services and equality of rights for clients who have a sight loss. Organisations using the Visibly Better package work with RNIB Cymru to develop their services across a range of standards, which include visual awareness training for *all* staff, a commitment to providing the same standard of information, choices and entitlements that are available to fully sighted residents, attention to internal and external design features, and the promotion of eye health. The costs and challenges that providers may face in tailoring the accreditation scheme to their own contexts are reflected in a range of four levels of accreditation that providers can work towards (ranging from Bronze to Platinum).

In terms of how Visibly Better may help people with high support needs to get along in the places where they live, there is a focus not only on person-centred work to enable someone to take part in the life of a scheme independently but also on raising awareness among staff and other residents to facilitate a more supportive environment for people with sight loss. One of the reported benefits of implementing Visibly Better is the potential for greater inclusion in the life of schemes. For example, an awareness of the individual needs of residents with a sight loss has led to greater participation

in activities such as bingo, by designing bingo cards that individuals with a sight loss can use, through to participation in gardening clubs by improving access to outdoor spaces that surround schemes.

For further information see www/rnib.org.uk/wales.

Opening Doors London

The checklist and training featuring in this example highlight generic principles that help to facilitate a tolerant and welcoming environment for LGBT residents with high support needs. There are two key aspects to this issue: to help older LGBT people feel confident enough to approach a scheme in the first place, and to enable people to get along within schemes, whatever their background. Key informants reported that older LGBT people are asking for information on housing providers such as Anchor, which has set out clear LGBT friendly policies (see Anchor Older LGBT tenant group on page 21), which demonstrates the need for approaches such as this.

Opening Doors London provides social activities, befriending, information and support services to, and with, men and women who identify as lesbian, gay, bisexual and/or transgender and who are over the age of 50. The project operates in boroughs north of the Thames, with a membership from across London and beyond. The aim of the project is to develop services for the older LGBT community that combat isolation. The project also provides information, guidance and training for other service providers, statutory and non-statutory, in order to help them develop appropriate and inclusive services for older LGBT people, as well as volunteering opportunities to work with the groups and with one-to-one befriending activities.

As part of this work, Opening Doors London published a checklist in October 2011: 'Supporting older Lesbian, Gay, Bisexual and Transgender people: a checklist for social care providers' (for further information see: www.openingdoorslondon.org.uk). The checklist aims to assist organisations become LGBT friendly by providing services for older LGBT people that are safe, and that enable people to be themselves. It highlights:

- organisation-wide ways to be LGBT friendly;
- ensuring older LGBT people are supported by LGBT-friendly staff, including a focus on care management and social care assessment, and carers.

Opening Doors London takes two approaches to the issue: first, the checklist, to facilitate cultural change from the top down across organisations, and secondly, training staff who work directly with older people. The project is currently developing a training package with a local authority tailored specifically for staff in housing with care (June 2012).

Older Lesbian, Gay, Bisexual and Trans Association Community Network (OLGA)

This example shows that schemes can draw on a local network for a variety of support to help make them welcoming places for older LGBT people.

The OLGA network is based in the Scarborough/Ryedale area and has worked primarily with health and social care providers (www.olga.uk.com). The forms of support available include workshops for health and social care providers to raise awareness of LGBT issues, with an emphasis on training for *all* staff. There is also advice available on the language that organisation can use in any printed material, such as marketing, advertising or application forms. If organisations pay attention to language and how they present themselves, they give reassurance to prospective residents that

they will be welcomed if they choose to move in, and can live in a tolerant environment where they will be respected as individuals. One of the ways that organisations can promote themselves as LGBT friendly is that they will be eligible to use a rainbow symbol if they have undertaken whole staff training and adopt key language in their documents.

The approach also illustrates the value of befriending and being able to maintain or develop links with wider communities outside of housing with care. OLGA also undertakes a befriending scheme that includes older people with high support needs in care settings. The befriending service provides opportunities to address isolation and to enable people with high support needs to sustain social contact with other gay people, including partners who may not be living in the same scheme.

Further thoughts

The case-study examples provide a diverse range of activities that help to foster inclusive and supportive environments for residents of housing with care schemes, whatever their circumstances. It is to be noted, however, that although our purpose was to explore particular examples, our discussions with residents and managers at housing with care schemes revealed a range of different parallel activities and initiatives that were also addressing the Better Life themes, and providing opportunities for residents with high support needs to take a more active part in the communities where they lived.

As part of capturing the practical detail of the approaches that have been described in this chapter, interviews provided important context. The topics included:

- the expectations people have of housing with care and the importance of information and how schemes are marketed;
- the collective experience of end of life in housing with care settings;
- the importance of privacy;
- the preservation of dignity;
- housing with care settings being a community of residents and staff.

Discussions with staff and residents also highlighted the hugely diverse and complex meaning of 'high support needs'. The term covers a vast range of conditions, impairments, attitudes and perceptions. It also covers lifelong or acquired conditions that may be stable or unpredictable, as well as very fluid – yet deeply personal – situations such as bereavement. This issue goes to the heart of the A Better Life programme.

Additionally, just as much as one individual may experience complex needs throughout their life in housing with care, the group dynamic of the overall resident body is also complex and ever-changing. This is important as the range and diversity of individual experiences both challenge and stretch the ability of residents and staff alike to collectively respond. It also creates a challenge for organisations to provide the necessary ongoing investment in the people who live and work in housing with care, given the constant state of flux as individual residents come and go.

These issues have informed our subsequent analysis and are discussed in the next chapter.

The case-study examples provide a diverse range of activities that help to foster inclusive and supportive environments for residents of housing with care schemes, whatever their circumstances.

3 WHAT MAKES THE APPROACHES WORK?

This chapter explores the key factors that influenced the development of the case-study examples and the ways in which the examples helped to promote inclusion and support people to get along in housing with care communities. The chapter also discusses the factors impacting upon achieving success in this particular context, alongside the learning to be drawn from the examples.

In considering what makes the approaches work, it is important to underline a fundamental point – that every housing with care scheme is a unique and dynamic community in its own right, with a unique and changing mix of residents and staff, located in wider communities that bring their own benefits, challenges and opportunities. Nevertheless, there are many common themes and experiences which could be applied and taken forward in most housing with care settings.

Organisational commitment to change

What marks out the organisations in the examples, and the approaches driven by provider organisations, is a receptiveness and commitment to change. This commitment was demonstrated via a variety of routes including:

- listening to and supporting residents;
- learning from and reflecting on previous experience;
- devoting resources to supporting the development of inclusive communities;
- linking with external agencies to help promote change.

The role and commitment of front-line staff

A further theme that linked organisationally led approaches was the recognition of the role that *all* staff play in determining how communities work within schemes. This theme was reflected in the value of offering training to everyone who works within housing with care settings (also noted in wider literature, see Barrett, 2012). This was a central factor noted by diverse agencies across a disparate range of issues, including: dementia, visual impairment, hearing loss, bereavement, and also sexual identity. An important aspect of training was raising awareness of the nature of conditions or aspects of a person's identity and experience, to foster greater understanding and tolerance of individuals.

A striking theme was the extent to which many staff gave up some of their own time to enable social activities and outings, and give support to individual residents. This extra commitment is an important point in terms of what can help to make schemes work well socially and also work as supportive environments.

The role of information

Part of the role of the organisation includes providing information to help 'set the scene' of what people can expect in housing with care. This scene setting includes how promotional material is used as part of the marketing of schemes, as well as information provided in welcome packs. As previous research has highlighted, there is a danger that marketing material can overplay environments as vibrant retirement lifestyles for the fit and well, which submerges the experiences of people with high support needs, especially people living with dementia (Croucher, *et al.*, 2003; Bernard, *et al.*, 2004). One respondent in our study stressed that this information was an opportunity to explain the ethos of housing with care in providing a supportive environment for people with a diverse range of care and support needs, and to help counteract the notion that housing with care is not for people with high support needs.

Information could also be targeted on groups who may themselves experience marginalisation, which, along with the use of positive language and images, helps to give individuals the reassurance that housing with care can be a welcoming place for them. This study found evidence that there was demand for such reassurances from certain groups, for example older LGBT people.

Brokerage

While there will always be certain individuals who are willing to engage and offer support for other residents for a range of quite personal motivations, there needs to be some brokerage from scheme staff. The discreet involvement of scheme staff with resident-led groups can ensure that residents with high support needs are given the opportunity to participate in resident-led activities. In the particular case of the volunteer group, the scheme managers played a crucial brokerage role, acting to introduce residents informally at events and meetings, thus enabling them to make their own friends and develop their own relationships. The role also included identifying people willing to volunteer, matching them to tasks that best suited their interests and preferences, and at the same time ensuring that no one was asked to do too much.

This particular example also highlighted a further role for organisations, as volunteers were also reassured that there was a next step up, 'someone to tell', if they were worried about an individual, or felt that a particular situation was more than they could cope with. Similarly, volunteers felt that the scheme manager was better placed than they were to persuade people to make a doctor's appointment, or seek additional and appropriate help. In turn the scheme managers felt that resident volunteers were their 'eyes and ears', and could alert them to any problems or difficulties that people were experiencing.

What makes active individuals or groups take the lead?

The resident-led examples undoubtedly reflect some of the activities that residents up and down the country are undertaking that are helping to promote supportive communities in the schemes where they live, whether through volunteering or through representative roles. It is to be noted that there was much evidence of good neighbourliness and informal support between residents in all the schemes we visited, in line with the findings of other studies (Croucher, *et al.*, 2007).

We were keen to explore with these various groups and individuals what motivated them. People were keen to maintain and develop their own identities as they grew older and continue to engage with others, and use and share their skills and experiences. So for example, individuals who had always been active volunteers, or members of groups (whatever these were – churches, clubs or political organisations) wanted to continue with these activities. Similarly, some continued to use the skills they had developed in their working lives, for example, those who had experience of the caring professions. Others had long-standing interests in crafts, gardening or literature, and again wanted to continue and share these interests. Others simply wanted to be busy, active and helpful, and were perhaps seeking to establish new identities as they grew older.

It is also important to note that many of these individuals could be described as having high support needs themselves, and many were certainly not the youngest in the schemes where they lived. Thus the examples reveal that the apparent tensions between 'fit and frail' people in housing with care are perhaps more complex than they would first appear, and may be more a manifestation or expression of something other than simple prejudice. It would appear in some instances that such tensions result from a lack of knowledge or awareness, or indeed life experience. It may be that in housing with care settings, regular encounters with people with high levels of need may over time become overwhelming, embarrassing and possibly quite frightening for some people. However, we can only reflect rather than put forward hard evidence of this. In any case, the awareness-raising approaches demonstrate that people's attitudes can and do change.

External volunteers also had their own motivations, and these were not dissimilar to those of housing with care residents. For example, many of the Hear to Meet volunteers have experienced hearing loss themselves, or have family members who have experienced hearing loss. Having been helped by Action on Hearing Loss they want to 'give something back'. Perhaps it is also important to note that external groups have a much wider remit than working with residents in housing with care schemes, although clearly a significant number of residents in such settings would obviously benefit from the help and support they offer.

The facilities – barrier-free accessible environments, meeting rooms, a pleasant café or restaurant, parking, gym equipment – work well for hosting groups or meetings for older and disabled people from the wider community. Thus the physical environment of housing with care schemes, and the willingness of organisations and staff to share these facilities and work with external groups, is an important incentive for external organisations to work within such schemes.

Who do the approaches work for?

We were eager to explore with residents and staff whether the various approaches played out in different ways for diverse groups of residents, and whether there were unexpected benefits or indeed disadvantages to some groups. Overall, it would seem that even those approaches that were directed at particular groups offered to a greater or lesser extent advantages to the whole community within housing with care schemes.

Raising awareness

With regard to the raising of awareness of dementia, a key aspect was the inclusion of residents as part of this process. Existing research suggests that running sessions to raise awareness of dementia among residents within sheltered housing schemes leads to an increase in volunteering among residents without dementia, who become more inclined to help their neighbours who live with this condition take part in, and retain involvement in, social and group activities (Moore, 2009). Respondents in different organisations in our study also confirmed this. For example, one respondent commented that raising awareness of dementia among residents without this condition had led to much greater social interaction within their schemes. The value of other approaches in helping to understand the experiences of people with dementia was also noted, such as person-centred approaches to life histories and life stories. In one scheme it was noted that when other residents had a greater understanding of *why* a particular individual living with dementia was knocking on their doors, they became much more understanding.

Background enabling

A couple of the approaches also illustrate examples that promote the needs of people with specific impairments, and help to break down barriers to individuals taking part in the social life of schemes. Generic design principles, such as the Lifetime Homes standards, tend to prioritise wheelchair access, but some of the examples in this study focused on the needs of people with sensory impairments. Organisations have drawn upon a range of approaches and techniques, including the design of indoor and outdoor spaces and whole staff training, as well as very practical and simple initiatives, such as the regular checking of hearing aids.

Linking with the outside community

Visits to case-study schemes revealed a range of different ways in which links with the local community were fostered. One of the case-study examples focused on how a restaurant which was open to the wider public as a community resource could offer opportunities for residents to engage with the wider community. In another example, the location of a day centre for older people within a scheme allowed residents to attend too. 'Partner' schemes, sometimes operated by the same provider and sometimes by a

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different provider, where events and outings were open to residents from both schemes, allowed opportunities for a change of company, as well as ensuring better attendance or support, and the sharing and more efficient use of resources across schemes.

Nevertheless, there is a potential tension around the balance between residents' sense of ownership, 'this is our home', and the use of scheme facilities by other outside groups. The case studies in this report seemed to suggest that residents' concerns could be allayed. The issue of privacy was important, and a physical and secure separation of living accommodation from the more accessible element of schemes was essential. Nevertheless, it was clear that more open access encouraged a wider range of support networks and social interactions. Indeed, the social networks of individual residents could be drawn into schemes – for example, a lunch club from a local church met regularly in the scheme restaurant that was open to the wider public because a resident was a member of the church and had suggested they should meet there.

A further benefit of opening access to schemes is the opportunity it allows the wider community to better understand housing with care, what it can offer and how it is different from residential care. This also serves to promote schemes to prospective residents, reassure them about what they might find when they move in, allow them to make their own observations and judgements about whether the scheme would suit them, and indeed get to know other residents and staff. Some of the residents we met had been regular visitors to their schemes prior to moving in. Gina was 100 years old with mobility problems and some visual impairment. She explained that before she moved into her flat (which she loved) in a housing with care scheme, she had regularly visited and knew both residents and staff. She knew that the scheme would be a far better alternative for her than a residential home where, from her experience of respite care, "people just sit around all day". Gina had a lifetime experience of community work and was determined to do what she could to support others in the scheme and contribute as best she could. Albert, a widower in his 90s, with significant sight loss, had regularly used the gym and restaurant in a scheme, and liked the facilities, the friendly atmosphere, and the attitudes and conduct of the staff. Consequently, he decided to move in himself.

What also seems to be apparent is that people's experience of communal living within schemes often compared very favourably with their experiences of living in the wider community (often on their own, and often feeling isolated) or indeed in residential care.

Reviews also note the importance of social connections in the wider area and beyond as highly significant in helping to foster social interaction and well-being (Evans and Vallelly, 2007; Owen, 2006). Enabling people with high support needs to maintain these links, and not be confined within the same place with the same group of people, is an important facet of social interaction. This was raised by respondents within our stakeholder group: opportunities to get out were highly prized.

Where the responsibility lies for promoting and assisting such external social interaction is unclear, and as one manager commented, linking with the wider community takes time. Nevertheless, this can be a distinctive and clearly defined role for the housing and/or care provider. Pooling of resources with other organisations, as discussed earlier, can help to reduce costs. There are also some examples of residents' groups organising and arranging outings that are inclusive of people with high support needs, although one issue to bear in mind (as noted by a respondent in the study) is that sometimes residents pay in advance for accessible transport to be laid

on, only for individuals to drop out at the last moment, leaving the resident group to bear the cost.

How do the examples work for marginalised groups?

One focus for this report is on people who may have a risk of being excluded as a result of a need for support, but who also risk marginalisation as a result of their race, ethnic background or sexuality. This issue begins with the decisions that people make regarding whether or not to move into housing with care in the first place. Crucial here is the extent to which housing with care is perceived by different groups as welcoming or not.

The importance of positive messages about housing with care is perhaps most evident in relation to people from LGBT communities. The current perception is that housing with care options can seem very hostile environments, leading to LGBT people having to submerge their identities. One way of overcoming the fear that people may have about 'getting through the door' of housing with care is the language that schemes use to communicate positive approaches towards different communities.

One scheme was established with a specific remit to address the need for housing with care for people from minority ethnic communities within a particular locality. The local Black Elders Association put forward the idea for a scheme, in response to the large number of older black people in the area. Thus the scheme was designed from the outset to reflect the needs of a mix of residents.

In another scheme where various faith groups were represented, all types of festivals were celebrated and all residents were invited to the celebrations.

Local agreements appeared to work well in a scheme serving a multicultural community where more than 50 per cent of residents had high support needs. Extra time was needed to enable people with high support needs to take part in consultations, as well as attention to different language requirements and ways of communicating.

What constitutes success in developing supportive and inclusive communities?

As noted above, some of the case studies have been the subject of formal evaluations and have shown positive outcomes (for example the Enriched Opportunities Programme). Others, however, have not been formally evaluated, and as part of our discussions with residents, scheme staff and other key informants we were eager to know how they measured or reflected on success or determined whether what they were doing led to more inclusive and supportive communities. The various examples could generate benefits across schemes; however, success and outcomes were more difficult to measure or assess in less formal examples, such as the resident-led groups and initiatives. It is also important to note that the various examples were in different stages of development; some were relatively new initiatives that were still evolving over time and played out in different ways in different schemes.

In terms of measuring success, the number of people taking part was not perceived to be that meaningful; what was meaningful was whether the *individuals* who were engaged were taking pleasure or interest in what was going on. An example here is that of a much-enjoyed celebration of the Royal Jubilee in one scheme. One resident with significant short-term

memory loss still spoke about the party the following day, and the scheme manager reflected that this was really significant for this particular individual. If one person who previously had declined to take part in social events came to an event, this was a considerable success too. Similarly, if awareness raising of particular conditions resulted in small changes of behaviour (an example here is of a resident who had been particularly critical of fellow residents with dementia, but had since become much more supportive) then this was – quite rightly – considered a success.

Perhaps the main message here is that in developing supportive communities, expectations of change should not necessarily be modest, but should be tempered by the recognition that change takes time; is a gradual process of learning, revisiting and reflecting; and has to be based on the principles of tolerance and respect, as well as on the recognition of the dynamic nature of housing with care settings. Furthermore, attempts to develop supportive communities need to take account of a number of factors: the value residents' place on privacy, independence and dignity, and the possibility that some individuals will always be difficult. These issues are addressed below.

Respect – the essential building block for supportive communities

In discussing how communities within housing and care schemes might be made more supportive of people with a range of needs and impairments, a consistent theme that emerged was that of respect, and promoting mutual respect between residents. Residents felt respect was something that every resident should not just expect but also generate in their behaviour and attitudes towards others. A key informant practitioner, reflecting on experience across a number of different housing with care schemes, suggested that building communities based on respect for fellow residents should perhaps be the key focus of attention for organisations, rather than an unrealistic expectation on the part of providers and commissioners that they could create inclusive communities.

Responding to change

As one scheme manager pointed out, the resident group was constantly changing. In this particular scheme, all residents had care needs (at a minimum of five hours' care per week), and half the residents had high care needs. Usually in any one year, a third of the residents would either die or move to nursing care. Thus there was a need to constantly revisit and rethink residents' needs, preferences and capacities, which might change on a daily basis. This meant that attention to awareness raising, for example, was a continuous process rather than a one-off exercise.

Residents' expectations and the value of privacy

With regard to residents' views on how any particular initiative improved their sense of community or belonging in their schemes, various discussions indicated that their expectations of community or support are, in fact, quite modest. People spoke about how they wanted to be welcoming to newcomers, friendly and pleasant, and also experience that welcoming and friendliness themselves. It was, however, very clear that residents are eager to maintain their own privacy and to respect the privacy of other people. Privacy is indeed – for some people – empowering. For example, Natasha, a woman with a number of lifelong physical impairments, had previously lived in residential care, where she had a single bedroom but all other facilities were shared with other residents. The best and most empowering thing about living in a housing with care scheme was the privacy and space she

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enjoyed in her own flat, with her own bathroom, bedroom, living room and kitchen, surrounded by her own possessions. She also wanted to contribute to the life of the scheme and be helpful, and so for example, she would guide her neighbours with cognitive impairments if they lost their way or became disorientated. She would also help to make the tea for small social groups. Nevertheless, her joy was having her own private space.

Respecting independence and individual choices

Residents and staff were adamant that participation in the community life of a housing with care scheme is a personal choice. It was recognised that some individuals want more privacy, including many who might be described as having high support needs but do not want to join in, go to meetings or make friends. There is then an evident caution around pushing engagement, or creating what to some would seem an institutionalised atmosphere. The discussion with residents in all the schemes we visited revealed the balance that people sought to strike between being helpful, supportive and friendly but also respecting other people's right to privacy and right to refuse assistance. The residents we met who were active volunteers or organisers were concerned not to force their company or offers of help on other people or to undermine people's sense of independence. They recognised that some people were 'fiercely independent', and determined to do things for themselves as far as they could, even if to others it seemed like they needed help. Alison, an active volunteer, talked about seeing her very elderly neighbours struggling home with shopping and offering them a lift, which they refused. She did, however, insist on taking their shopping, which she felt she could do because she knew them well enough to be able to insist. As she said, "You need to know how far to go with it" .

Nicola from the volunteer group also noted, "Some people don't want help; you have to respect that".

A clear illustration of someone with high support needs who would not accept help was Edna, a widow in her 80s who was confined to her flat due to mobility problems. She explained that she knew there were plenty of people who would help her with different things; however, she noted: "You have to be careful, [or] people would come in all the time".

Another example was a gentleman in his 90s whose wife had recently died. The Sunshine Club members invited him (and all other residents in their scheme) to various events, meetings and outings, and he thanked them for these invitations, but would never come. In this case, if there was a party, someone would take him a plate of party food. Again, the club members noted the importance of privacy and allowing people to take part as they chose, and not being, or perceived to be, nosy or interfering.

Conversely, there was some caution about becoming too involved with individuals, and crossing the boundary between being a supportive, good neighbour to taking on tasks and roles that should be undertaken by professionals. Some had experience of this, either as neighbours or indeed as family carers. People spoke about needing to be able to "step back" when people needed "proper help".

Preserving dignity

Some of the residents we met who might be described as having high support needs did not want to take an active, or social role in the schemes where they lived, or be supported or helped by other residents. Louisa, for example, was a woman in her 80s. She had difficulties with concentration, and explained that sometimes during a conversation she went "blank", and

for brief periods could not follow or understand what others were saying. She did not want to explain her difficulties to others, or for anyone to explain them to others on her behalf, and preferred to keep her own company.

Christopher, a relatively new arrival to a large village-style housing with care scheme, had suffered a stroke which had left him with mobility problems, as well as problems with his speech and memory. He did not want help from other residents, as he felt it was for staff to offer help and support, otherwise where was the 'extra care'? He described his success since moving to a housing with care village in establishing a small literature group.

Another man, Rory, did not always want to go down to communal rooms and events as he suffered with incontinence. Remaining in his room was a way of preserving his dignity. Residents in another scheme remarked on a couple where the husband was caring for his wife who lived with severe dementia and who were rarely seen out of their flat. The husband could not bear for people to see his wife in such a condition.

For some residents then, living with particular conditions or impairments that made them feel embarrassed or uncomfortable in company, the preservation of dignity was more important that joining in or feeling included.

Difficult characters

Almost every scheme will have a 'character' (see, for example, Percival, 2000), who is well known to everyone, but not necessarily well liked, for a range of reasons. Sometimes these individuals will have high support needs, impairments or illnesses, and sometimes not. In one scheme a resident was generally perceived to be rude and unpleasant, and other residents simply chose to avoid him, leaving him very isolated. The scheme manager would sometimes sit with him at lunch time to provide some company, but it seemed unlikely that other residents would willingly seek his company. Residents' meetings were also forums where outspoken individuals could cause offence, and were rude to others – both scheme staff and other residents.

How do residents and staff cope with such individuals, in terms of reducing both the disruption and offence they might cause, but also in reducing the social isolation people often experience? Some residents were more assertive than others in challenging what they thought was rudeness or bad behaviour, either openly or by having a "quiet word" with the particular individual. Others felt that, "there's always one", and that you should always expect some individuals in a group to be difficult. However, for staff, simple unpleasantness or rudeness (as opposed to openly homophobic or racist behaviour) was not something they always felt they could easily deal with, and much depended on the confidence and skills of individual staff members, and their knowledge of the particular individuals. On reflection, in measuring the success of any attempt to develop a supportive community, it is perhaps important to remember that there will always be those who, regardless of any impairment or support need, remain on the edges of communities.

The meaning of success

It would seem that the meaning of success needs to be carefully considered. It is related to the point on background enabling, and generating an environment characterised by respect and tolerance. Staff and indeed residents can offer opportunities and appropriate assistance to enable people to engage and take part in the social life of schemes. They can

promote awareness and a better understanding of conditions such as dementia, but ultimately, whether a scheme is experienced as a supportive and inclusive environment will be very much a judgement to be made by individual residents.

Where does the responsibility lie for promoting more supportive communities?

Everyone who lives and works within any housing with care scheme is part of the community of that scheme, whether they like it or not. Everyone helps to set the tone and feel of a place, and in this respect everyone has a collective responsibility for shaping how far a scheme may be a supportive community. The difference in the degree to which there may be an onus on individuals depends on whether someone works in a scheme or lives there. The central role of residents in promoting supportive communities in the places where they live was discussed in the earlier sections of this chapter. Organisations, however, are in the crucial position of being able to work towards the ethos and culture they aspire to within their schemes: it is the organisation that can set the tone.

Attention to establishing the culture and ethos of a place is a central component of the background enabling role that organisations can undertake. It helps to foster an environment of tolerance in which residents can trust that other residents and staff will respect them as individuals. Background enabling is also about providing a physical and social environment that is conducive to residents being able to participate in the life of schemes if they want to. Part of this role lies in brokering opportunities for residents.

However, the fluidity of housing with care schemes in terms of staff turnover and movement in and out of schemes by residents means that the underlying ethos and culture that any one community may aspire to is under constant challenge and in a state of flux. A central feature of the approaches discussed is that they cannot be one-off exercises but need to be seen as an ongoing process of observation, reflection and response to the changing dynamics of residents and staff within each housing with care scheme. In a recent study Wright, *et al.* (2010) noted the difficulties that turnover of care staff in extra care schemes can present. Members of one organisation in our study noted that their training and awareness raising was a continuous process.

A couple of respondents discussed changes within wider society in helping to foster positive change within their schemes. For instance, the process of awareness raising, training and person-centred work around dementia within housing with care was felt to be assisted by broader shifts in attitudes about dementia resulting from advertising campaigns in various media outlets and storylines in soaps on TV and radio. Some issues are more intractable than others. Communities can work towards mediating and challenging negative behaviour in relation to attitudes towards identity, even if the fundamental beliefs held by individuals cannot necessarily be altered. Current difficulties experienced by LGBT people with high support needs in relation to negative attitudes by some residents may dissipate over time. Residents who lived through an era when homosexuality was illegal will gradually be replaced by up-coming generations who have experienced wider societal norms that are much more tolerant. That said, there is also the danger that trends towards more benign environments are subject to

> Everyone who lives and works within any housing with care scheme is part of the community of that scheme, whether they like it or not.

renewed challenges, as homosexuality remains anathema to the religious beliefs of some residents and staff.

The enabling role

There is a distinctive role for care or housing providers to enable and facilitate the participation of those who have high care and support needs. There is, however, no 'one-size fits all' approach to this. The building of a culture of respect and tolerance is very much an organisational and staff function, albeit one that can be taken forward by residents themselves. This can happen through simple measures such as raising awareness of dementia. Similarly, background enabling must be coordinated by staff, and be based on their knowledge of individuals and their needs and preferences, but might be undertaken by scheme staff, or by voluntary-sector groups and organisations coming into schemes from outside. Such initiatives still address the key housing with care concept of 'helping to do', rather than 'doing for'. Brokerage is also very much a function for staff, which in essence is very dependent on developing an understanding of individuals over time, and gently prompting participation, or negotiating partnerships and supportive networks between residents.

Nevertheless, attempts to overcome the isolation and loneliness that can mar the experience of living in housing with care for frailer people can introduce new tensions into schemes. Brooker, *et al.* (2009) noted that providing greater opportunities for people with dementia to take part in activities led to an increase in resentment among other residents. Their finding that this resentment tended to die down over time points towards the value of investing the time in mediating these tensions.

Finally, those residents who we met who wanted to organise things themselves also valued the input and guidance of staff, even in just a low-key way, as a sounding board for ideas and suggestions:

> Organisations should encourage us, should ask, "How can I help?", so you know you've got support if you've got a difficulty or a problem, being on your own, you've got to make decisions and no one to talk it through — anybody can find half an hour.
> — Resident volunteer

Scheme managers noted the importance of spending time with residents, observing what was going on, constantly trying out new ideas, but not being put off if events or opportunities were not always embraced by residents, or by large numbers of residents. Thus, thinking about inclusion and support and engagement was an ongoing process, and what worked for or was welcomed by some residents did not always work for others.

Costs and resourcing

Underpinning the examples is the recognition of a specific role — either for organisations, residents or external groups — that can be played in helping to promote communities that are inclusive of people with high support needs, which requires a commitment in time and/or money.

For many of the case-study examples, it is difficult to calculate the costs or resources that were dedicated to taking them forward. For some examples, notably training and awareness raising, there were ongoing costs.

Almost all the examples required a level of staff time, but it might be argued that this investment has the capacity to reduce a range of resources required further down the line. As discussed earlier, evidence such as the evaluations of the Enriched Opportunities Programme demonstrates the value of this type of approach, as well as the cost savings to wider society that can accrue as a result of putting in place the kind of approaches that lead to a more inclusive environment (Brooker, *et al.*, 2009; National Audit Office, 2010).

The scheme-based agreements required a considerable initial input from housing managers to draft the first agreement, and in the context of housing with care, one-to-one work with some residents who might not be able to participate easily in group meetings. Scheme staff felt, however, that over time such agreements proved their worth. The Hear to Meet and Hear to Help schemes were not cost neutral, although there was no direct cost to residents or to the schemes, apart from offering a space where people could meet. Similarly, the brokerage of groups of residents who actively volunteer within their schemes takes staff time, but nevertheless has the potential to produce a range of benefits for individuals and the whole community.

Visits to schemes also revealed a sharing of resources, and in some cases income generation, from opening resources to the wider public. The community restaurant charged higher prices to people living outside the scheme, reducing costs for residents themselves. Another scheme hosted the local day centre, with the benefit to residents of being able to join in if they wished, and also opportunities to share the wheelchair-accessible minibuses for outings, again making these more viable. It was crucial here to ensure that residents understood the way in which opening access to facilities brought them benefits, either in reduced costs or in increased opportunities.

Many practitioners were concerned about the implications of cuts to the Supporting People programme, and the possible reduction in housing-related support available within schemes. It was felt that if this support element were to be lost, there would be serious consequences for the social lives and social cohesion of the schemes. Similarly, personalisation and the use of individual budgets, while allowing individuals freedom, might mean that elements of services that needed to be collectively funded would be lost. Whether such changes will have any impact on the social life and social support within housing with care schemes remains a question.

At a time when services in the wider community such as day centres are being cut, housing with care has a great potential to act as a hub for surrounding neighbourhoods – as long as the kind of approaches that are inclusive of people with high support needs are maintained. A question therefore remains about the extent to which supporting the inclusion of people with high support needs is a recognised role for care or housing providers, and how this support should be funded.

Wider learning and transferability

Despite the diversity of approaches explored and the need to acknowledge both the uniqueness and dynamic nature of individual housing with care schemes, as well as the needs, preferences and aspirations of residents, there

are some underlying commonalities which cut across approaches regardless of whether these are driven by organisations or by residents, such as promoting and generating respect and tolerance, background enabling and brokerage.

However, some approaches are more context specific, and are likely to work better in some circumstances than others. An example is helping people to maintain social networks outside of schemes. For some individuals, communities of interest or identity will sometimes lie outside of the housing with care setting where people currently live. Knocker (2012) points out that many individuals are keen to reinforce a distinct identity and maintain links with social networks specifically for older LGBT people. A large organisation such as Anchor has the advantage of being able to sustain a LGBT support group across its schemes; smaller organisations may not have the capacity to replicate this approach, but an alternative is offered by organisations such as OLGA, Scarborough, and the Opening Doors project, London.

4 CONCLUSIONS

The examples identified in the report illustrate a range of approaches that either facilitate environments that are more inclusive and empowering of people with high support needs or highlight examples where residents, providers and other organisations are making this happen. A key focus has been on what organisations can do to promote greater inclusion, and whether they have a responsibility to promote this. In terms of drawing out wider learning and transferability of the examples, the emphasis in this report is on what organisations can do to promote greater inclusion.

Promoting tolerance and respect

Of the range of ways that communities can be developed to be more inclusive of people with high support needs, the one that residents in the stakeholder event particularly highlighted was the encouragement of respect and tolerance for people. Many of the examples highlight techniques and approaches that promote equality and diversity with this objective in mind. A baseline aspiration is that all residents should be able to live in communal settings without experiencing hostility and negative reactions from their peers, staff or visitors. Obviously this does not mean that tensions, fallouts, the formation of cliques and the ostracism of individuals can be eradicated: this is just not credible. However, a crucial role for provider organisations that emerges from the case-study examples is fostering tolerance and respect for individuals, which helps communities — residents, staff and visitors — to see beyond an impairment or condition, or facets of an individual's identity.

Awareness raising

A significant way of fostering tolerance and respect within housing with care is by raising awareness of the nature of specific conditions or aspects of a person's identity to foster greater understanding and tolerance of individuals (see also Mitchell, 2012). One theme linking a number of approaches has been the recognition of the role played by all staff in determining how communities work within schemes. This has been reflected in the value of offering training to everyone who works within a housing with care setting: a central factor noted by diverse agencies across a disparate range of issues, including dementia, visual impairment and also sexual identity, and one that is also noted in wider literature. The inclusion of residents in awareness raising is another aspect that has been reported as having positive outcomes in the schemes where this has taken place (see also Moore, 2009).

A second and essential mechanism for promoting supportive communities would seem to be the provision of information to incoming residents about what housing with care aims to achieve and the diversity of needs and experiences of the people who live there. Few if any of us have experience of community life as lived in housing with care settings. Residents' expectations and motivations for moving to housing with care are diverse, and it appears important to ensure that there are clear messages about what life is like in housing with care. Similarly, those schemes which are open to the wider community, including older people, offer the opportunity for people to see for themselves what housing with care is like.

Background enabling

The examples in the report also illustrate a range of other approaches that organisations could take in order to create an underlying environment which is more conducive to the inclusion of people with diverse support needs: providing an environment where individuals can flourish, whatever their circumstances. Background enabling has helped to set the scene in a housing with care scheme where residents can more readily take advantage of opportunities to participate. These approaches have included:

- attention to the design of indoor and outdoor spaces, with a focus on physical, cognitive and sensory impairments;
- providing support as part of care packages to enable individuals to take part in activities and events;
- ensuring that hearing aids work effectively or glasses are the correct prescription;
- specific opportunities for people with higher support needs to have a greater voice within schemes, and also more widely within organisations;
- providing information and using positive language and images to give individuals the reassurance that housing with care can be a welcoming place for them regardless of identities and backgrounds.

Brokerage

A further dimension to the examples is the brokering of opportunities for individuals to take part in the life of schemes. This could include staff making sure that individuals with higher support needs are able to take advantage of activities within schemes. A number of examples have also highlighted

the positive outcomes arising from person-centred approaches to provide opportunities for individuals to take part within schemes to the extent that they choose to, rather than being stymied by the experience of their condition or illness (such as those utilised by the Enriched Opportunities Programme and the 'dementia champions' within Accord Housing Association schemes).

The training and skill sets of staff are an important aspect of facilitating this brokering role, as is a recognition in the examples cited that everyone who works within housing with care has a valuable role to play in setting the tone and ethos of a scheme. This role includes brokering opportunities that residents can take advantage of if they so choose, including guidance and support to residents who are willing to reach out to others. Perhaps most important of all is the key role of the scheme manager: the examples uncovered a huge commitment being made by these individuals to sustain an environment that was inclusive of all residents. Crucial to this, therefore, is the way that organisations recognise and support this role.

Respecting autonomy, privacy, choice, and dignity

While organisations and staff within housing with care schemes have a crucial role to play in developing supportive communities, residents themselves are key players too. The wider literature, as well as the interviews and stakeholder discussions with residents that were undertaken during the course of this project, demonstrate that for many people living within housing with care settings, autonomy, privacy and choice are key aspects to how they want to live their lives in such schemes, and that opportunities for activities, companionship, friendliness and neighbourliness may be valued and often welcomed as part of this. Active participation, or not, in the community life of the schemes is seen very much as the individual's choice.

It is important to note that individual residents may have different and changing life experiences that impact on their capacity and willingness to engage or take an active part in community life. Some individuals have active and busy lives and various family and social networks, which, naturally, they want to maintain, and do not necessarily need to be making new friends or taking part in scheme-based activities; this applies to people with high support needs and those without. For others, including some people we met, the preservation of their dignity, or the dignity of their partner, came before being sociable. As noted above, motivations for moving into housing with care are highly individual, and indeed the routes into housing with care schemes are highly varied. Some welcome living in a community; others, however, do not wish to take an active part. Indeed, at certain points, some individuals may actively wish to withdraw from community life.

Linking with resources in the local community

In difficult times, when resources are becoming ever scarcer, it would seem there are many advantages to making housing with care schemes outward looking, and receptive to opportunities to share resources and draw on resources that may be located in the wider community and elsewhere. While this may require some negotiation with residents, regarding how their privacy is protected, it would appear that embedding housing with care schemes within the local community (where a local community exists) or partnering with other schemes or organisations to share resources, offers advantages

Perhaps most important of all is the key role of the scheme manager: the examples uncovered a huge commitment being made by these individuals to sustain an environment that was inclusive of all residents.

to individual residents and provider organisations. Yet it is important to note that drawing in external resources from the wider community is not in itself a resource-neutral exercise. If nothing else, someone has to give their time to connect with other organisations and to negotiate with them and with residents regarding the use of space or their preferences for new opportunities, and then to take such opportunities forward.

Taking forwards inclusive and supportive communities

As the case studies clearly demonstrate, there is much work already being undertaken to ensure that older people with high support needs living in housing with care are able to enjoy a good quality of life, and that schemes can be welcoming and inclusive of minority groups. It is also clear that communities within housing with care settings are each unique, diverse, complex and constantly evolving, reflecting the changing lives and different experiences and expectations of both residents and staff.

The diversity and complexity have implications for how success can be assessed when it might not be possible to undertake formal (and potentially expensive) evaluations. The constant evolution of schemes in terms of the make-up of the people who live and work within them also means that there is not a linear progression of change against which success can be judged. In developing supportive communities, expectations of change should not necessarily be modest, but should be tempered by the recognition that change takes time and is a gradual process of learning, revisiting and reflecting, often at the level of individuals. One important, and meaningful, way of demonstrating success is by the use of case studies of individuals and the way their lives have changed.

It appears that in order to reflect that diversity and complexity, 'light touch' responses are required by staff and provider organisations to:

* create an ethos of respect and tolerance;
* take forward person-centred approaches to care and support;
* carefully raise awareness of the lived experience of conditions that come with ageing (for example, dementia);
* work discreetly in the background to help ensure that individuals and groups of residents can retain their privacy and autonomy, and yet at the same time be encouraged to contribute in whatever ways they wish to their various communities, both inside and outside of the schemes where they live.

The first issue – creating an ethos of respect and tolerance – provides the foundation for achieving the things people as individuals want and value. It can be argued that the development of positive opportunities to enable inclusive communities, and the choices that individual residents can make – whatever their circumstances – flow most readily where this central ethos has been specifically fostered within schemes.

It would seem that living together and getting along within the context of housing with care is a dynamic process that can be fostered and nurtured but not forced or imposed. The experience of ageing in the 21st century will be very different from what has gone before. We will all have to find new ways in which we can live together and get along as we grow older. This project has explored the particular context of housing with care, but offers useful lessons for other settings – care homes, particularly, but also perhaps for developing neighbourhoods that are age-friendly.

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NOTES

1   For further details of the programme and its various outputs see www.jrf.org.uk/work/
     workarea/better-life.

2   See for example, The Brighter Futures project, undertaken by the Mental Health Foundation,
     Ageing Artfully by the Baring Foundation, Equal Arts, Live Music Now, Hanover in Practice.

3   This does not include the key informants who assisted with the identification and selection of
     the case studies.

4   An example of a case study is available at www.rnib.org.uk/aboutus/contactdetails/cymru/
     cymrumedia/pages/platinum_visibly_better.aspx.

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