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“A vision for care fit
for the twenty-first
century...”

THE COMMISSION ON RESIDENTIAL CARE

Chaired by
Paul Burstow MP

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Contents

Acknowledgements	7
Foreword	9
The Commissioners	13
Executive summary	19
1 About the Commission on Residential Care	37
2 What housing with care can achieve	45
3 What do people want from housing with care?	63
4 Where are we now?	87
5 A better way	121
6 What needs to change?	179
7 Recommendations for change	211
Concluding thoughts	237
Appendix 1 Glossary of abbreviations	237
Notes	241
References	259

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We would also like to thank the very many experts, care providers and frontline practitioners who contributed to the work through interviews and our call for evidence, and opened their doors to us (both in the UK and abroad) so we could witness first hand how housing with care was achieving life changing support for older and disabled people.

Finally, we would like to thank all those people living in housing with care who contributed to our focus groups to give us greater insights into what they wanted and expected from the support they received.

Claudia Wood
Chief Executive of Demos
September 2014

Foreword

Over 450,000 older and working-age disabled people live in residential care, yet the many acts of hospitality, human kindness and great care are drowned out by stories of shocking abuse.

This report starts with a simple proposition: residential care has a future; it is an essential part of our health and social care system. At its best it has lessons to teach the NHS about the care and support of frail older people.

Over the past 12 months our Commission has taken a long hard look at the state of residential care and its potential future. There are some tough messages. The brand of residential care is fatally damaged. Unloved, even feared, for most people residential care is not a positive choice. Linked in the public mind to a loss of independence, residential care is seen as a place of last resort.

We are optimistic about the potential of residential care to change. During the course of our inquiry we have witnessed great care: we have seen what the future can look like, because it already exists in the present.

For most people, going into residential care is synonymous with an end to independence, of loss. Personal independence is wrongly linked in the public mind with remaining in one's own home. In the UK and around the world we have seen great examples of how residential care can reinvent itself. It is no longer a last resort, but a respected part of a continuum of 'housing with care', which is enabling people to lead bigger and more fulfilling lives.

Rebranding residential care as a part of a spectrum of housing options with care is a prerequisite of delivering the twenty-first-century care system we want to see. Housing with care separates the decisions about the 'what' of care from the 'where' we live. It starts with the goal of maintaining the

everyday rhythms and routines of life; it recognises that feeling included and purposeful matter.

At Lasell retirement village in Boston MA I eavesdropped on a conversation between residents. The village is part of the campus of Lasell College and residents must take 150 hours of education a year. The conversation was all about their courses and the future, not their ailments and age.

In the Netherlands I visited De Hogeweyk, where people live in 'houses' with a small number of others who share similar tastes and outlooks on life. It is intended that people lead as normal lives as possible. Hospitality is at the heart of the training and behaviour of staff and volunteers. Supporting people to lead everyday lives was 'on stage' while the nursing care was seen as 'back stage'.

At Humanitas Bergweg in Rotterdam I met the inspirational Hans Becker, the founder of Humanitas, who described his philosophy as moving from a focus on cure and care, which create 'islands of misery', to a focus on happiness. He believes there are two elements to happiness: the individual and the communal.

At Florence Leonard Centre for Living in Boston, I met Steve, who has motor neurone disease (MND). When the idea of building a green house scheme for MND first surfaced, Steve helped to design automation systems that give him and fellow residents of the MND and multiple sclerosis houses control over their environment.

In all my visits for the Commission I found a shared philosophy of supporting the self-determination, self-reliance, fun and community bonding among residents, employees and families.

These ideas are not new, nor exclusively from abroad. The communal dimension has been central to the mission of the Whitely Village in Surrey since it was founded in 1917. Glendale Lodge in Kent also demonstrated the importance of bonding between residents and staff as part of its ethos and practice.

As one of the authors of the Care Act I believe it offers an opportunity for the reinvention or rebranding of residential care that this report calls for. By placing the promotion of individual

wellbeing at the heart of the care system it challenges regulators, commissioners and providers alike to look afresh at what they are doing.

However, chronic underfunding of social care is undermining the best endeavours of those who would reform and reinvent residential care. Without a fair funding settlement for social care the trend towards a two-tier system of residential care will accelerate, with those who cannot afford the cost of care condemned to a mediocre, life-limiting experience in the poorest quality homes, staffed by the lowest paid, least qualified staff.

Westminster, Whitehall and town hall leaders can create the conditions for a better kind of residential care, which starts by recognising the importance we attach to home and social connectedness. It involves breaking the false link between the ‘what’ of care and ‘where’ we live. Breaking this arbitrary link will enable much more innovation and greater transparency and clarity between the costs of care, accommodation and services.

Such a change would end anomalies in the way care is commissioned, regulated and inspected depending on where the care is provided. It challenges the idea that a frail or disabled person should have less security of tenure simply because of where they live. Much can be achieved with the existing stock of residential care to realise this vision. As this report demonstrates, technology is opening up many new possibilities to make better use of existing bricks and mortar and deliver great care.

Whether it is in new or old bricks and mortar the workforce is critical to delivering the Commission’s vision. Too often working in care is seen as a ‘job’ that is temporary and low skilled. There is little career progression; society attaches a low value and low pay to the work, unlike the value it attaches to those working in the NHS.

We are under no illusions about the difficulties of moving away from a low wage to a living-wage sector, but we believe that government, local and national, cannot stand by and do nothing. I want to thank Claudia Wood and Jo Salter from Demos, and Natasha Kutchinsky from my office. This report would not have been possible without them. Above all I want to thank my fellow Commissioners for their time and commitment to this project.

We share a common belief that great care can liberate people, enabling them to maintain, even regain, their sense of worth, purpose and connection. Housing with care can offer a life and laughter, fun and friendship.

Much has been said and written about residential care, but less has been done. Through this report, therefore, we have sought to create a powerful case for change and an action plan to deliver it – identifying what needs to be done and who needs to be responsible for these actions. Our aim is to inspire a joint effort. I am confident that, with this effort, housing with care can claim its rightful place in a twenty-first-century care system.

Rt Hon Paul Burstow MP
Chair of the Commission on Residential Care
September 2014

The Commissioners



Rt Hon Paul Burstow MP (Chair)

Paul served as Minister of State for Care Services in the Department of Health between 2010 and 2012, and has a long-term interest in the provision of care in society. In his ministerial role, he was responsible for care for the elderly, adult social care, mental health services and learning disability programmes.

He has served as the Liberal Democrat MP for Sutton and Cheam since 1997, and during that time has been their spokesperson for local government, and for older people. He was invited to join the Shadow Cabinet in 2001, covering issues affecting the elderly and vulnerable, before being promoted to Shadow Health Secretary in 2003. Prior to his election to Parliament, Paul was a councillor in Sutton, where he chaired the Council's Disability Forum.



Dr Chai Patel CBE

Chai is the chair of HC-One, a UK care home provider formed in 2011 when Court Cavendish merged with NHP (Nursing Home Properties) to take over the running of around 250 care homes formerly operated by Southern Cross. Chai brought back the Court Cavendish name he had established in 1988, to create a new health and social care turn-around consultancy.

Chai has over 30 years experience in healthcare – leading and advising a number of care providers, including CareFirst, Westminster Health Care and the Priory Group. Chai is a Fellow of the Royal College of Physicians, has been a member of Government Task Forces for Older People and Better Regulation, and in 1999 was awarded a CBE for services to the development of social care policies.

Guy Geller



After a successful three years as Managing Director of Sunrise Senior Living UK, Guy Geller now focuses on new business development, including Mergers and Acquisitions. He brings unique transatlantic experience to the Commission on Residential Care.

Guy joined Sunrise in 2011 and has more than a decade's experience in health and social care management, spanning operations, marketing and property. Before joining Sunrise, he was a Senior Director at Brookdale Senior Living, the largest operator of retirement housing in the USA.

Guy is particularly passionate about supporting people suffering from dementia and helping to find a cure. Guy was a Board Member of the Alzheimer's Association's Great Illinois Chapter in the US, and Sunrise helps to fund the Alzheimer's Society's Research Network in the UK.



Professor Julienne Meyer

Julienne leads the *My Home Life* Programme, which was established in 2006 to promote quality of life in care homes – not just among residents, but also for staff and visitors. She also leads research in care for older people at City University London, where she is Professor of Nursing and Care for Older Adults.



Des Kelly OBE

Des has been Executive Director of the National Care Forum (NCF) since the organisation was formed in 2003. Between 1998 and 2003, Des was Partnerships Director for BUPA Care Homes, and has previously held positions with a number of care home providers and social care organisations.

He served on the Committee for the Wagner Review of Residential Care, which published its high-profile report *Residential Care: A positive choice* in 1988. He is currently the chair of the Centre for Policy on Ageing, and the *My Home Life* programme advisory group. Des is a Director of both the National Skills Academy for Social Care and the charity the Residential Forum.



Simon Arnold

Simon joined Tunstall from Aviva Health in the summer of 2011 and has responsibility for shaping the strategy of the business to deliver services that are built around the needs of care users. He is a driving force in reshaping the industry's approach to telehealth and telecare away from focusing on the technology alone and onto integrated care delivery, with technology as the enabler.

Simon is a Non-Executive Director of the Telecare Services Association, representing the industry in standard-setting and stakeholder engagement, and is also a member of the Government's 3MillionLives working group, which is seeking to ensure that assistive technology is effectively embedded within health, social care and housing environments. Simon has also spent a number of years in consultancy, and working for British Gas.

Richard Jones CBE



Richard is the Director of NHS England in Lancashire, on secondment from Lancashire County Council, where he has been the Director of Adult and Community Services for 10 years. He served as President of the Association of Directors of Adult Social Services (ADASS) in 2010/11.

Richard was a member of the Social Work Task Force, and was instrumental in setting up the Think Local, Act Personal Partnership, which was established in 2011 to drive forward personalisation and community-based care.

He was awarded a CBE for services to adult social care in 2012.

Jane Ashcroft



Jane was appointed as the Chief Executive of Anchor, England's largest not-for-profit provider of care and housing for older people, in March 2010.

She joined Anchor in 1999 from BUPA, which had acquired Care First plc where she was Personnel Director. She was previously HR Manager and Company Secretary with Bromford

Housing Group, and before that Assistant Secretary with Midlands Electricity plc.

Jane chairs the English Community Care Association, the largest representative body for providers of adult social care, and is a Fellow of the Institute of Chartered Secretaries and a member of that Institute's council.

Clare Pelham



Clare is Chief Executive of Leonard Cheshire Disability. Previously she was the inaugural chief executive of the Judicial Appointments Commission, and has also held senior positions in the Cabinet Office, Home Office and Department of Constitutional Affairs.

Clare believes passionately in working towards a society in which every person is equally valued, and where disabled people have the freedom to live their lives in the way that they choose.

Executive summary

This is the final report from the Commission on Residential Care (CORC) – a group of academics, experts and practitioners, chaired by Paul Burstow MP, who have over the past year examined a range of evidence and consulted a number of experts and practitioners in the UK and abroad regarding the future of residential care for disabled and older people.

The Commission first of all set out to create a vision for housing with care in a twenty-first-century care system, not bound by existing definitions of ‘residential care’ or ‘care home’ but based on a new offer (or range of offers) of housing with care, broadly defined, which can deliver the outcomes people want and value. This vision includes older and disabled people.

Its second task was to set out how the existing housing with care offer could change to deliver this vision, across financial, operational, governance and cultural aspects of care – drawing on existing good practice at home and abroad.

Throughout this report, ‘residential care’ is referred to as ‘housing with care’ and used to encapsulate the entire spectrum of options, from care homes to extra-care villages and supported living apartments. This choice of terminology was based on the evidence the Commission heard relating to the negative perceptions associated with the term ‘residential care’; the confusion between this and the term ‘care home’; and the need the Commission recognises to separate the ‘what’ (the care and support people need) from the ‘where’ this care is delivered (which should involve a freer choice of housing to meet individual preferences). The Commission felt the term ‘housing with care’ better described the sector as a housing option first and foremost, with a care package attached.

The Commission set out from the position that housing with care remains a vital option in a modern health and care

system, and that for some people, delivering care in a residential setting has unique advantages over other forms of care, enabling them to lead lives that are not just better supported, but also more fulfilling and engaged. Disabled and older people need a full range of housing and care options to choose from. For those who choose it, the right housing with care option can offer both better value for money and a high quality, empowering service.

Chapter 2 of the report details some of the many stories of people's' lives that have been transformed for the better when they moved into housing with care from living at home, where they were often alone and struggling to cope. Throughout the report we describe how, when real choice is offered, and the right housing with care options are made available, people can live *less* restricted, *more* connected and *more* fulfilling lives after moving into housing with care. For people whose daily lives are suffering because of the amount of support that they need to manage things like dressing, washing, going to the toilet, cooking, eating and moving around in their existing home (and for self-funders, the cost of paying for this), housing with care can have a transformative impact. Given its ability to provide personalised, round-the-clock support to a group of people who might otherwise be supported in isolation, it can also be a resource-effective way of meeting high and complex needs while creating opportunities for building friendships and community.

And yet the value of housing with care does not always translate into either positive public perceptions or commissioning decisions. Many people feel desperately unhappy at the thought of 'moving into a home', and assessment and commissioning have adjusted accordingly to keep people 'in their own homes' for as long as possible. We are currently a far cry from being able to reap the full benefits of housing with care which would come by ensuring people could make a pro-active choice if their needs and preferences best suit it, rather than as a rushed, last resort and therefore, often traumatic experience.

In chapter three, we explore in more detail what disabled and older people want from housing with care now, and how this might change in the future. Combining the findings of an extensive literature review, focus groups carried out by the

commission and new public polling, we give an insight into people's priorities for care and support at various stages of their lives, as well as what people would want to see from housing with care if they needed it.

People felt their priorities for later life would be: remaining independent, being close to family, living somewhere safe or easy to maintain. By and large, people imagine themselves wanting the same kinds of things in old age that they have enjoyed all their lives – the opportunity to explore and discover new things, a sense of belonging, good relationships with friends and family, not feeling restricted in what they can do, and plenty of opportunities to enjoy the things that give them pleasure. Only the final two priorities identified in the research – maintaining dignity and having appropriate support – point to a recognition that their lifestyle would need to change and adapt to the inevitable process of ageing – the desire for dignity when this is no longer in their hands, and help with some of the activities of daily living. These new findings resonate with much of the existing research on this subject, including the Joseph Rowntree Foundation's research on *Keys to a Good Life*.

When asked what their priorities would be if they acquired a disability earlier in their life, people felt that being close to family, remaining independent and having carers/medical professionals nearby were most important. However, the Commission identified less existing evidence on quality of life for disabled people in housing with care and disabled people's preferences were they to live in housing with care. There is certainly nothing equivalent to the body of research that exists on this subject for older people, which represents a challenge for housing with care providers as they formulate their future offer for the next generation of disabled people. The safest course may be to assume that disabled people want to live their lives in the same way as non-disabled people, and their housing should be sufficiently flexible to support this.

A housing with care sector built on current demand runs the risk of becoming outdated within a generation. One way of avoiding this is to build a care market that is flexible and responsive, so that as tastes change, provision can change with

them. But it is also crucial that we look ahead, and scope out what future demand will look like – particularly where this deviates from what people currently choose and value.

The generalised view of ‘what people want’ set out in chapter three should not be interpreted as a ‘one-size-fits-all’ model that will suit every older or disabled person’s tastes. Some people enjoy spending time alone, and prefer to take a more individual approach to decision making. Other people enjoy gaining a sense of purpose and direction from being around other people. These preferences are very personal to individuals.

The unspoken addendum to everything that people told us that they wanted – whether it be in later life or if they were disabled – could have been ‘as I do now’ (‘I want the freedom to come and go as I please... as I do now’). This – and the fact that many of the features people say they would look for in housing with care were the same things that they reported as markers of a good life – suggests that what people want from housing with care, above all things, is to apply the same standards to it as to the rest of life.

The step from a person’s existing home into housing with care is currently viewed by many as a huge leap in environment, lifestyle and quality of life, but the research findings suggest that people would prefer the perceived gap to be a lot narrower, and anecdotally may experience it as narrower. In chapter 4 we consider the current challenges facing housing with care. In some ways, the future of social care is balancing on an axis. On the one hand, the Care Act 2014 promises to be revolutionary – bringing in a new duty of wellbeing, carers’ rights and commitment to preventative action – measures which have been long awaited and much welcomed by practitioners and representatives of disabled and older people’s groups. On the other hand, the funding crisis looms large. These parallel developments – the Care Act and reduced resources – present a significant challenge for the housing with care sector. The latter has led to year-on-year below-inflationary increases in the weekly fees local authorities pay to care homes for state-funded individuals, but expectations of what care and support can achieve are rising. The importance of achieving independence

and empowerment through personalised support has now been enshrined in the Care Act and is established good practice in many parts of the social care system. The traditional care home, with collective routines and shared living spaces, may need to work hard to keep abreast of these new expectations and demands from policy makers and the public.

Unless the funding challenges outlined are tackled, it is likely the housing with care sector will continue to bifurcate to the point where the poorest quality homes staffed by the lowest paid, least qualified employees are reserved for a dwindling number of state-funded individuals – reinforcing public perceptions of care homes as places to be avoided and feared – while more modern, higher-quality settings become the exclusive preserve of people who can afford it.

In chapter 4 we categorise the most pressing challenges to housing with care:

- funding and the pressures of the housing with care business model and difficulty in securing investment
- the related problem of staff recruitment, retention, training and wages
- the negative public perceptions of housing with care and confusion over the terminology used and range of options on offer
- the wider pressures of demographic change, including the increased prevalence of complex and multi-morbidities in the very old, and exponential growth in the number of people with dementia
- the fact that disabled people, many who might have died in childhood just 20 years ago, are living longer – into adulthood and with a desire to live independent lives
- increased expectations of the sector from the NHS, and less support from primary and other health services.

One of the most striking findings from the Commission is the sheer impact of negative public perceptions, driven by much-publicised abuse scandals in care homes in the past few years. The public survey commissioned by Demos on behalf of the

Commission found that only 1 in 4 people say that they would consider moving into a care home if they became frailer in old age, while 43 per cent said that they would definitely not move. One man in the focus groups conducted by Demos for the Commission summarised this feeling when he said: ‘Nobody wants to go into a care home. That’s like saying “we’ll go to Tower Bridge and jump off!”’¹

Alarmingly, the risk of neglect or abuse is the second most commonly given reason for not moving to a care home – with 54 per cent of members of the public citing this. The latest statistics on reports of cases of abuse by housing with care staff suggests there were 7,654 cases in England last year – affecting just under 2 per cent of the 432,000 people living in housing with care.²

The picture from the research was clear – the public broadly see residential care homes as places of illness and frailty, where boredom and loneliness pervades, and where you would only go as a last resort. Nonetheless, we found that people who work in care homes were much less likely than members of the general public to select negative words to describe care homes and more likely to state they would go into a care home themselves. This is encouraging, as it suggests that people with first-hand experience of care homes have more positive perceptions of the sector than average.

It is inevitable that recent abuse and neglect scandals, exposed through *Panorama* and other media investigations, which receive wide publicity, have negatively affected public perceptions. There is a lack of positive publicity for care homes, and care homes are often poor at promoting themselves and being proactive and positive about what they can achieve. This impacts on how staff and managers feel about their jobs – care is not viewed as a vocation in the same way as nursing is, and some experts consulted during the Commission felt there was a degree of ‘shame’ attached to the role of care workers.

But despite the pressures and poor perceptions facing the housing with care sector, it is full of innovative and excellent examples of delivering high-quality care for people with complex needs and dementia, delivering personalised and empowering care, and giving people opportunities to regain their

independence and build social networks. In chapter 5 we provide many examples of domestic good practice in the US, Denmark and the Netherlands, although there is no single identikit model that makes a perfect housing with care setting. Great care is an art, rather than a science, and we must strive to deliver a diversity of housing options to suit different needs and preferences.

Nonetheless, there are some common features of different housing with care settings the Commission has identified as powerful levers for life-changing support and likely to be effective in meeting the needs and expectations of future generations of disabled and older people, as we describe in chapter 3.

Chapter 5 describes examples of housing with care that work to ensure people gain and maintain independence and autonomy (including being able to progress to greater independence), take control and have a sense of ownership over one's life and environment, have personalised and relationship-centred support, are an active and visible part of their community, and engage in meaningful activity and a sense of purpose. It is loosely grouped into these themes, though great housing with care delivers on all fronts simultaneously. We end with a reflection on how housing with care is looking to the future – considering approaches that are responsive to an increasingly diverse disabled and older population and increased numbers of people with dementia, and using technology (in the form of telecare and telehealth) as an enabler for those living and working in housing with care.

This is clearly not an exhaustive review, but it serves to illustrate that at its best, housing with care is already delivering exactly the sorts of things that people say they want and expect in a long-term care setting, and provides a vision of what the sector might strive for in future.

The final two chapters of this report set out how the Commissioners believe the existing housing with care offer could change to deliver this vision across financial, operational, governance and cultural aspects of care. In chapter 6 we identify 'what needs to change' – and outline the following four priority steps.

The first step

The first step is to build on what we have by recognising that the current housing with care sector is an asset, which needs to be maximised. It is an under-used resource and unfortunately it is frequently overlooked as a source of specialist support and expertise, and as a hub for related activity. Current housing with care services could prove an excellent resource in various situations:

- as step-down and step-up care and reablement services for people leaving hospital or at risk of entering acute care where a move straight back to their usual home is not feasible
- as a provider of rehabilitation services for people with a serious physical or cognitive injury
- as a short-stay or respite care setting for family carers
- as an outreach service to provide ‘housing with care in the home’ just as ‘hospice in the home’ is currently available to support family carers who look after terminally ill relatives at home.

These are just some of the potential complementary services that housing with care providers can offer, if engaged more systematically by informed and innovative health and local care commissioners, building on relationships that often already exist.

The Commissioners believe that internal and cultural change within the sector needs to be supported by an external shift. Having reviewed the evidence gathered and consulted experts on this matter, the Commission has concluded that each person’s care and housing requirements should be considered separately. The assessment of individuals’ care needs should be independent of any presupposition of where any required care might be delivered. In turn, housing with care options need to be diverse enough to cater to a range of different housing and lifestyle preferences, as well as care needs, so that when a person has an assessment of their support needs, they have a real and valid choice over where they might live to have these needs met along a spectrum of care settings.

The proposed ‘care cap’ funding system has the potential to support such an approach but a better funding strategy is the

tripartite system used in Denmark, where charges are split into three distinct components – rent, service charges (for cooking, cleaning, laundry, etc) and care costs. The tripartite system has the benefit of bringing with it something that is currently absent from the housing with care sector in the UK – a concept of ‘tenants’ rights’. Commissioners believe the separation of ‘what and where’ of housing with care should also be applied to the commissioning and regulation of care. While health and care commissioners and regulators need to help secure and improve the quality of care and support according to the outcomes each person wants to achieve, where that occurs should be a matter of personal choice.

No commissioner should attempt to commission a ‘bed’, or a ‘room’, but a package of support based on outcomes each person wants to achieve. Once that package has been developed with individuals and their family, where best to achieve those outcomes should be a matter of preference – facilitated by commissioners as part of their market shaping responsibility (underpinned by a shared vision of what good housing with care looks like), but not driven through their own purchasing decisions. Similarly, regulators need to inspect and set standards for care and support, based (like commissioning) on an appreciation of outcome-based support and a shared vision as a society of what good care should be achieving. However, for the inspection and regulation of care homes, the inspection of the ‘where’ alongside and entirely tied up in the ‘what’ being delivered is unnecessary and unhelpful. Ideally, the Commission would like to see a new regime where the ‘what’ of care is regulated and inspected by the Care Quality Commission (CQC), while the ‘where’ falls within the variety of quality standards used for housing.

The second step

The second step in changing the existing housing with care offer is to create a flourishing market of supply. The evidence gathered for this Commission suggests that housing with care is frequently hindered by the structures around it – the statutory definition

used by regulators of a ‘care home’ as a location involving ‘the provision of residential accommodation, together with nursing or personal care’ can prevent the development of more flexible innovative models. Planning also plays a part in dampening the ability of care providers to innovate. Local plans often do not recognise the need for housing with care, nor are they obliged to ensure there is adequate land for such developments to serve the local community. Planning-use classes cement the distinction between care homes and extra care villages and preclude variations that might fall between or around them.

If commissioning and inspection were to be limited to the commissioning, regulation and inspection of care, and if planning were more conducive to the provision of housing with care and allowed for greater flexibility, then the diversity of housing models suitable for care delivery becomes almost limitless, allowing for more mixed tenure models across a wider range of housing with care types – giving people more choice and linking more readily to the property market.

The third step

The third step in changing the existing housing with care offer is to tackle how we think about housing with care. Commissioners believe a separation of ‘what’ support someone needs and ‘where’ this is delivered would be a step-change in the housing with care sector, its regulation, funding and commissioning. But it would also be revolutionary for people’s perceptions of the sector, where the ‘care home’ looms large as a place of frailty and vulnerability. Yet as with public perceptions on any issue, change can be slow to achieve. We therefore believe we need to be equally bold in how we discuss and think about housing with care, and change the terminology used, in order to lead the way in changing the public mindset.

The Commissioners feel that the term ‘housing with care’ could replace ‘residential care’ to describe a spectrum of different housing options where care is delivered on site. It is a more explicit and transparent term, cutting through some of the existing confusion and better reflecting the proposed separation

of the accommodation and care component outlined above. By placing ‘housing’ front and centre in the term, it suggests that moving to housing with care is making a choice about where you live, based on one’s preferences, as with any other move during one’s life. As a housing decision rather than a care decision, this carries with it less emotive associations of physical or mental decline and dispels the idea that moving to housing with care is a move from ‘staying in my own home’ or ‘selling my home’ to pay for care.

The fourth step

The fourth step in changing the existing housing with care offer is to decide how to fund care. Much has been written and said on the subject of care funding over the past decade, but less has been done. We may feel closer to a funding settlement following the Government’s intention to use a new capped-funding regime – based on Andrew Dilnot’s 2011 plan. But Dilnot was not asked to address the most crucial question in his review: how much funding would be needed to deliver the volume and quality of care outlined in the Care Act? This is a crucial issue. We have a potential answer as to how the responsibility for care funding can be divided between individuals and the state, but we do not know how much we will need or where the resources will come from.

Commissioners believe this will undermine the successful implementation of the Care Act and jeopardise the future of the care system. It seems impossible that the duty of wellbeing, delivery of prevention services to reduce or delay care needs in the future and other provisions of the Care Act can be implemented if eligibility for state support is reserved for people with substantial needs and above. In the housing with care sector, a lack of investment in quality care is creating instability and bifurcation in the market, which Commissioners believe is a recipe for financial disaster; it suggests that the NHS and housing budgets need to be directed towards improving the provision of housing with care. With demographic change and increased demand for care and support services, housing with

care is a growth employment sector and source of regeneration for local communities – where housing with care is built, it generates employment for a range of industries, can reinvigorate declining town centres, and provides stimulus to local housing markets where older people move into housing with care. It also supports families juggling work and caring responsibilities, offering temporary and permanent substitute care. And yet most of these economic benefits are overlooked, with social care funding often viewed as a ‘cost’, with no benefit – a chronically underfunded regime in need of an injection of resources no government seems willing to part with.

In chapter 7 the Commission presents its recommendations as an actionable plan for change, grouped into several themes. We have summarised these recommendations below.

Summary of recommendations

Leading from the front

- 1 The Government should establish a shared vision of what role housing with care plays and what it should achieve for people it serves in a twenty-first-century care system.
- 2 The Government should promote a shared evidence-based vision for what we know people needing support, relatives and staff want from housing with care and what we know works.
- 3 The terms ‘residential care’ and ‘care home’ should no longer be used in government policy and guidance; they should be replaced with the sector-wide term ‘housing with care’ to encapsulate all forms of care delivered in specialist housing settings.
- 4 The Government should investigate and develop proposals for tenancy in care homes so that people do not pay ‘hotel costs’, but rent, alongside service charges and care fees.

Working in housing with care

- 1 The care sector should become a living-wage sector, with a transparent and fair funding formula developed by national government, local commissioners and providers to make this viable.
- 2 Skills for Care should become the national professional organisation to represent housing with care staff and promote excellence in housing with care practice.
- 3 A minimum level of training and development should be introduced across housing with care and linked to a licence to practice.
- 4 Management of housing with care should be recognised as a distinct skill set, vocation and career path, and specialist training, qualifications and pay should be offered accordingly.
- 5 Paid internships and apprenticeships should be introduced, sponsored by housing with care providers, for those interested in working in housing with care.
- 6 A vocational nursing role that allows nurses to be trained while working in care settings, mentored by qualified nurses, should be explored by Skills for Care, the Department of Health, providers and other key stakeholders.

Commissioning and assessment

- 1 Consideration of the ‘what’ should be decoupled from the ‘where’ in the assessment and subsequent local commissioning of care services.
- 2 Local commissioners across health and social care should develop integrated commissioning models that are driven by outcomes rather than specify ‘how’ or indeed ‘where’ these outcomes are achieved.

- 3 Local commissioners should use their market shaping duties to encourage existing housing with care providers to deliver a shared vision of good practice, including good practice related to staff pay and conditions.
- 4 Local authorities must also encourage the widest possible range of housing options where care can be delivered on site.
- 5 Local authorities should ensure their duty to provide advice and guidance under the Care Act 2014 includes practical and emotional support for people and their families moving to housing with care.
- 6 The statutory right to a social care assessment should always include a consideration for technology enabled care services, appropriate to need.
- 7 Both health and local care commissioners must do more to ensure that people living in housing with care settings have access to primary care and other health services.

Providing housing with care

- 1 Housing with care providers, the government, local commissioners, regulators and the people using their services should work together to develop a shared vision for housing with care and do their part to achieve this.
- 2 The Government should sponsor grants for innovative redesigns, refurbishment and the implementation of enabling technology for care homes seeking to pioneer new approaches; as well as the launch of a design competition and a call for new designs and ideas in housing with care to stimulate innovation.
- 3 Care home providers should work with national government and local commissioners to investigate the possibility of the

aforementioned tenancy framework applicable for care home settings, as well as look into cooperative, mutual or profit-sharing ownership models.

Building housing with care

- 1 Local plans should be coproduced with care commissioners and those responsible for drafting local JSNAs.
- 2 Local plans must include an assessment of the population's future housing with care and retirement housing needs alongside an assessment of need for general accessible (disabled-friendly) housing.
- 3 Local planning authorities should reflect a preference in planning permission guidance set out in the local plans for colocated housing with care facilities, those embedded with the wider community, and innovative and diverse design.
- 4 The CIL should be reviewed to establish whether housing with care providers are disproportionately disadvantaged by this regime.
- 5 The use of planning incentives should be explored for providers willing to build housing with care which contributes to services for people funded by the local authority, and other related conditions linked to good practice in design.
- 6 There should be a change in planning-use classes to create a dedicated use class covering all housing with care.
- 7 The relaxed change of use measures introduced in 2013³ to help local authorities convert offices to housing should be extended to enable NHS, MoD and university land banks, and appropriate office buildings, to be converted into housing with care models more easily.

- 8 Over the longer term, all new housing should be to Lifetime Homes standards and at least 10 per cent of new housing should be built to fully wheelchair accessible standards.

Regulation, registration, inspection

- 1 CQC should conduct an annual survey of people using all housing with care services to run alongside the CQC's current surveys.
- 2 The CQC should also conduct an annual workforce survey to monitor staff engagement and instances of abuse and neglect.
- 3 Providers should be required to publish standardised feedback reports from their customers and their families on their website, alongside whistleblowing and complaints policies and data relating to complaints.
- 4 Several review sources should be consolidated on the CQC website.
- 5 Outcomes-based inspections should be carried out by the CQC in all housing with care settings.
- 6 The CQC's role should be expanded to the inspection of local authority commissioning practice.
- 7 The CQC should not be responsible for inspecting the homes of people living in housing with care settings, including care homes.
- 8 A single category covering all residential care should be used in CQC registration, called housing with care.
- 9 Building inspection for communal care settings (eg traditional care home models where all space outside one's bedroom, apartment or 'bedsit' is communal) should be increased to match the level seen in other communal establishments, such as hotels.

Funding

- 1 HMT should commission the Office for Budget Responsibility to conduct a five-yearly, 20-year projection of demand for care services.
- 2 Open book accounting and a fair funding formula should be implemented for the care provided in housing with care settings, and the cost of accommodation. This must be reviewed annually in line with inflation and changes to the minimum and living wages.
- 3 Housing with care providers should adopt the tripartite funding system, separating out rental charges, service charges and care fees and making these transparent.

The Commissioners began this yearlong investigation into the future of the housing with care sector with the view that housing with care has the capacity to change lives for the better, to help people gain independence and participate in community life where they might once have been isolated in their family homes, to provide the best form of support for people with complex needs and dementia, and to be a good place to die. The research undertaken and evidence gathered to support this Commission certainly demonstrates what good housing with care can achieve, what people want when they need support following frailty in old age, or a disability earlier in life, and what good care ‘looks like’ in specialist residential settings. We have also heard about the challenges the sector faces and the need for commissioners, regulators, the NHS and national governments to help overcome them.

Throughout this report we therefore want to create a powerful action plan for change – identifying what needs to be done and who needs to be responsible for these actions, with a view to inspiring a joint effort.

1 About the Commission on Residential Care

In July 2013, the Commission on Residential Care (CORC) was formed. Composed of a group of academics, experts and practitioners related to residential care – henceforth called ‘housing with care’ and chaired by the former Care Services Minister Paul Burstow MP, the Commission was tasked with exploring what the future of housing with care should be in the wake of the Care Act 2014 and the vision for care and support in the twenty-first century.

The Commission began with an understanding that social and demographic change would render housing with care all the more important in the future. It took its inspiration from the Wagner review – *Residential Care: A positive choice* (1988) – in that it wanted to shift the emphasis away from the view that housing with care is the ‘last resort’ and to value its role as a vital part of community care; and to recognise the importance of choice and participation by prospective residents in decisions about a move into housing with care.⁴ Twenty-five years after the Wagner review, it was felt that more was needed to make this position a reality.

The Commissioners are at one in the view that housing with care can have a vital, life-changing role in supporting a wide range of people, of all ages, as they maintain and regain independence, build social networks, and pursue activities and interests that might otherwise be out of their reach. They believe it can provide crucial, specialist support for people with dementia and good end-of-life care as our society ages and dementia becomes more prevalent. In the face of demographic change housing with care will be more in demand, not less, because of the rapid increase in the numbers of older people (and a more diverse older population), the growing prevalence of dementia and very old people with complex needs, and

medical advances allowing many more disabled people to live into adulthood and demand more independence over how and where they live. Providers of residential services have to make sure they are agile and responsive to the needs and expectations of future generations of disabled and older people. The legislative, regulatory and commissioning landscape in which the sector operates must facilitate this, however, and our wider societal response to housing with care must be challenged if we are to see the sector fulfil its vital role in our future care system.

The Commissioners are:

- Rt Hon Paul Burstow MP (Chair)
- Dr Chai Patel CBE, Chairman of HC-One
- Guy Geller, Senior Vice-President, Sunrise Senior Living
- Professor Julianne Meyer, Executive Director of *My Home Life*
- Des Kelly OBE, Executive Director, National Care Forum
- Simon Arnold, Managing Director, Tunstall Healthcare
- Richard Jones CBE, Area Director, NHS England
- Jane Ashcroft CBE, Chief Executive of Anchor
- Clare Pelham, Chief Executive, Leonard Cheshire Disability

At the Commission's first meeting, the Commissioners agreed that its terms of reference would be:

- to create a vision for housing with care in a twenty-first-century care system, not bound by existing definitions of 'residential care' or 'care home' but based on a new offer (or range of offers) of housing with care, broadly defined, which can deliver on the outcomes people want and value; this vision includes both older and working-age disabled people
- to set out how the existing housing with care offer (broadly defined) could change to deliver this vision, across financial, operational, governance and cultural aspects of care – drawing on existing good practice at home and abroad.

It is worth noting that the Commissioners chose to include older people and disabled people's care in their remit, as well as all forms of 'housing with care' – all care services delivered in specialist accommodation, including extra care, supported living, and so on.

Over the course of 12 months, the Commission has met five times to review the evidence gathered by Demos, which has acted as the Secretariat for the Commission, providing research support and hosting Commission meetings throughout 2013 and 2014.

Gathering evidence

This is the final report of the CORC, drawing on evidence gathered over the course of 12 months which was discussed, scrutinised and debated by the group in and between quarterly Commission meetings. The research and evidence gathered by Demos on behalf of the CORC included:

- a literature review of relevant English language research, think pieces and evaluations related to housing with care from 2008; around 40 substantial reports were identified and key messages collated
- a survey of 2,000 members of the public asking about what they might want from care and support when older or disabled at an earlier age, their perceptions and understanding of housing with care and other related terminology
- three focus groups with people in their 60s and 70s, representing the 'next generation' of people who might need care in the future, exploring what form future demand for housing with care will take
- three visits to different housing with care settings, where we spoke informally to people living and working there about their experiences of life in housing with care – the positive features and the scope for improvement
- four good practice case studies; the Demos team visited, observed and interviewed front line staff in four different

housing with care settings pioneering innovative approaches to care and support

- interviews with 18 experts across the care, health and housing fields about their vision of the future of housing with care
- two calls for evidence: one sent to specific organisations and one published and publicised widely by Demos to gather opinions from a range of different viewpoints, generating over 50 individual responses
- three international trips (to Boston in the US, Denmark and the Netherlands) by the Chair of the Commission to visit different housing with care services for disabled and older people

The next chapters present the findings of the research undertaken for the CORC, reflect on the evidence gathered, and draw conclusions (chapters 5 and 6) regarding what the Commission has identified must change to ensure the housing with care sector can play its central role in a future care system. In box 1 we define some of the key terms used in this report.

Box 1

Definition of terms

Housing with care is fraught by confusion between terminology and connotations associated with some terms. This report uses the following definitions:

Care home is a housing with care setting usually with communal living and dining areas, separate bedrooms, and care staff on site. People living in care homes might be older or disabled people. The CQC defines care homes as offering 'accommodation and personal care for people who may not be able to live independently. Some homes also offer care from qualified nurses or specialise in caring for particular groups such as younger adults with learning disabilities.' Unless stated, this report will use 'care home' to refer to both residential care home and nursing homes.

CCGs – clinical commissioning groups, whose function is to commission health services in their local area.

Commissioning – includes local care commissioning and health commissioning, with the sub-type specified in the

text as required. Commissioning is the process by which commissioners – for social care, the local authority and for health services, the CCG – assess local needs and plan and secure services to meet those needs. In social care this has increasingly been undertaken with personal budgets in mind, ensuring there is an affordable and diverse range of good quality services in an area for people to use, armed with their personal budgets.

Extra care – describes a range of settings where people have their own apartments, set around communal living and dining areas and other on-site leisure or health facilities. These are often in ‘village’-style layouts but can also be more widely dispersed within neighbourhoods.

Housing with care – the definition this report proposes to replace the general (but frequently misused) term ‘residential care’ to refer to all specialist housing settings where health and social care is delivered on site, either round the clock or for part of the day.

Residential care – all care delivered in specialist accommodation. While commonly used interchangeably with ‘care home’, the CORC is employing its proper and broader definition. Residential care therefore includes not only residential care and nursing homes, but also extra care and care village settings, as well as supported living.

Supporting living – describes apartments lived in individually or by small groups of people where care is provided on site – this might be round-the-clock support, or for part of the day.

Other work

The Commission is not carrying out this work in a vacuum. The King’s Fund is currently finalising its important Commission on the Future of Health and Social Care in England, chaired by Kate Barker CBE. Its remit is to explore the following questions:

- Does the boundary between health and social care need to be redrawn? If so, where and how? What other ways of

defining health and social care needs could be more relevant or useful?

- Should the entitlements and criteria used to decide who can access health and care be aligned? If so, who should be entitled to what and on what grounds?
- Should health and social care funding be brought together? If so, at what level (local or national) and in what ways? What is the balance between the individual and the state in funding services?

The final report, due in September 2014, is therefore likely to provide vital context to the Commission on Residential Care, exploring as it does questions which are central to the continued sustainability and healthy growth of the housing with care sector.

In Wales, the Review into the Quality of Life and Care of Older People Living in Residential Care in Wales will also publish its recommendations in September 2014. The Commissioner for Older People will investigate the extent to which services safeguard and promote the interests of older people living in residential care settings in Wales, assessing local authorities, health boards, residential care providers, care and social services, councils and the Welsh Government. In announcing the review, the Commissioner indicated her concerns about the quality and perceptions of existing services, linked to ‘unacceptable variations’ and how the label ‘residential care’ ‘does not adequately reflect the fact that it is someone’s home’.⁵ The review will highlight the best of care, and the recommendations will be binding to regulated services in Wales, with follow-up responses and actions subject to a legal timeline and reporting requirements.⁶

The implications of this review are highly relevant to the Commission on Residential Care, potentially raising many of the same issues that we do in the next chapters regarding the terminology used and perceptions about the sector. The fact it will be binding to regulated services is also very interesting, and the Commission looks forward to seeing whether, following the review, Wales will become more progressive in its provision and treatment of housing with care than their English counterparts,

and whether the Welsh inspectorate, Care and Social Services Inspectorate Wales (CSSIW), will pioneer a more coherent approach to housing with care.

A note on regional variation

Health and care services vary significantly between England, Scotland, Wales and Northern Ireland. Many of the challenges facing housing with care – funding pressures, demographic change, negative public perceptions and other issues we highlight in chapter 4 – are broadly similar across the four nations. However, how these can be overcome with changes to local structures of provision, commissioning, planning and inspection vary widely. In this regard, this report has primary application in England. Nonetheless, the Commission hopes that many of the principles of good practice and evidence presented below will inspire housing with care providers across the UK. We also hope that the recommendations made with English commissioners, inspectors and regulators in mind will be of interest and value to their counterparts in the four nations, all of whom are facing similar challenges in ensuring housing with care can fulfil its potential in a twenty-first-century care system.

2 What housing with care can achieve

The Commission sets out from the position that housing with care not only has an essential place in a modern health and care system, but that delivering care in a residential setting has unique advantages over other forms of care for some people, enabling them to lead lives that are not just better supported, but also more fulfilling and engaged. In some cases, it can also offer better value for money than attempting to offer people 24-hour support in private homes and is an important growth area for the economy.

During the course of the Commission, Demos researchers spoke to people living and working in housing with care settings up and down the country, as well as members of the public – many of whom had friends or relatives living in housing with care. We heard many stories of people's lives being transformed for the better when they moved into housing with care from living at home, where they were often alone and struggling to cope. This chapter considers some of the ways in which housing with care can change lives.

A positive place to be

The people we spoke to – disabled and older people – were quick to talk positively about their quality of life in housing with care. Some of the things that they particularly valued are discussed below.

Friendship and companionship

One of the most frequently cited pleasures of life in housing with care, particularly by people who had previously been isolated at home and whose only human contact had been short daily

domiciliary care visits, was being around other people – both staff and other people living there – and developing close friendships with them. Almost everyone we spoke to felt close to many of the staff, describing them as welcoming, friendly, supportive, polite, competent, easy to speak to and patient.

People also mentioned that they had made friends since moving into housing with care – within the home and through being part of wider networks (eg a church). Where people had made friends within the home, they liked being able to spend a lot of time with their friends because they were close by. Some of these friendships were deep and enduring – two women the research team met in one scheme had previously lived together in another home, and had chosen to move to the same place so that they could continue living together. Several of the people we spoke to said they did not have friends or family outside the home – and others did not have friends or family living nearby – so living in a residential environment helped them to have a more developed social life.

When such relationships are facilitated in the care sector this is often described as ‘relationship-centred care’ – an approach that values relationships between people living in housing with care, their relatives and staff working there, and recognises the importance of partnership working between care homes, their local community and the wider health and social care system. Relationship-centred care is actively facilitated and encouraged through helping people to feel a sense of security, belonging, continuity, purpose, achievement and significance (box 2).⁷ Opportunities for relationship-centred care can be greater in residential settings than in private housing, where individuals usually live alone, may be isolated and rely on brief care visits.

Box 2

Winnie’s story

Winnie⁸ is 98 and lives in a nursing home in the West Midlands. Her husband died when she was a young woman during the Second World War, and although one of her daughters lives close by, prior to moving to housing with care,

she had been living alone for several years, and was feeling increasingly isolated. Determined not to let her life pass her by, Winnie set out to make some positive changes that would help her meet new people, try new things and feel part of a community again.

Since arriving in her new home three years ago, she has been able to do all of these things. She has lived a long and exciting life, and is happy to have found new people to share her stories with. Winnie was particularly glad to be able to bring one friend with her – her cat Toffee, which she rescued a few years previously and had been her only companion during the years she spent living alone. Special adjustments were made to her rooms, so that Toffee could continue to live with her.

Source: Sunrise case study

Having an active and engaged life

The people we spoke to told us they had opportunities to do things once they were living in housing with care that they might not have previously been able to do – such as go on holiday, get together to celebrate festive occasions, and access services and amenities on site.

Staff in the housing with care settings we visited made particular efforts to develop a range of experiences with people living there – for example, by re-creating a pop-up tea shop and pub, and opening a small beauty salon – and this was appreciated and enjoyed. People also spoke about occasions and celebrations that they were looking forward to, such as celebrating Halloween together. Staff had organised a surprise Chinese-themed dinner party for one lady's birthday, decorating a room with Chinese lanterns and ordering Chinese take-away – her favourite food. The opportunity to mark occasions like this as a group is something that may not be possible for some people living alone.

It is also easier within a housing with care setting to organise group trips and outings, usually with the support of a care worker. People at one scheme for adults with physical disabilities we visited had recently been on holiday together to the seaside, and individuals had also been able to visit family and

attend reunions and social events. In this case, spending time away from home was facilitated by the key worker model, whereby a person's key worker could travel with them on overnight visits.

People in housing with care can often access better facilities than is possible for people with care and support needs who live in private housing, such as specialist equipment and assistive technology, and amenities unrelated to care needs. For instance, one facility for adults with neurological conditions offered a computer suite with internet access, Kindles and Nintendo Wii games – a volunteer had even designed a special holder for people who had limited movement and could not move the Wii controller around. Since 2013, Anchor has provided iPads to older people living in all of their care homes. Staff use the tablets to communicate with the people they support, including people with dementia, to help tailor activities, capture life experiences, and help people stay connected with current affairs, family and friends.⁹

Again, those we spoke to compared having these experiences with life before moving to housing with care, which had often involved isolation and lack of activities and opportunities to engage in hobbies and interests. This might be due to a combination of their support needs making travel (or indeed leaving the house) unsupported difficult, lack of accessible facilities nearby, and not having friends or family nearby.

Box 3

Springfield

Leonard Cheshire's Springfield scheme provides reablement support to adults with physical disabilities, supporting them to develop and regain the skills needed for independent living. The service showcases an alternative model of residential care – people at Springfield live in self-contained flats and are supported by staff to perform daily living tasks such as cooking, cleaning and washing.

Emma¹⁰ describes how such housing with care settings can help people gain independence, confidence, and an active social life:

We are a community here but we don't live in each other's pockets. So while we do things like host barbeques together we don't have to do the same thing all the time. I like that we don't have group activities unless we choose to organise them.

I lived on my own before moving here. My flat wasn't accessible and I was frightened to go out because the area I lived in wasn't very nice. My flat felt more like a cage than a home.

Since moving to Springfield I've realised that people aren't all bad and I am much more confident about myself. I know people are here to help me if I need it but if I want to go I can go out alone. I talk to people in the library and market, which I wouldn't have felt confident enough to do before.

I like that there is a variety of people around to support me and they all have different skills. I have learnt how to direct the people who support me better. I know that people care what happens to me now and that means I care more about myself. I like going to the hairdresser and straightening my hair, which I never did before.

Since moving here I've joined Weight Watchers and learnt how to cook healthy meals. As a result I've lost 4 stone. I couldn't get into my kitchen before so I used to have frozen meals delivered – I had never learnt to cook a meal from scratch.

As well as learning how to cook, staff have supported me to learn about good portion sizes and shopping for food. I have the confidence to ask for help in the shop if I don't know where something is. I also have support to do my physio exercises even though I don't like doing them – before I came here I wasn't walking.

Now I'm more confident about myself I have joined lots of adult education classes including archery, basic maths, cartooning, sign language and photography. I would never have done this before. Eventually I want to do a child care course and I have been trying to find volunteering opportunities in schools to get me started.

Living here has helped me realise I can do things I thought I couldn't before. When I move into my own place I will be able to use the person-centred techniques I have learnt here to help me

think about what is working and what isn't. The fact that I feel confident to think about the future again is a massive step for me.

A sense of empowerment to live one's life

Staff being on hand in housing with care can give people living in these settings a lot more control over their lives than they would have on their own, or even with home carers visiting them. Housing with care – being adapted, accessible and with support staff available to enable people to carry out everyday tasks, pursue hobbies or go out – can provide opportunities to people living in housing with care that they would not have elsewhere, as we have seen in the previous section. The Springfield example in box 3 describes some outstanding facilities for disabled people that are specifically designed to help people gain life skills and prepare them for independent living. However, the housing with care sector is diverse – with different styles of housing, locations, prevailing organisational cultures and so on – which offers people needing support the ability to choose their homes and lifestyle according to their individual needs and preferences. We return to how the sector needs to continue to diversify and cater to an ever-wider range of preferences in chapter 6.

Regardless of which housing with care setting is chosen, the widespread implementation of person-centred support across the sector has ensured that people have greater choice and control over their care and day-to-day life and more opportunities to gain or regain independence. Those we spoke to were overwhelmingly positive about staff, saying they tried to solve problems with them and acted as enablers. One woman even said that the reason she had no complaints about the place where she was living was because they had all already been dealt with! A 'try anything' attitude among staff could not only fix problems when they arose, but could also help people take on significant challenges, as the case study in box 4 illustrates.

Box 4

Christina

Christina's case shows how housing with care can provide more opportunities to develop the interests of people with more complex needs.

Christina¹¹ has locked-in syndrome and has been living in a nursing home for people with neurological conditions for the past seven years. She had previously been living at home with a round-the-clock care package; when this collapsed she moved into housing with care, where she had slowly been able to regain her independence: 'I love it here because with a lot of love and patience, they fixed me back to how I was.'

Recently, Christina decided that she wanted to do something mentally challenging, and the home has stepped up to provide her with an IT volunteer and the assistive technology needed to help her study for a degree in sociology online. Christina told us, 'I really like doing my own thing, and they [the staff] all think I am mad' – but they still try everything they can to help her put her plans into action.

Source: Demos interview

As we have seen, housing with care has a unique communal offer that enables people to have better quality lives – by nurturing new friendships with staff and others living there, by organising group activities and festivities, and by helping people to pursue their individual interests and implement plans – related to education, interests and regaining independence – that they might struggle to do on their own. It is easy to take for granted some things, such as having the opportunity to observe occasions such as birthdays, Christmas and other holidays, or to take control of one's environment, which for some people may be extremely challenging.

A move to some form of housing with care can be extremely positive for people whose support needs or environment leads to isolation and inactivity, in particular. Census data show that around 31 per cent of over-65s were living

alone in 2011;¹² although not all of these people feel isolated, and many lead busy social lives outside their homes, there are some older people for whom physical isolation is a particular problem. Research by Age UK found that 6 per cent of older people (around 600,000) leave their house less than once a week.¹³

Isolation can be no less acute for disabled adults. A survey of disabled people by the Office for Disability Issues found that 12 per cent of disabled adults found it difficult to move about within their home, or get in and out of the house, compared with just 1 per cent of able-bodied adults.¹⁴ Many find that having home care in one's private property gives them a sense of independence and autonomy – this is to be expected. However, there are some for whom home care can be isolating, even oppressive, if they are unable to leave their home. It can be frustrating, boring and lonely for older people and disabled people alike to be on their own for most of the time even if they have a number of care visits through the day. Housing with care – providing an opportunity to pursue one's own interests, hobbies or life goals, with staff support and accessible surroundings, combined with being able to live with one's peers and engage in social activity – can (despite common perceptions) therefore enable people to regain independence and take part in community life (box 5).

Box 5

Rachel

Rachel's story shows how housing with care can combat isolation and provide a more holistic and enabling support structure than domiciliary care.

Rachael¹⁵ is in her early 50s living with multiple sclerosis, and was finding it increasingly difficult to care for herself at home. Although she was living in a ground floor flat access was difficult. She had to go through a number of heavy doors to get to her entrance and couldn't manoeuvre her wheelchair and the doors on her own. She receive home help twice a day but it wasn't enough and she admits it was tough and lonely getting by.

Rachael's social worker put her in touch with a home for people with physical disabilities and so she went to have a look around. Rachael remembers:

It was difficult living at home. When I came here to have a look I fell in love with it. Coming here you get all the help you need. I am not in one room, I have a whole house, I can go out and socialise when I want. Once, when I was at home I had gone out but almost fell out of my wheelchair when I hit a curb. Now I have a carer who can go with me when I want, which makes me feel safer and more confident.

It's brilliant having the chance to socialise again. Living at home, I couldn't go to church as there was no one to take me. But now I am able to go every Sunday and the church service comes into the centre each Wednesday. I have been welcomed by my new church with open arms and I now feel like part of the community again.

I can live how I want here. I am an early starter and like getting out of bed at 6am every day. When I wake up I want to get up. I can't do it myself. The staff make it possible for me to do it. I still have a choice and have more independence. I like having chocolate Weetabix for breakfast. At 9.30am every morning there are different activities, which change each week. I like art and scrabble. I enjoy going in the pool and get a chance to go in every 2-3 weeks.

The physiotherapy is great. The MS often makes my legs spasm. The physiotherapy on the bed and the bike relax my legs and reduces the spasms, making me much more comfortable.

The personal care here is more dignified than it was living at home. I don't have to wait for a carer or for someone to come and help; it's planned around my needs and I'm in control. I see the same staff every day, which is great as I can build a friendship with them.

Living here has made it easier for me to keep in touch with my family. The carers help me to phone my Dad and Skype my daughter and granddaughter every week. I couldn't do this before because my tremors were so bad I couldn't hold the phone on my

own. My family enjoy coming to see me and we can have quality time; the door is always open here.

My grandson was born recently. When I found out, the carer took me to the shops to get a card so I had it ready for when they came to visit. If I had been at home I wouldn't have been able to do this. It means a lot to my family as well to see me being able to hand over a card and a present; it means I have my own independence.

Rachael is part of the residents' group, which feeds back to the care centre manager suggestions on how to develop the service, and interviews candidates as part of the centre's recruitment process. She was a nurse and likes to be involved in the running of the centre so she can have a say about who is supporting her. Rachael says:

I like being part of the group. Every meeting I am more and more relaxed and confident about speaking. I like going out for a drink with my friends to the pub or shopping. Every Friday I now go into my friend's house within the home and the four of us hang out. I like being social and it's good to have a social life. My home town isn't far away. My local friends can come and visit any time they want and get a tea and coffee. There are kettles in the sitting room so I can make my own tea and coffee if I want to.

I try to think positively. I love the fact that I have more independence now and feel part of the community.

Source: Sue Ryder

Meeting needs

Realistically, needing to live in housing with care and wanting to live there will not always coincide. There is a range of health and care needs that can be addressed better with housing with care than domiciliary care – such as supporting people with dementia, multiple and complex needs; people in need of intensive support, including rehabilitative care for people discharged from hospital but not yet ready to go home or people needing help with life skills before living alone; and people

approaching the end of life. For example, estimates suggest that up to 80 per cent of people in care homes have some form of dementia, while according to the Centre for Policy on Ageing, 50 per cent of people living in care homes live there for less than 19 months. Since 2001, the length of stay has been in decline, and on current trajectories it will be one year for people with dementia, and nine months for frail elderly by 2015.¹⁶ These figures suggest that a lot of older people are entering housing with care when they are frail and potentially terminally ill,¹⁷ and so require staff to have greater medical expertise.

These people might need rather than prefer to move to housing with care – recognising that their support needs cannot be met adequately outside a specialist setting. Indeed, only one person to whom Demos researchers spoke at three residential care and nursing homes had actively chosen to move into housing with care – with his wife – in order to be closer to their son. Recognising that neither of them was as fit and able as they used to be, they had opted for a care home rather than buying a new house.

Others Demos spoke to said that the ‘push’ factors prompting the move had been stronger than the ‘pull’ factors; rather than seeking out housing with care, they had moved to housing with care reluctantly (though subsequently they were happy with the move). The same tendency to be reluctant to accept the prospect of housing with care in times of need was evident in the public polling results carried out for the Commission. Demos asked all those who had said they would consider a care home for themselves in later life why that was the case, and provided an equal number of positive and negative multiple choice options.

The reasons for considering a care home in later life are listed below, in order of popularity:

- ‘So I had carers on hand to help manage my health and keep me safe’ (63 per cent)
- ‘Because I wouldn’t want to be a burden on my family’ (60 per cent)

- ‘Because I wouldn’t be able to support myself at home’ (51 per cent)
- ‘So I would not have to worry about maintaining my home’ (39 per cent)
- ‘So I had the support to stay active and pursue my interests’ (30 per cent)
- ‘Because there would be no one at home to look after me’ (30 per cent)
- ‘So I had company/could form social networks’ (26 per cent)
- ‘I would be worried about my personal security in my own home (eg crime)’ (22 per cent)

Looking at these results, negative reasons tend to be given higher priority when making a decision to move to housing with care than positive ones – and where people are being drawn to housing with care it tends to be by considerations about the level of care they need, or practical concerns about upkeep of a property, rather than by considerations about their quality of life. Pursuing activities and gaining access to social networks were relatively low considerations in the priority list, selected by 30 per cent and 26 per cent of the public respectively. This suggests that the public believes the primary purpose of housing with care is to be a place of care and safety rather than a place for activity, interests and social networks.

Bradshaw and colleagues’ 2013 meta-analysis of 31 studies of quality of life in housing with care,¹⁸ and many of the organisations and individuals who gave evidence to the Commission, have suggested that the attitude with which people enter housing with care can make a big difference to their longer-term experiences and outcomes. Entering care reluctantly – or in distress or fearfully – is linked to poorer outcomes as the trauma of the move can be linked to withdrawal and depression.

This is one reason why life in housing with care needs to be more widely understood, and to have greater visibility in communities, so that the move can be a positive choice, engaged with in the same way as any other housing move, rather than as a moment of loss and anguish. In our focus groups it was clear that those who had originally entered housing with care

reluctantly, and for reasons of needing support, had subsequently been happy with the move – they had made new friends, had the opportunity to rediscover old hobbies or interests, and could relax without worrying about maintaining their property.

People with more complex needs clearly experienced more comprehensive support and were more comfortable, while some of the people Demos spoke to – particularly disabled adults who had previously been living with family – said they were receiving much better care since moving into a residential setting than they had in the past, and were less worried about being a burden to their relatives. If these people had had the opportunity to know what their life was going to be like before they moved in, the move to housing with care might not have been as worrying for them as it had in practice been, nor might they have put it off for as long. A challenge for housing with care settings where people move in who are very frail – perhaps needing palliative care, or with advanced dementia – is that staff have not had an opportunity to build relationships with them nor fully understand their individual preferences, and may not be able to find out what they are if the newcomer cannot explain them.

The economic case for housing with care

When people are receiving a lot of community care, people coming in to dress them, to give them breakfast... lunch [etc.], it is as expensive – it can be – as residential care, but that is not always recognised. The powers that be think that if you keep people out of residential it's cheaper, and also because they don't want it. It's this perverse thing – people don't want it, so you don't fund it, so it's more expensive.

Dame Gillian Wagner – chair, Residential Forum

Housing with care might offer a new opportunity for friendship, independence and activity, and better value for money (for both local commissioners and self funders) if a person has complex support needs.

The Department of Health's decision in 2009 to promote domiciliary care over housing with care was largely based on

comparisons of the costs of caring for people with very different levels of need.¹⁹ Figures from the Health and Social Care Information Centre reported that in 2013/14 the average cost per week of housing with care for an older person was £528, while the cost of home care was £214 per person.²⁰

However, these figures are misleading as there are several inconsistencies in the way they were calculated. First, the weekly cost of home care obviously depends on the number of hours of support required, which is lower for those who only need a low level of support. For people needing a comparable level of care at home as they would receive in housing with care, the general view is that housing with care offers better value for money. A recent study by Four Seasons Health Care found that a person with more complex nursing needs living in private housing and requiring more than two hours of home care a day could cost local authorities more than a full-time place in a housing with care setting.²¹

The charity Alzheimer's Disease International has claimed that estimates of the cost of domiciliary care ignore the value of unpaid, informal care that people living at home may receive from neighbours and family members.²² The charity noted that the cost of housing with care is higher because it includes the cost of accommodation, not just care; the costs are therefore not comparable.

Those funding the costs of their own care usually find themselves paying more than the local authority rate for domiciliary care and housing with care. The Money Advice Service estimates that a stay in a residential care-home costs £28,000 per year (or £37,500 in a nursing home), while home care costs £30,000 per year for full-time day care. People requiring 24-hour care in their private homes can face costs of as much as £150,000 per year.²³

As the housing with care population changes and ages, other European countries have begun to change their policy around care delivered in people's private housing. For example, the manager of one care home in Copenhagen which the Chair of this Commission visited told us that there is a growing recognition in Denmark that keeping people out of housing with

care can cost more and deliver poorer outcomes. As a result, policy and assessment processes are changing so that people are admitted to housing with care earlier as a positive and proactive move.

However, the economic case for housing with care is not simply about potential cost efficiency when compared with domiciliary care packages. Housing with care is an essential part of the UK's economic infrastructure – it is a growth employment sector (the workforce grew by 15 per cent between 2009 and 2012, while estimates suggest it will grow by between 20 per cent and 60 per cent in the next 20 years²⁴) and source of regeneration for local communities – where a housing with care development is built, it generates employment for a range of industries, can reinvigorate declining town centres and provide stimulus to local housing markets where older people downsize into housing with care. It supports families juggling work and caring responsibilities, offering temporary and permanent substitute care. It also occupies a vital place in the continuum of care, ensuring people whose needs cannot be supported by domiciliary care do not end up unnecessarily in highly expensive hospital-based settings.

Most of these economic benefits are overlooked; there are reports that local planning authorities are often cautious in giving planning permission to new housing with care developments for fear of 'importing' large numbers of older or disabled people into a community and overburdening local services. These fears have been proven to be unfounded. Good housing with care often acts as a preventative service, and there are fewer instances of hospitalisation and accidents such as falls than among those living in private housing. Many people living in these settings maintain an active life, including visiting and spending their money in local shops and facilities.

Conclusion

There are countless stories of people living less restricted, more connected and more enjoyable lives after moving into housing with care – and it is important that these are heard. Housing

with care can have a transformative impact on those who need significant support to manage things like dressing, washing, going to the toilet, cooking, eating and moving around in their existing home. Given its ability to provide round-the-clock support to a group of people who would otherwise be supported potentially in isolation, it can also be a more resource-effective way of meeting high and complex needs while creating opportunities for building friendships and community.

Yet the value of housing with care has not always been recognised by the public or those commissioning decisions. Many disabled and older people feel desperately unhappy at the thought of ‘moving into a home’, and assessment and commissioning have adjusted accordingly to keep people ‘in their own homes’ for as long as possible. We are currently a far cry from being able to reap the full benefits of housing with care which would come by using it as a proactive choice for people whose needs and preferences best suit it, rather than as a last resort and forced, often traumatic experience.

At its best, housing with care is not only a way of ensuring that people’s health and care needs are being met appropriately, but can also be a big step closer to allowing them to lead the kind of life that they want. It is however vital that the housing with care sector can deliver the outcomes people want and value in order to claim its rightful place in a future care system. In the next chapter, we use our research and the substantial existing body of evidence to explore what these outcomes are for people who are older and frailer, or living with a disability.

Summary

In this chapter we have explored the ways in which housing with care can support disabled and older people to achieve the outcomes they value. Everyone’s lifestyle preferences are different, but through case studies and individual’s own stories, this chapter has identified some common themes which can make housing with care a life-changing experience for people who live there.

These include:

- the opportunity to develop friendship and meaningful relationships; this is particularly of value to people who had been receiving care in isolation in their private homes and without the ability to leave
- the ability to be more active and engaged and to pursue one's interests and goals individually and in groups of peers and friends
- gaining or regaining independence and a greater sense of control and empowerment over one's life and decisions, including for disabled people the opportunity to learn life skills and make the prospect of living independently a reality
- catering to support needs, including more complex needs and dementia, where domiciliary care is either not practical or affordable, or does not achieve the outcomes people want in life

The chapter then discussed the economic case for housing with care and its cost effectiveness, particularly for people who need more significant levels of support; it reflected on how housing with care is a growth area and can have important regenerative benefits for local communities, and generate savings to health services and housing.

3 What do people want from housing with care?

A truly person-centred approach to care places the things that matter to people front and centre in designing care services. The Commission wanted to adopt a similar approach in developing its vision of a modern housing with care system, which is why the first stage of research Demos was tasked with was to review the existing evidence on this issue and to ask people directly what they would expect from housing with care if they needed support because of old age or disability.

Demos purposely did not ask people directly what kind of housing with care they would like to live in, as they wanted to encourage people to think outside the constraints of what they would expect to be able to achieve within housing with care, and instead talk about the outcomes that would be important to them, not qualified by the location in which they would be living.

Because people's priorities are different depending on whether they imagine themselves needing support earlier in life because of disability, or when they are older, Demos asked people to picture themselves separately in each of these two hypothetical situations. Our survey of 2050 people aged 18 and above allowed us to compare and contrast the preferences of different ages and generations.

What do people want in later life?

Demos first asked people to select the three things that would be most important to them if they found themselves needing support in later life, from a list of 11 options. The percentage of top-three answers was aggregated:

- remaining independent (62 per cent)

- being close to family (46 per cent)
- living somewhere safe/easy to maintain (40 per cent)
- being able to pursue my hobbies/interests (29 per cent)
- having home comforts around me (29 per cent)
- being connected to wider world (20 per cent)
- being able to keep in contact with friends/networks (14 per cent)
- being able to work as much as I can (13 per cent)
- having carers/medical professionals nearby (13 per cent)
- having someone on hand to look after me (9 per cent)

Overall, remaining independent in old age was listed as a top-three priority for around two-thirds of people (62 per cent). The next most important factors for people looking ahead to their old age were being close to their family and living somewhere safe and easy to maintain. Having care and support, or personal assistance, were much lower priorities – people were more likely to say that they wanted to be able to continue working than that they wanted somebody to help look after them.

This may reflect people downplaying their need for care and support in their later years, or suggest that even when people imagine themselves in a situation where they will need a little more help in life, other factors are still more important to them – like staying active and connected. It also strengthens the message about independence – people prefer not to have to rely on others for help, opting instead to live in an environment where they can cope on their own (40 per cent of respondents said that living somewhere safe and easy to maintain would be important – the third highest priority).

Demos carried out further focus group research with people in their 60s and 70s – potentially the next generation of older people moving in to housing with care – asking them what they wanted to be able to do as they grew older, wherever they were living.

The people we spoke to were realistic about the changes that would come with ageing – declining physical health, possibly accompanied by dementia, leading to reduced activity.

Participants spoke about wanting safety in old age and this was considered to place legitimate limits on what activities they could or could not carry out – in any environment. For the most part, people accepted that some of the restrictions placed on people in care homes were necessary for their own safety, but beyond these necessary restrictions, people desired ‘as much choice as possible’ over their lives, including what they did, who they spent time with and when. People wanted:

- their own rhythms and routines – particularly a choice over what to do in the evening, and not being forced to go to bed before they were ready
- to maintain their social networks – including with family, friends and former neighbours
- to feel that they belonged to a community of people who shared their tastes and interests (either by maintaining existing friendships, or by being surrounded by people of a similar mindset to themselves); one woman spoke about her friend – an artist and art-lover – who had recently moved into a care home, and was bored by all the people around her, with whom she felt she had nothing in common and nothing to talk about
- plenty of leisure activities inside and outside the building – museums, theatres, concerts, football matches, art classes, gardening, dancing, swimming and quizzes were all mentioned as things that people would enjoy
- freedom of movement – to continue to travel, including taking holidays abroad, and to continue to own a car and drive for as long as possible
- to be surrounded by familiar things (furniture and possessions); to be able to have pets living with them, if they chose – particularly dogs and cats, which were seen as ‘part of the family’
- access to a computer and the internet, especially for keeping in touch with friends and family – a lot of people in the groups brought out their smart phones to demonstrate that they were accustomed to feeling ‘connected’
- to keep control of their money
- to have help with some things as they become less able to manage on their own (eg housework, cooking, personal care)

- to retain their dignity; participants felt that even if they had severe dementia and were not aware of their surroundings, this would still be important, while all of the criteria mentioned above would become largely irrelevant

By and large, people imagine themselves wanting the same kinds of things in old age that they have enjoyed all their lives – the opportunity to explore and discover new things, a sense of belonging, good relationships with friends and family, not feeling restricted in what they can do, and plenty of opportunities to enjoy the things that give them pleasure. Only the final two features point to a recognition that their lifestyle would need to change and adapt to the inevitable process of ageing – the desire for dignity when this is no longer in their hands, and help with some of the activities of daily living.

These findings resonate with much of the existing research on this subject. The Joseph Rowntree Foundation has brought together a significant body of research looking at older people's vision of a good life. In 2009, Bowers et al found that older people with high support needs living in different settings (including residential and extra care) consistently identified the following points as key to a good quality of life:

- people knowing and caring about you
- the importance of belonging, relationships and links with your local or chosen communities
- being able to contribute (to family, social, community and communal life) and being valued for what you do
- being treated as an equal and as an adult
- staff having respect for your routines and commitments
- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with
- having and retaining your own sense of self and personal identity – including being able to express your views and feelings²⁵

They translated these into six interlinked 'keys to a good life' – personal identity and self-esteem, meaningful relation-

Figure 1 **Comparison of three studies on what older people want**²⁷

Bower's Keys to a Good Life	Williamson's quality of life indicators	Our framework
<i>Older care residents</i>	<i>People with a dementia diagnosis</i>	<i>Older (and some younger) people with high support needs</i>
Personal identity and self-esteem	Relationships or someone to talk to	Personal relationships Good relationships with carers
Meaningful relationships	Environment	Social interaction
Personal control and autonomy	Physical health	Making a contribution
Home and personal surroundings	Sense of humour	Cultural activities
Meaningful daily and community life	Independence	Self-determination
Personalised support and care	Ability and opportunity	Continuity and adjusting to change
	Sense of personal identity	Humour and pleasure
	Ability and opportunity to engage in activities	Sense of self
	Ability to practise faith or religion	Mental health
	Experience of stigma	Safety and security
		Good environment
		Physical health
		Physical activities
		Getting out and about

Source: Katz et al²⁸

ships, personal control and autonomy, home and personal surroundings, meaningful daily and community life, and personalised support and care. 'Personal' and 'meaningful' could be considered to be the cohering themes in this list, and indeed of many other reviews of quality of life among older people.

In 2011, in *A Better Life* Katz et al compared three reviews of what older people want, highlighting similar themes emerging across the three studies (figure 1).²⁶ The findings from our focus group discussions with people aged 60+ shows that these findings also clustered around similar themes, with a particularly strong emphasis on personal control and autonomy (figure 2).

Obviously, there is some overlap between the themes – wanting to live around people with similar interests represents a desire for meaningful relationships and meaningful daily and community life (and potentially also personal identity). The different features highlighted in the Williamson and Katz lists – and our own – illustrate the different routes to achieving the ‘keys’, and the different emphasis placed on them by different groups of older people.

A cohering theme through this evidence base, and the findings of Demos’ work, is the importance of relationships between people living in housing with care, and between them and the staff working in residential settings. Relationship-centred care is a natural extension of person-centred care; it recognises that people do not often, and do not like to, function as entirely independent individuals. While choice and control, personal autonomy and dignity are vital to quality of life, so too is the quality of the interactions individuals have with one another, friends, families and support staff. This is particularly important in residential settings, where people live close together and share communal space, and was identified in 2007 in *Quality of Life in Care Homes: A review of the literature*.²⁹ Since then the organisation My Home Life (founded by National Care Forum and now endorsed by the Relatives & Residents Association and all national provider organisations representing care homes across the UK;³⁰ www.myhomelife.org.uk) has developed substantially and is now hosted by City University in partnership with Age UK. My Home Life’s evidence base for quality of life in care homes is synthesised into eight themes, underpinned by relationship-centred care (figure 3).

This was developed into a vision for home care improvement, with a substantial programme of work underpinning it. It

Figure 2 **Things that are important for people aged 60+ not living in housing with care (Demos focus group)**

Browsers Key to a Good Life	Demos focus group
Personal control and autonomy	Own rhythms and routines – choice over what to do and when Freedom of movement – continuing to travel and to own and drive a car Ability to manage own money
Meaningful relationships	Maintaining social networks Being connected through technology and the internet
Meaningful daily and community life	Belonging to a community of people with similar tastes and interests A range of leisure activities, within and outside the house To be surrounded by familiar things and pets
Personalised support and care	To have help with some aspects of daily living
Personal identity and self esteem	Dignity
Source: Demos focus groups	

has now evolved into a partnership programme across the UK with recommendations and resources to help providers and commissioners help turn the *My Home Life* vision into care-home practice. For instance, in England, the MHL Leadership Support and Community Development programme has been delivered in twenty-three local authorities and Essex County Council has embedded *My Home Life* principles into its local commissioning, with the overarching question: How can local authority commissioners work with the care-home sector to ensure older people consistently receive high-quality,

Figure 3 **The eight personalisation themes linked to quality of life identified by My Home Life**

The best practices that seek to personalise and individualise care – tailoring care to each individual to ensure quality of life:

- 1 Maintaining identity: working creatively with residents to maintain their sense of personal identity and engage in meaningful activity.
- 2 Sharing decision-making: facilitating informed risk taking and the involvement of residents, relatives and staff in shared decision-making in all aspects of home life.
- 3 Creating community: optimising relationships between and across staff, residents, family, friends and the wider local community. Encouraging a sense of security, continuity, belonging, purpose, achievement and significance for all.

Navigation themes (linked to quality of care), supporting people as they navigate their way through the journey of care:

- 4 Managing transitions: supporting people both to manage the loss and upheaval associated with going into a home and to move forward.
- 5 Improving health and healthcare: ensuring adequate access to healthcare services and promoting health to optimise resident quality of life.
- 6 Supporting good end of life: valuing the 'living' and 'dying' in care homes and helping residents to prepare for a 'good death' with the support of their families.

Transformation themes (linked to quality of management), concerned with the leadership and management required to transform care into best practice to better meet the changing needs of residents:

- 7 Keeping workforce fit for purpose: identifying and meeting ever-changing training needs within the care-home workforce.
- 8 Promoting a positive culture: developing leadership, management and expertise to deliver a culture of care where care homes are seen as a positive option.

relationship-centred care?³¹ Like other local authorities (eg Southwark), it has based its care-home strategy on that of My Home Life, developed its own My Home Life community website (www.mhlec.org/) and successfully piloted a community visiting scheme in care homes.³²

In Wales, *My Home Life* has been supported by the Welsh Assembly Government for five years.³³ In Scotland, the *My Home Life* Leadership Support and Community Development Programme has been delivered to care-home managers in 14 different regions and is about to start in Northern Ireland.

The success of the *My Home Life* initiative is thought to be its focus on being evidence-based, relationship-centred, appreciative and action oriented – an example of best practice in and of itself, which has been driven by the care-home sector.

What would people value if they were a disabled person?

No two people are alike, and different people prioritise different things in life, based on their age, background, personality, health, level of independence, and so on. In particular, working-age disabled people have a very distinct set of needs and preferences, which are different from those required by older recipients of care and support.

For example, older people we spoke to who live in housing with care missed being able to do things that they did when they were younger (eg DIY, gardening) and being able to live independently. In contrast, many of the disabled people we spoke to in residential settings had needed support since they were very young, and so did not have the same sense of loss of independence – in fact, being in housing with care enabled many of them to be more independent, because there were staff around to help them undertake activities and they lived in an appropriate environment (eg it was wheelchair accessible). Similarly, older people said that having fewer responsibilities (eg for maintaining a house and looking after themselves) was the main positive feature of housing with care, while disabled people did not mention this. Having the opportunity to work and start a family may be important priorities for them instead, which is not a concern for older people.

In a separate polling question, we asked people to select their top-three priorities if they found themselves needing

support because of a disability earlier in life (before they reached retirement age). The percentage of aggregated top-three answers is shown below, and differs significantly from the priorities given for people who needed care and support when they were older:

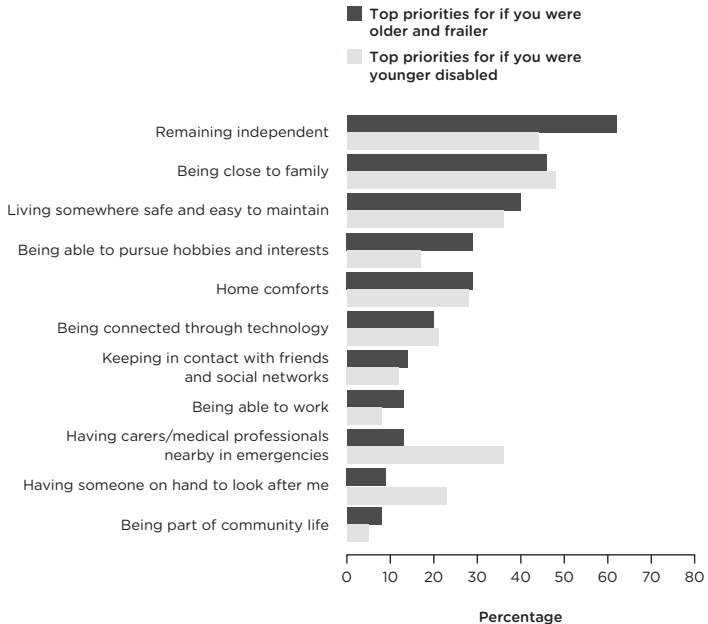
- being close to family (48 per cent)
- remaining independent (44 per cent)
- having carers/medical professionals nearby (36 per cent)
- living somewhere safe/easy to maintain (36 per cent)
- having home comforts around me (28 per cent)
- having someone on hand to look after me (23 per cent)
- being connected to wider world (21 per cent)
- being able to pursue my hobbies/interests (17 per cent)
- being able to keep in contact with friends/networks (12 per cent)
- being able to work as much as much as I can (8 per cent)

The top priority for people imagining themselves living with a disability is being close to family (almost half the respondents said this would be important to them), followed by remaining independent. These two things were also ranked as the top two priorities for people looking ahead to old age, though beyond this, it is clear that the care elements of living with a disability were more important than people perceived them to be in old age.

Figure 4 compares the relative importance of different features of quality of life, depending on whether people were thinking of themselves as older and frailer, or long-term ill or disabled at a younger age.

People picturing how they would live if they were disabled tend to place a far greater emphasis on having care, medical support and personal assistance than people looking ahead to old age, and correspondingly less emphasis on independence, hobbies and activities. This perhaps reflects the fact that the concept of ill health and a need for care is explicit in this question, whereas being older may not necessarily involve having poor health. It may also reflect a feeling that with the right care

Figure 4 **Comparison of the relative importance of different features of quality of life for the old and frail and the young and long-term ill or disabled**



Source: Demos survey

and support, the freedom to do all of the rest of the things listed would naturally follow.

We were not able to probe these preferences in more detail in focus groups, as with the older age groups, as disabled people who are likely to move from a community setting into some form of housing with care in the future are a trickier group to recruit. They are likely to be living with degenerative illnesses that will become difficult to manage without home care or family support,

or will enter housing with care because of a breakdown in their care and support package. In addition, for disabled people, the term ‘housing with care’ generally refers to independent or supported living, rather than the more traditional image of a care or nursing home.

This reflects a trend in the wider literature, in which we identified a dearth of evidence on quality of life for disabled people and people’s preferences and demands were they to live in housing with care or more generally. There is certainly nothing equivalent to the body of research that exists on this subject for older people; this is a challenge for housing with care providers as they plan new developments and define their future offer for the next generations of disabled people.

What do people want from housing with care?

So far, we have explored the kind of life that people would want for themselves if they needed extra care and support, regardless of whether this was in their private home, in some form of specialist housing or in a residential care or nursing home.

Older people

We wanted people initially to describe to us ‘what makes a good life’ rather than ‘what makes a good life in housing with care’, as we did not want people’s priorities to be coloured by their preconceptions of housing with care. But we also wanted to hear what kind of housing with care people felt would best help people achieve the things they had outlined as important.

Demos therefore asked people in the survey to identify the characteristics that they would look for if they were choosing a care home for themselves – regardless of whether or not they would actually be willing to move to one. The top-three characteristics chosen are shown in table 1.

These priorities are consistent with what people said would be important to them if they were a disabled person or frail and elderly. Independence, in particular, emerges as a key marker of good quality of life (43 per cent selected ability to be

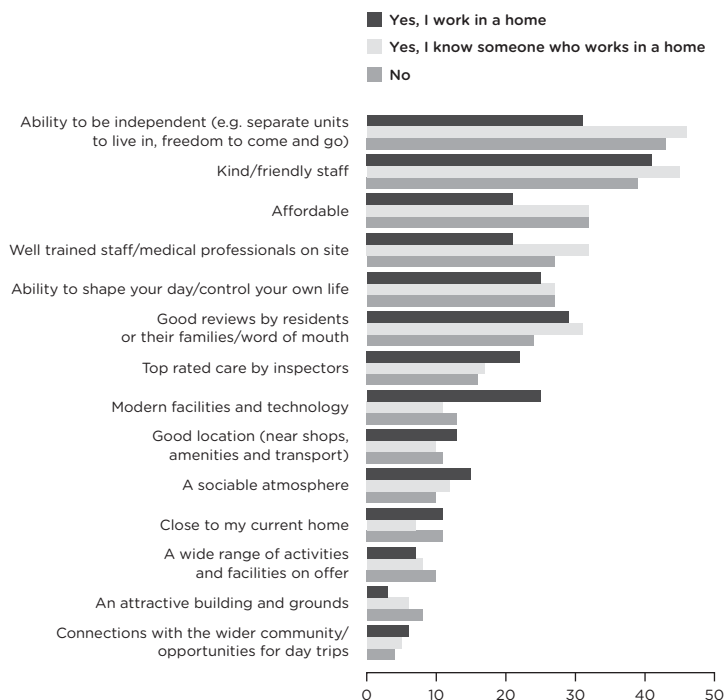
Table 1 **Characteristics Demos survey respondents look for when choosing a care home**

Ability to be independent (eg separate units to live in, freedom to come and go)	43%
Kind/friendly staff	40%
Affordable	32%
Well-trained staff/medical professionals on site	28%
Ability to shape your day/control your life	27%
Good reviews by residents or their families/word of mouth	26%
Top rated care by inspectors	16%
Modern facilities and technology	13%
Good location (near shops, amenities and transport)	11%
A sociable atmosphere	11%
Close to my current home	10%
A wide range of activities and facilities on offer	10%
An attractive building and grounds	7%
Connections with the wider community/opportunities for day trips	4%

independent as something they would look for in housing with care). Two of the four top-ranked preferences relating to staff – 40 per cent of people said they would look for a place where staff were kind and friendly, while 28 per cent said they would look for well-trained staff. This suggests that the attitudes and behaviour of staff in housing with care is more important to people selecting a care home than their level of training per se (though the two are likely to go hand in hand).

There is some divergence in the survey between what people currently living in housing with care reported as important, and what people projecting ahead to a hypothetical future scenario said they might look for from housing with care. There are several possible reasons for this – one is that the importance of some aspects of housing with care only become apparent once you walk through the door. Our polling found people who said they worked in housing with care placed far more importance on certain features of a residential environment than members of the public in general, including connections with the wider community, as well as a sociable atmosphere. Modern facilities and technology were also ranked higher, while independence, affordability and well-trained staff were all lesser

Figure 5 **Factors looked for when choosing housing with care, by level of contact with housing with care**



Source: Demos survey

considerations. Figure 5 shows the factors people looked for when choosing housing with care, according to whether they worked in or knew someone who worked in housing with care, or had no contact with anyone living in housing with care.

The second possible reason for the difference between preferences of people with experience of housing with care and people without is the vicious cycle of low expectation that surrounds housing with care. Our polling sample included a

sizeable proportion of people (43 per cent) who said that they would not consider moving into housing with care, citing fears about loss of independence, risk of neglect or abuse, and being in an unfamiliar environment (discussed in more detail in the next chapter). People who see housing with care as isolated and ‘ghetto-ising’ are unlikely to think that it is realistic that the people living there can be part of the community, while people who see abuse as a real risk within housing with care understandably place reassurance that staff are kind and caring and finding positive reviews by people living there above considerations about social opportunities within and around the home.

The over-60s who participated in our focus groups had a clear vision of the type of housing with care that they would like to see; it would be stimulating, flexible, personal, affordable, accountable and characterised by continuity between different settings:

- *Stimulation* would come from frequent activities being organised within the home (eg classes, film nights) and outside it (eg trips to the theatre and music concerts). One person suggested that there should be more partnerships between housing with care and other community organisations (eg churches or community centres) to help provide some of these activities. Having lots of facilities on site (eg a GP, dentist, cinema, hairdresser, spa and swimming pool) was an attractive feature of housing with care in other countries (such as Australia) that people had heard about.
- *Flexibility* would replace a regimented, structured environment, with people able to come and go as they pleased without restrictions on mealtimes and visiting hours, for example. People were also keen to see a shift from risk prevention to managed positive risk taking in housing with care – current levels of supervision by staff were felt to be over-protective and stifling.
- At a sector-wide level, people were also keen to see more flexible models offering different levels of care in one place, thereby allowing *continuity* of care and community. One of the reasons people seemed to want to put off moving into housing with care for as long as possible was that they were worried about having

to move again as their health deteriorated further. The idea of having different levels of care all on one site was very appealing – in one of the groups, somebody mentioned Whiteley Village in Surrey (which Demos researchers visited for this report, see the next chapter for details), which has independent living, extra care and a nursing home all located within a ‘garden city’ style arrangement. People liked the idea of being able to get settled within a community without facing the prospect of moving again, which can be very distressing for older people.

- Housing with care could be made to feel more *personal* and less institutional by allowing people to personalise their space, bringing in their own furniture and decorations. Attention to detail in decorating and furnishing the communal areas of a home to make it feel less institutional and more welcoming was also important – people made frequent comparisons with the standard of décor that they would expect from a hotel (including tablecloths in the dining room, armchairs, mirrors and lamps in the hallways). The size of the home was also a factor in this – one of the groups suggested that homes for disabled people were built on a better scale, with six to eight people living in each house. This would create a more intimate, less institutionalised environment. The cultural aspects of the environment are also important to consider (especially for people with dementia), as not all people moving into housing with care are born in the UK.
- The *affordability* of housing with care – and care more generally – was viewed as a big concern by all people who attended our focus groups. Plans to increase the availability of deferred payment (whereby the local authority pays the upfront costs of a person’s care, which are then repaid out of the estate after their death) were not very popular, and seen as another way for the government to ‘rob’ older people. On the other hand, people felt strongly that price was directly linked to quality – and that if they could not afford a really high-quality home, they would be forced to live in a substandard one.
- People were keen on the idea of homes being more *accountable* to people living there, and that people should have a stake in the running of the home. One group suggested that having a

higher level of engagement would be important, such as monthly meetings between owners or managers, people living there and their relatives. They were also keen on some form of profit-sharing or cooperative model of ownership so that profits could be returned to those with a stake in the home.

In all of the focus groups at least one person raised the issue of staff in housing with care, particularly the need to increase staffing levels and to ensure that people working in the sector are properly rewarded and motivated. Staff were considered to be low paid, overstretched, poorly trained and thus under-motivated. This led to them sometimes providing poor care, making it more difficult to meet people's individual needs, and in some extreme cases neglect and abuse. Participants were keen to see more one-to-one care and support – more like a personal carer – to allow staff to get to know each individual's preferences and needs – rather than having lots of different staff on rotation. This clearly links to the concept of relationship-centred care, outlined above. As we will go on to discuss in chapter 5, higher staffing levels are associated with more flexible care and personal interaction, and so act as a vehicle to bring about some of the other outcomes people identified as important.

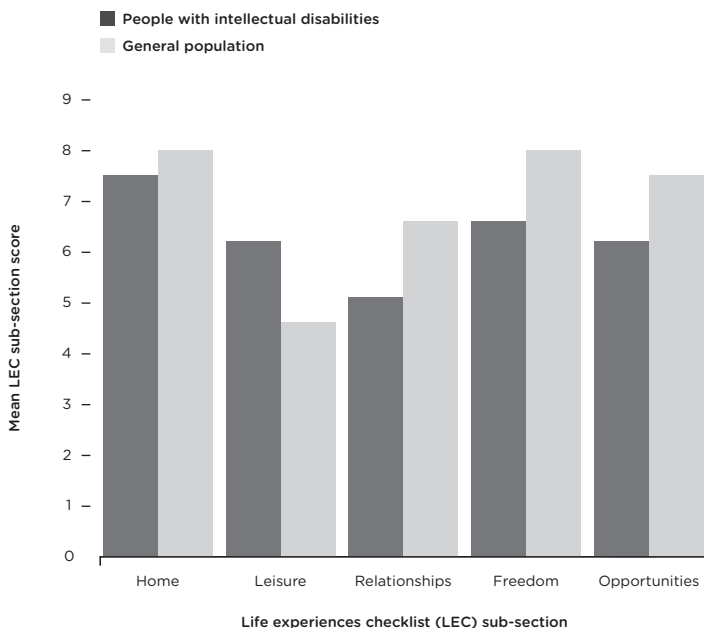
Another feature that focus group participants felt could help facilitate the priorities for housing with care outlined above was for people who might move into housing with care to have a lot more reliable information than is currently available about their different options, to help them make an informed choice about moving. One focus group member suggested having a comparison website for housing with care, similar to TripAdvisor ('HomeAdvisor'), which could help them make an informed choice. Such services already exist (eg Care Home Advisor; www.carehomeadvisor.com/) – which allows people to share their care experiences – but they are not well developed and awareness of them is low. The CQC encourages the public to share their experience of care homes to inform their inspection process, but those who knew of the CQC were sceptical that the organisation could be a source of information.

As mentioned above, the evidence we have gathered from our review of recent literature suggests that there are fewer substantive pieces of research on ‘what people want’ from housing with care catering to the 18–64 age range than there are on older people. The Commission therefore believes more could be done to understand the specific needs and preferences of younger people using housing with care services. Some organisations, such as Voluntary Organisations Disability Group, have carried out research into the transition from children’s to adults services and the difficulties encountered by people moving to independent living,³⁴ while National Development Team for Inclusion published an interesting guide on how to turn a care home into a supported living unit, following the general trend of people with learning disabilities moving out of care homes.³⁵

However, published research into the use of care homes specifically and quality of life and care in these homes for working-age adults are very thin on the ground, especially for adults who are physically disabled, or who have neurological conditions. People with learning disabilities have been the subject of slightly more research. A 2008 study by Huddersfield University exploring the quality of life measures in nine homes for people with learning disabilities compared this to the averages in a comparator sample of the general population. They found that only in leisure activities did people living in the nine homes report more satisfaction than the rest of the population (figure 6).³⁶

The results of the survey are telling – for example, only 50 per cent of people said they had their own room, compared with 88 per cent of the general population; only 55 per cent said they had several close friends (compared with 78 per cent of the general population). Staying overnight with friends and having friends to stay was much less common among people living in the care homes (18 per cent vs 47 per cent and 7 per cent vs 51 per cent respectively). People living in the homes were much less likely to choose their home décor (13 per cent vs 84 per cent), to choose where they lived (52 per cent vs 76 per cent) and to choose their own clothes (75 per cent vs 95 per cent). These findings are linked to the important features of quality of life around identity, choice, relationships and making a ‘home’ of a

Figure 6 **Comparison of the level of satisfaction people with intellectual disabilities and the general population have with various life experiences**



Source: Skea³⁷

care home identified in the research with older people.

Anecdotal evidence from care providers supporting disabled people suggests that budgetary pressures may be creating a regression where deregulated, small independent living units are adopting care home practice and operation. While there is a small proportion of disabled people with very complex conditions for whom a highly medicalised setting is most appropriate, working-age disabled people should have the same choice and variety of housing with care options as anyone else and these will not necessarily look the same as those available for older people – in particular, bringing in training,

work or other economic or social contributions, and developing relationships and starting families are all elements of support which need to be central in an 18–64 offer. In the next chapter we discuss how some residential settings, including those in Denmark, have pioneered the colocation of housing with care with education providers.

Future demand

A housing with care sector built on current demand runs the risk of becoming outdated within a generation. One way of avoiding this is to build a care market that is flexible and responsive, so that provision of housing with care can change with changing tastes. But it is also crucial that we look ahead, and consider what future demand will look like – particularly where this deviates from what care users of today choose and value.

The experts interviewed for the Commission considered maintaining independence for people living in housing with care to be a key priority in the future – even more so than it is currently, as future generations will increasingly expect more choice and control over what they do and when. This reflects higher expectations around care, within which personalisation will be seen as the norm. It is right that expectations and standards continue to rise, but this poses challenges, requiring much more flexible staffing, more one-to-one support, and a reduction in the potential for economies of scale. These all have implications for the cost of delivering housing with care, which we tackle in the next chapter.

The focus groups carried out by Demos captured the views of those who may move into housing with care in the future, but some conclusions about how demand might change can also be drawn from the polling carried out for the Commission, which took into account the full age range of British adults – though it is impossible to tell which of the differences are to do with generation (cohort effects) and which are more to do with age (lifestyle effects – where the views of those currently aged 18–24 converge with those of people currently aged 65 and above).

There were clear differences in priorities about

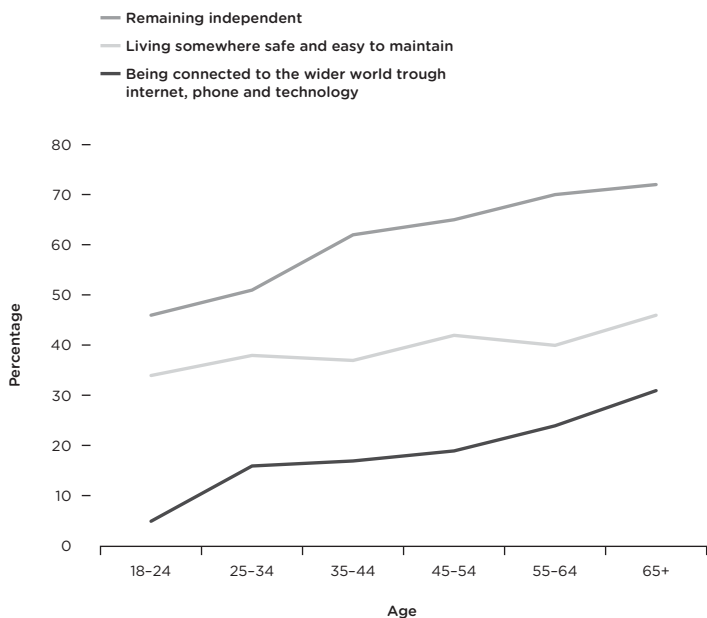
independent living by age in many areas. For example, being independent becomes more important with age, as does living somewhere easy to maintain. Conversely, being close to family becomes less important, perhaps as older respondents in the sample have less contact with their families or have fewer surviving close relatives, or perhaps because they worry about becoming a burden as they grow older. The importance of being cared for also declined slightly with age, perhaps linked to the parallel increase in independence being a priority.

Surprisingly, the priority of being connected through technology increased with age, perhaps because younger people do not envisage ‘old people’ using technology, comparing them with the (relatively unconnected) older generation of today. Alternatively, this could be because older people are currently more socially isolated, and therefore recognise the importance of technology as a means of staying in touch. This finding is interesting in the light of a recent Ofcom report, which found a significant increase in the use of internet among older people in the past two years, in part because of the availability of tablets and their intuitive design. It found that the number of adults using tablets to go online has almost doubled, from 16 per cent in 2012 to 30 per cent in 2013, but among those aged 65–74, there has been a threefold increase, from 5 per cent to 17 per cent.³⁸ Overall, areas that older people prioritise over younger people are remaining independent, living somewhere safe and easy to maintain, and being technologically connected (figure 7).

Looking at this the other way around, factors that younger people prioritise over older people – and might be considered to demonstrate a shift in views from older to younger generations – include being close to family, being able to stay in contact with friends and social networks, and having someone on hand to help you out. People aged 35–44 were also particularly keen to be part of the life of the community (figure 8).

If younger people retain these priorities in later life, relationships and social life will take centre stage in a future housing with care system, while care and support – which are likely to cater for more complex needs to reflect demographic change – will take place as much in the background as possible.

Figure 7 **The priority given to being connected through technology, by age**



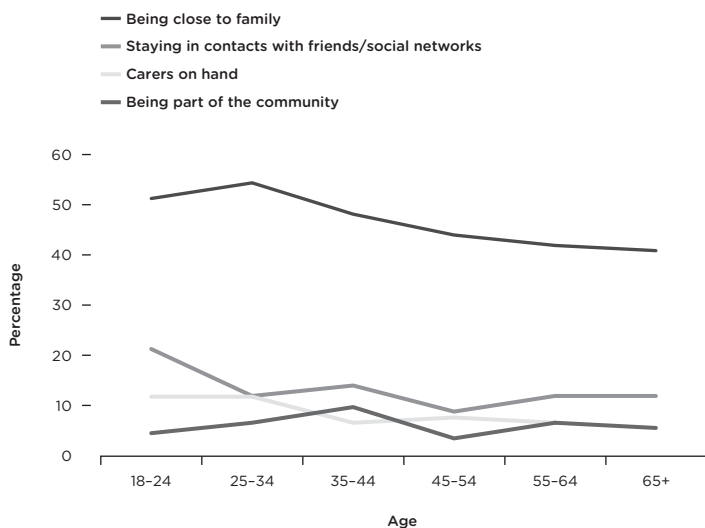
Source: Demos survey

Conclusion

The generalised view of ‘what older people (or disabled people) want’ set out here should not be mistaken for a one-size-fits-all model that will suit every disabled or older person’s tastes. Some people prize their independence, enjoy spending time alone, and are unwilling to let other people make their decisions for them – others may be happy to go with the flow, and enjoy gaining a sense of purpose and direction from being around other people. These things are very personal to individuals.

In addition, as we cautioned above, building a sector based exclusively on future demand is likely to be problematic because of the vicious cycle of low expectation, which sets a limit on what people look for when choosing housing with care for themselves,

Figure 8 **What would be important to people needing care and support in later life, by age**



Source: Demos survey

and because people may imagine themselves needing and wanting very different things in housing with care in theory from what they require in practice once they live there. There will always be a need for the expertise of providers, commissioners, inspectors, policy makers and others in shaping the future market distinct from raw ‘market’ data.

The unspoken addendum to everything that people told us that they wanted – whether from later life or life with a disability – could have been ‘as I would in my own home’ (as in ‘I want the freedom to come and go as I please... as I would in my own home’). This – and the fact that many of these things were the same as any of us would see as the markers of a good life – suggests that what people want from housing with care, above all things, is to apply the same standards to it as to the rest of life. When people move house under any other circumstances, they

have a wide range of housing options and can choose the one that best meets their preferences and requirements; exactly the same should be true of housing with care.

Ideally, we will reach a stage where the concept of ‘staying in my own home’ disappears, as housing with care becomes simply another form of ‘home’, in its most positive sense. The step from a person’s existing home into housing with care is currently viewed by many as a huge leap in environment, lifestyle and quality of life – as we will explore in the next chapter. The research findings presented in this chapter suggest that people would prefer the gap to be a lot narrower.

Summary

In this chapter we have drawn together evidence from reviewing research literature and the polling, focus groups and interviews undertaken by Demos on behalf of the Commission to explore what people say they would want if they were disabled or older and frail. Much of the new primary research draws the same conclusions as more substantial research by the Joseph Rowntree Foundation and *My Home Life*, identifying the importance of independence, meaningful relationships, identity, choice and autonomy and so on.

We then discussed a related question – what would people want from housing with care if they were a disabled person, or older and in need of support? Many respondents had the same priorities, but were also concerned about the need for positive relationships with support staff and opportunities to maintain one’s routines and interests. We also note that the research literature on what disabled people want from housing with care is more limited than that on older people.

We concluded this chapter with a discussion on future demand, comparing the research findings by age group to reflect on what future generations of disabled and older people might expect and demand from housing with care.

4 Where are we now?

In the previous chapters we explained why housing with care can be so effective and efficient in promoting autonomy and creating social opportunities, and serve as a realistic housing option – particularly when the whole spectrum of housing with care (from care home to extra care and village options) is taken into account. We have also reflected on what people want and expect from housing with care if they were disabled, or older and frailer, should they need it.

These findings provide a constructive, informative base on which to consider the future of the housing with care sector in the widest sense, and how future generations of care provision will need to cater to preferences and personal taste. However, the Commission is acutely aware that this research is not operating in a vacuum. The implications for the sector need to be set against a challenging social, political and economic context, which we explore in more detail in this chapter.

The context

In some ways, the future of social care is balancing on an axis. On the one hand, the Care Act 2014 promises to be revolutionary – bringing in a new duty of wellbeing, carers' rights and commitment to preventative action – measures which have been long awaited and much welcomed by practitioners and representatives of disabled and older people's groups alike. On the other hand, the funding crisis looms large. The 2014 budget survey by the Association of Directors of Adult Social Services (ADASS) reports that since 2010/11 councils have had to make service reductions of £725 million.³⁹ Spending on adult social care has fallen by 12 per cent in real terms⁴⁰ at a time when the population of people looking for support has increased by 14 per

cent.⁴¹ By 2021 the spending gap on adult social care is estimated to be between £7 billion and £9 billion.⁴² At the time of writing (September 2014), the new president of ADASS has declared adult social care is fast becoming unsustainable owing to the extent of these budgetary cuts. He commented:

*Substantial additional financial burdens will flow from implementing the Care Act. These will include the welcome additional rights to be given to carers; implementing the Dilnot proposals, and responding to the Supreme Court judgement on Deprivation of Liberty Safeguards. But combined with these budget reductions, as resources reduce and need increases, directors are increasingly concerned about the impact on countless vulnerable people who will fail to receive, or not be able to afford, the social care services they need and deserve.*⁴³

These parallel developments – the Care Act and reduced resources – present a significant challenge for the housing with care sector. The latter has led to year-on-year below-inflationary increases in the weekly fees local authorities pay to care homes for state-funded individuals, but expectations of what care and support can achieve are rising. The importance of achieving independence and empowerment through personalised support has now been enshrined in the Care Act and is established good practice in many parts of the social care system. The traditional care home, with collective routines and shared living spaces, may need to work hard to keep abreast of these new expectations and demands from policy makers and the public.

In the following sections we consider these financial and social challenges and the context in which the residential sector exists.

The Care Act – creating a vision for twenty-first-century care

The process the bill has gone through has meant it has come out the other end improved and signed up to across the parties and across the sector. In a way it feels modest because everyone agrees with it, but it contains some

revolutionary ideas that, given their head over the next few years, will be really very important.

Paul Burstow MP, former Care Services Minister, architect of the Care Bill, Chair of the Joint Scrutiny Committee, Chair of the Commission on Residential Care

The Care Act is a significant piece of legislation, the first major reform of social care law for over 60 years. It presents a new vision for a care system based on a more holistic range of support, a recognition of the importance of informal carers, and a more transparent and consistent support offer underpinned by far better information and advice than is currently available. These are some of the key measures the Act introduces:

- a local authority duty to promote ‘wellbeing’ – consider the physical, mental and emotional wellbeing of the individual needing support, not just their narrow care needs
- a local authority duty to provide preventative services to maintain people’s health
- a new responsibility for local authorities to ensure that there is a range of care and support services available to meet the needs of the whole population, not just those the council funds
- a minimum eligibility threshold across the country – a set of criteria that make it clear when local authorities will have to provide support to people
- new responsibilities for the CQC and local authorities to tackle provider failure and protect people receiving services
- the framework for a new care funding model, based on a cap on personal ‘care costs’ (not including accommodation costs) of £72,000
- carers to be entitled to an assessment of their wellbeing needs and for the first time to have a legal right to have those eligible needs met

These various elements create a vision of care and support which is more holistic, focused towards earlier intervention and preserving independence, and with an assumption that

personalised care (often wielded through personal budgets) is the heart of a twenty-first-century care system.

This clearly raises expectations of how all stakeholders – from commissioners to regulators and providers of support services – should be operating.

These raised expectations could be a major challenge for care-home providers. As mentioned above, as the Care Act moves our understanding and expectation of what care and support should achieve many might question what role care homes – a model which may seem anachronistic in the light of this new regime – have to play. In order to deliver what new cohorts of people needing support want, and meet the expectations of policy makers and commissioners, housing with care providers of all types must modernise and/or diversify their offer. However, such operational and cultural changes will need to be carried out in the face of significant financial and social pressures. The following sections consider some of the most pressing of them.

Funding – the biggest challenge to the housing with care sector?

Firstly, what you need to do is make it clearer. Do an assessment of what the overall cost is – to the population, to individuals, and then you've got to come up with funding models that'll make it attractive enough to bring the capital in to re-provide all these services. So the first thing you have to do is clear the mud away, the uncertainty away, from the funding climate, and say what it's going to cost and how much money is going to be needed to pay for it and where it's going to come from.

Nick Sanderson, CEO, Audley Retirement

The Office for Budget Responsibility estimates that public spending on long-term care (in the current, unreformed system) is expected to increase from 1.2 per cent (2009/10) to 1.7 per cent (2029/30) as a percentage of total gross domestic product. As the 2011 Dilnot report explained, this is growth of 40 per cent: faster than any other area of age-related public spending – and is largely driven by demographic change. Dilnot concluded this

expenditure would need to come partly from increased public spending, partly from private contributions, and partly from unpaid care.⁴⁴ However, public spending through local authorities has reduced substantially in the last four years, with a planned reduction of £800 million in 2013/14. ADASS calculates that by March 2014 spending will have fallen by £2.68 billion – a cut of 20 per cent over the current spending review period.⁴⁵

These cuts have been delivered via efficiency savings, the restriction of eligibility for state funding of care packages, and the reduction in the availability of some services. Partly as a result of this, older people who pay entirely for their own social care and support now account for 45 per cent of residential care-home places, 47.6 per cent of nursing home placements and 20 per cent of home care support.

These people are often referred to as ‘self-funders’. The self-funded registered residential care and registered nursing home market is worth £4.9 billion per year, and the self-funded home care market £652 million.⁴⁶ As we explain below, self-funders often pay more than non-self-funders for their housing with care, because of a growing trend of providers offering high standard housing with care targeted only at self-funders, or because providers still working in the local-authority-funded market and state-funded market may cross-subsidise, charging higher fees to the latter to compensate for the below-cost fees paid by local authorities. So-called ‘top-ups’ are also becoming more common, whereby the families of people living in housing with care pay part or all of the difference between what local authorities pay for their relative’s housing with care and the actual fee charged by the provider.

Despite the recent funding pressures bringing these issues into sharp focus, social care has been underfunded for many years. In 1997, the new Blair government announced a Royal Commission on Long Term Care, tasked with addressing the funding of a care and support system for the UK’s rapidly growing older population. Many of the recommendations of the Commission were rejected when they reported in 1999,⁴⁷ including the recommendation that long-term care should be free.⁴⁸ In recognising such a proposal was unaffordable, the

Commission's Minority Report recommended some form of insurance or copayment system instead, so that individuals and the state would share the cost burden for care services.⁴⁹ The idea of introducing a copayment model has also been toyed with by the Coalition Government, but it has not implemented the proposal.

In 2006, armed with new projections from the Government's Actuarial Service as to just how rapidly life expectancy was increasing, the Wanless report, *Securing Good Care for Older People*, reflected on the funding needs of the care system over the following 20 years. It proposed yet another copayment variant for care funding, concluding,

*The potential to achieve economically justifiable outcomes is not currently being realised. Unless society is less inclined to support the same improvement in outcomes from social care as it would from, say, health care, then more should be spent on social care for older people.*⁵⁰

In 2010, the new Coalition Government tasked Andrew Dilnot with establishing a new care funding regime. But the timing was challenging, coming as it did at the start of the Government's deficit reduction programme, with cuts to local authority funding being announced (27 per cent over the next four years) later the same year. Unlike the NHS, the local resources for social care were not ring-fenced and rapidly drying up, making a new system which would enable individuals to contribute to their own care in a more reliable way even more crucial. In 2011 the Dilnot Commission proposed a new 'capped care' model, creating an opportunity for just such a system.⁵¹

Nonetheless, the Dilnot model does not in itself present a solution to the funding gap. It designed a regime which would reduce the risk of 'catastrophic' care costs for individuals, but was not tasked with quantifying how much funding was needed to support a care regime that fulfilled the vision outlined in the Care Act, nor where this resource would come from. While the Care Act provides the framework for introducing a cap on care costs, the implementation date is set for April 2016. As the next general election is due to take place in May 2015, there remains a

question mark as to when – and if – the capped system will be implemented; Shadow Care Minister Liz Kendall supports the model in principle but has raised questions about the way in which the Government plans to implement it.⁵²

In the intervening years, the care regime has exhibited ever-greater symptoms of chronic underfunding. Eligibility for state-funded care has tightened, excluding increasing numbers of disabled people and older people from support. Local authority fees paid for this dwindling number of state-funded individuals has also been tightened for care providers, making cross-subsidisation between private and state-funded customers and top-ups asked from people moving into housing with care an increasingly common occurrence. A LaingBuisson report shows that the use of top-ups has reached a record high: 175,000 older people living in housing with care (43.4 per cent) paid the full costs of their long-term care fees in 2012, and a further 56,000 (14 per cent), although supported by councils, also relied on ‘top-ups’ from family or friends.⁵³ Thus a total of 231,000 older people were paying in full or in part from their own or their families’ resources in 2012 – this marks a record high of 57 per cent of all (403,000) older people in independent sector care homes in the UK. The remaining 43 per cent either had their fees paid in full by councils (143,000) or by the NHS under the continuing healthcare programme (29,000).

Independent Age released a report on top-ups in 2013 pointing out that they should only be used when a relative expresses a preference for more expensive accommodation, and only granted if the relative is ‘able and willing’ to pay.⁵⁴ However, their researchers found that some local authorities were now making top-ups the norm for all care, because the standard rate they are willing to pay is below any bed rate in the local area. The use of top-ups increased by 4 per cent in 2011/12, but local authorities do not monitor top-up contracts and many are not aware that people are entering into such contracts with care homes. In a recent debate on top-ups, Paul Burstow MP commented,

The rules are clear. The trouble is that evidence is mounting that they are being broken. Local authorities are confused about how to apply the rules

*consistently... Whether it is malign or not, it is ignorance, and when it comes to a local authority, that ignorance is not acceptable.*⁵⁵

The use and misuse of top-ups is less surprising when considering the funding pressures on local authorities being passed down to providers. Analysis from Laing and Buisson found that in 2012/13, fees paid to care homes increased by just 1.6 per cent in the face of a 2.5 per cent increase in care-home costs.⁵⁶ This year, costs increased by 1.9 per cent while fees increased by 1.7 per cent, prompting speculation that the widening margin between actual costs and fees was slowing down, but still pointing to a 5 per cent real terms reduction in fees since 2010/11.⁵⁷ While care-home fees paid by local authorities are on average £500 per week across the country, actual costs of care range between £531 and £600.⁵⁸

Such large differences between care costs and what local authorities pay for care has led to many problems – the largest single cost in housing with care is staffing – and wages, training and progression are first in line for cuts when resources are limited. We return to this issue in the next section.

The business model

Limited resources are having other impacts – for example, some of the practitioners we consulted during the course of this work reported that local commissioners were leaning towards larger homes, where economies of scale can be more easily achieved, but larger homes may not suit everyone's tastes. Some practitioners we consulted concluded that without changes in the funding of care the trend would continue towards providers building bigger homes concentrated in more affluent areas, with higher occupancy rates and catering to people with greater needs. These measures were needed in order to achieve economies of scale and prevent a decline in standards (eg having to rely on poorly paid staff and low quality facilities), but therefore created a divergence in the market – where better quality housing with care becomes the preserve only of people who can afford the higher fees. We discuss the growing division

of the market – where the differences between housing with care aimed at affluent self-funders and the settings left for state-funded individuals become more dramatic – further below.

We need to avoid this vision of housing with care driven by economics at all costs. Despite the efforts of providers to create economies of scale and avoid a decline in standards, there remains uncertainty in the market. The case of Southern Cross suggested the models operated by some providers were not sustainable, and others have worrying debts. A 2012 report by Corporate Watch found that care-home providers collectively owed more than £4.5 billion, while three of the top ten providers were deemed ‘at risk’ of being unable to pay off their debts in the face of difficult economic times.⁵⁹ The report concluded that complex financial arrangements made it hard to predict whether care homes were struggling or not, ‘Buy-outs, bond issues, refinancing and inter-company loans contribute to the complex and sometimes risky financial arrangements of some private investors and companies.’⁶⁰ While some providers are privately owned and therefore need to make rates of return demanded by their shareholders, others are family businesses with little or no ability to borrow and invest. Many experts Demos consulted felt that the lack of clarity from the Government about their position on housing with care, future funding streams and projected future costs made developers and investors nervous about entering or investing in the sector – placing pressure on large and small, private and not-for-profit homes alike.

Understandably, the shortage of funding to meet existing demand – let alone drive the changes needed to fulfil the vision in the Care Act – was frequently raised by the experts we consulted during the Commission’s investigations. The tendency towards scaling up had a mixed reception, both for providing care on a human scale, and – from a planning perspective – for making large new developments (eg retirement villages) fit within an existing setting, and making them acceptable to local communities. Nonetheless, the economic reality of taking such steps to prevent cuts in the quality of care was recognised as a necessity.

Some felt that private funding from individuals was the obvious solution to this funding impasse. They pointed out that

while local authorities are facing a chronic shortage of funding, older people have historic levels of wealth, raising questions about how much people should be expected to contribute to pay for their own care. Another reflected that the system is currently being propped up by the high house prices of self-funders, but if and when house prices fall, this will no longer be sustainable. On the other hand, many warned against making generalisations about the older population – while around 80 per cent of the over 60s are home owners, a fifth are in social or privately rented accommodation and many homeowners have very low levels of equity and inadequate pensions – making it all the more important that housing with care options are diverse, not just to reflect a variety of needs and preferences, but also to cater to people with different resources to spend, including those who may be wholly or partially state-funded, of self-funded with limited resources.

Workforce

Care Workers are under-valued, under-paid and under-trained. They don't have the status of Nurses. They don't have the status of Child-Minders. The sector is subject to weak regulation. We don't know who they are, we don't know what qualifications they hold and they are not registered with any professional body. This workforce of 1.8 million people in England is almost invisible.

Baroness Kingsmill⁶¹

And they're not properly trained. I remember when I went to see my aunt in the home and we had a problem and I said to them, the manager of the care home and I said 'well what sort of training do you give them?' and she said 'well we give them three weeks'. I mean what sort of training can you get in three weeks? They just don't give them anything.

Member of the public in focus group

Pay, progression, recruitment and retention in care services has been problematic for many years. Training and skills levels often reflect a lack of resources to invest in the workforce: 36.9

per cent of housing with care staff have no qualifications whatsoever; again, this is a challenge to the vision of making the sector a well-regarded, specialist profession. While many people working in housing with care settings have vast experience, emotional intelligence and interpersonal skills which make them ideal for their roles, they may not have the literacy or English language skills to obtain a level 2 or 3 qualification. The call for evidence for the Commission frequently encountered the view that it was necessary to ensure that the skills needed in housing with care match the qualifications framework, while up-skilling and accrediting (and professionalising) the workforce. In chapter 7 we consider how this might be done – through minimum training certification and a licence to practice, which reflects the distinct skills set needed for staff working in housing with care.

A related problem is poor rates of pay, another clear sign that the workforce is not being properly invested in within an environment of chronic underfunding. Care work is widely perceived to be low skilled, low paid and of low status; the Low Pay Commission identified pay rates in this sector as among the lowest in the UK in recent years⁶² and staff in this sector are often paid below the minimum wage.⁶³ Partly because of this, the sector experiences some of the highest vacancy (3 per cent) and turnover (19 per cent) rates in the economy. According to the International Longevity Centre (ILC) the highest vacancy and turnover rates (4 per cent and 22 per cent respectively) are for direct care roles, which make up three-quarters of all care positions, compared with a UK job market median turnover of 11.9 per cent.⁶⁴ Directors of the care homes Demos visited on behalf of the Commission felt their staff were not able to spend as much time with people living there as they would like. Some staff said that they often did not have time to give people individual attention and were aware that people did not like spending so much time sitting inside, and would like to go out more, but to do this would require more staff. However, one of the carers we spoke to had previously worked as a domiciliary carer, and said that she liked the more relaxed timescale of the care home in which she worked, which allowed her to build up a rapport with people she was supporting.

Despite these figures, Skills for Care analysis suggests less than 5 per cent of those changing jobs in the care sector say pay was their primary factor; most (over 20 per cent) leave their jobs ‘for personal reasons’. The ILC suggests that as 41 per cent of the care workforce is under 39 and the vast majority are women, a lack of childcare support might be a significant problem.⁶⁵ Nevertheless, we should not dismiss pay as unimportant. The Joseph Rowntree Foundation has found that ‘care work is often seen as a “job” that is temporary or to supplement income, particularly for women with family caring roles, so “career” progression is not necessarily built into the reward structure in some organisations’.⁶⁶ There is an argument to be made that the substantial churn in the care sector (nearly 30 per cent of those leaving a caring job are moving to another caring job) and the relatively high proportions of people coming and going according to family circumstances may be because care work is considered a ‘job’, not a ‘career’. This, in turn, is directly related to the pay, status and progression available in care work. While wage levels do not of themselves dictate whether someone enjoys and stays in their job, pay certainly helps to create a culture of feeling valued and of vocation, which are closely linked to improved morale and staff retention.⁶⁷

Unfortunately, the reduction in resources for social care has exacerbated the level of poor pay in the sector: the Office for National Statistics’ Annual Survey of Hours and Earnings (ASHE) data indicate that the median gross pay of ‘care assistants and home carers’ has decreased by almost 2 per cent (–1.7 per cent) since 2010, compared with an average 2 per cent increase in earnings across the UK over the same period.⁶⁸

A bigger concern for the Commission, however, is that it seems that within the care sector itself, housing with care staff are paid less their domiciliary or day-care counterparts. Table 2, reproduced from Skills for Care analysis, shows that in almost every form of work, the adult residential sector has lower pay than other sectors.⁶⁹ The recent Kingsmill review into working conditions in the care sector, commissioned by the Labour party for their policy review, provides some explanation for this:

Table 2 **Hourly wages of different care workers in 2012**

	All adult services	Adult residential	Adult day	Adult domiciliary	Adult community care	Other
	(£)	(£)	(£)	(£)	(£)	(£)
Manager/Supervisor	10	9.70	13.28	9.25	18.28	22.03
Professional	12	11.87	11.88	13	-	13.97
Direct care	6.72	6.45	7.64	7	7.30	7
Other	6.30	6.18	7.33	7.71	8.81	9.23
Registered manager	14.40	13.92	18.90	16.27	15.34	21.72
Registered nurse	11.96	11.88	11.88	13.18	11.75	13
Social worker	25	6.68	1108	6.61	-	28.25
Occupational therapist	14.92	8.33	*	-	-	11.15
Senior care worker	7.15	7.02	9.19	7.42	8.15	9.95
Care worker	6.65	6.32	7.50	8.15	7	7
Community support and Outreach work	7.22	7	8.32	6.97	7.64	7.50

Source – Skills for Care⁷¹

For Residential Care Workers, the National Minimum Wage is often ignored for night shifts, overtime or ‘sleepover’ time when employers calculate the average amount of time that Care Recipients are awake... [they] suffer similar non-payment for training time, charges for uniform, extended hours that are not paid for, and can be charged excessive rates for accommodation.⁷⁰

If providing care in specialist housing settings is going to be recognised as the specialism and profession that it deserves, then such pay levels clearly send out the wrong signal. With turnover rates in direct care roles in housing with care at 20 per cent and shortages of 2.5 per cent, attracting people who thrive and stay in the sector – or better yet, the same care setting – will no doubt be undermined by such rates of pay. In chapter 7 we discuss the cost implications of implementing the living wage in the care sector. The Commission recognises that such a boost for this poorly paid workforce comes at a high price – one that the vast majority of care providers would be unable to afford given

the current funding constraints placed on them, unless they removed themselves entirely from the local-authority-funded market. Adequate funding from local health and care commissioners, plus additional resource from government, will be necessary to prevent an entire bifurcation of the market where better-trained, better-paid staff are the preserve of wealthier self-funders. Commissioners believe that the additional cost of introducing a higher wage level for housing with care workers is not simply a price worth paying but vital to the continued sustainability and quality of the sector.

What happens if you don't qualify for council help? That's my big fear. I live in a housing association and I have very little savings and I would qualify for them to pay for me. And they would just put you in the cheapest place you could be because you don't have a choice.

Member of the public – focus group

Public perceptions

So far, we have discussed the difficult funding situation facing the housing with care sector, and the implications this may have for the care workforce as the biggest single cost in housing with care. Throughout the course of the Commission the problem of public perceptions of the sector also loomed large. It is likely that negative perceptions and an underestimation of the importance of care underpins the funding and workforce problems outlined above. As a 'poor relation' of the NHS, social care and support has never been given the status and priority it deserves, even in the face of clear evidence of its growing role in an ageing society. Housing with care – care homes in particular – is in an even worse place and often the 'last resort' of the care sector, once all community care options have been exhausted. The perception that housing with care is of poor quality – even a place of neglect or abuse – creates a vicious circle: the perception is exacerbated by the poor levels of pay and training, but also drives the difficulties associated with recruitment and retention.

An all-pervading political narrative which focuses on being able to stay in one's 'own home' as the ultimate prize for older

people certainly does not help, when policy makers and local health and care commissioners do not recognise that in many cases high levels of domiciliary care for someone with substantial care needs, who perhaps cannot leave their home, is an isolating – even oppressive – experience. Instead, a move to housing with care is often prompted by a person's support needs becoming 'too complex' for domiciliary care, at least for local-authority-funded individuals. In reality, this is often a result of financial considerations – if a person needs near round-the-clock care, it can be more cost-effective for a local authority to fund a care-home placement than pay for one-to-one home care. Because of this, the move to the care home is understandably seen as 'the end of the line' – an end to independence. The public, led by commissioners and central government, wrongly conflate 'independence' with 'one's own home':

We heard evidence that people have low expectations of residential care, and a tendency to characterise it as 'warehousing' that meets only the basic needs of residents. We believe that this view should be challenged and we concluded that much can be done to make residential care more responsive to older people's needs.

Submission to Commission call for evidence from David Rees AM, Chair, Health and Social Care Committee, Welsh Assembly

Negative views of care homes

Well I mean it's an institution, if you see them in there, they're clocked into this '6 o'clock – eat your dinner, go to your room, we'll undress you, go to bed'. There's no life, it becomes an institution where you're just a vegetable basically. So even if you've got your mental faculties, there's absolutely nothing there to stimulate you.

Member of the public, focus group

It is unsurprising that the public survey commissioned by Demos on behalf of the Commission found that only 1 in 4 people say that they would consider moving into a care home if they became frailer in old age, while 43 per cent said that they

would definitely not move. In the survey, Demos asked all those who said they would not move into housing with care in later life their reason for their answer. The most common answers are given below:

- because I would lose my independence (69 per cent)
- because I would be at risk of neglect or abuse (54 per cent)
- because it wouldn't be like home/would be a foreign environment (48 per cent)
- because I would not want to be surrounded by people who are also old or disabled (42 per cent)
- because the care would not be good quality (42 per cent)
- because I would have to sell my house to pay for it (33 per cent)
- because I would lose contact with friends, family and community (31 per cent)

Worryingly, the risk of neglect or abuse is the second most commonly given reason for not moving to a care home, although 'abuse' was not the most common word people selected when thinking about a care home (see below). Nonetheless, the most common reason given here (losing independence) resonates with people's priorities in later life – where the polling revealed the top priority across the entire sample was to remain independent.

Demos provided eight negative and eight positive words and asked the public to select which they most associated with the phrase 'care home'. As can be seen from table 3, the negative words were far more popular, and of the positives, 'care' was the most frequently chosen – and it is questionable whether this is a fully positive aspect of a care home.

There were some differences in responses given by different age groups, and they suggested that older people know more about care homes: they are more likely to select both the negative and the positive words presented, while young people were more likely to select 'none of the above'. This could be because younger people do not know enough about care homes to select appropriate words. Nonetheless this did not apply to all words – younger people were more likely to associate care homes

Table 3 **The public's responses to negative and positive words associated with 'care home'**

Negative words	Positive words
Old age (76%)	Care (41%)
Boredom (48%)	Safety (22%)
Loneliness (42%)	Community (19%)
Illness (38%)	Comfort (16%)
Isolation (34%)	Friendships (13%)
Disability (31%)	Respect (9%)
Abuse (27%)	Modern (9%)
Uncaring (26%)	Fun (3%)

with 'loneliness', for example, while older people are less likely to believe care homes are associated with loneliness or isolation, and more likely to think they provide safety.

Demos also asked three focus groups of people aged 60 and above what words or phrases they associate with care homes. Their responses included:

- 'old'
- 'stultifying'
- 'petrified'
- 'vegetating'
- 'end of the world'
- 'lots of people asleep in chairs with the TV on very loud'
- 'lack of privacy and dignity'
- 'uncaring'
- 'smelly'
- 'expensive'

The picture that emerges is that the public broadly see residential care homes as places of illness and frailty, pervaded by boredom and loneliness, and where you would only go as a last resort. It is therefore encouraging that we found that those who work in care homes were much less likely to select negative words to describe care homes and more likely to state they would go to a care home. This suggests those with first-hand experience

of care homes have more positive perceptions of the sector than average (see also chapter 2).

Confusion about 'residential care'

The very negative messages about care homes coming from the polling and focus groups were not the only finding from Demos' qualitative research. It was also clear that members of the public were somewhat confused about what a 'care home' might be, particularly as it might relate to the term 'residential care'.

Demos provided a series of descriptions and asked people to select the one most closely linked to the term 'housing with care'. The public tend to see 'housing with care' primarily as a form of care home. The description including medical care was the second most popular option picked, while all sheltered housing, independent living or extra-care variants were distant runners-up to the top two:

- a home with multiple bedrooms, a communal lounge, communal mealtimes and activities organised for residents by staff (40 per cent)
- a home with multiple bedrooms, with carers or nurses who look after people (23 per cent)
- a block of apartments where people live independently, but a warden is on hand in emergencies, ie 'warden assisted' (13 per cent)
- a group of people in a similar situation living together for mutual support, with some input from professional carers or medical staff (9 per cent)
- a 'retirement village' with independent flats or houses and community facilities, eg a café, doctor's surgery (8 per cent)

Unsurprisingly, the biggest age-related difference between responses came in the 'don't know' category – 17 per cent of 18–24s and just 1 per cent of the over 65s selected 'don't know' when asked to select a description for what they thought housing with care was. The linear relationship between one's age and familiarity with the concept of housing with care is unsurprising,

but nonetheless confirms the lack of earlier preparation for one's later years prevalent in the UK population, as well as the sense that housing with care is not a visible and understood part of community life.

In focus groups Demos found that most people used the terms 'housing with care' and 'care home' interchangeably. The groups also revealed that the policy and funding issues described above have entered the public consciousness, and this has had an effect on how people perceive housing with care. For example, some of the over-60s in the focus groups felt that the lack of government spending on housing with care reflected a view that the elderly are not valued in our society. Several people wanted to see substantial government investment in housing with care, to be reassured that it is improving.

The impact of abuse scandals

I do blame the media a lot because they never, never give a counterview. If they're doing something like Winterbourne or whatever, it's always negative, negative, negative. But very, very seldom do you get positive publicity. Very seldom indeed. I believe that the managers of homes are the most important people in the homes. They make such a difference. And they're not honoured like nurses or anybody else; people are rather ashamed of being – not ashamed, but they don't see that it's really a vocation and it is. For some people, it is a vocation and I think it should be recognised and, you know, I'm passionate about this, I really am.

Dame Gillian Wagner, Chair, Residential Forum

It is inevitable that recent abuse and neglect scandals, exposed through *Panorama* investigations and so on and receiving widespread media attention, have negatively affected public perceptions. It is no coincidence that the fear of abuse was reported by over half of those surveyed as the primary reason they would resist moving into a care home – significantly more than those reporting the fear of having to sell one's home.

While high-profile scandals in care homes have characterised the sector, and there is a lack of positive publicity for care

homes, care homes too are often poor at promoting themselves and being proactive and positive about what they can achieve. This impacts on how staff and managers feel about their jobs – care is not viewed as a vocation as readily as is nursing, and some experts consulted during the Commission felt there was a degree of shame attached to the role.

Nonetheless, the experts we consulted in the sector and many of the submissions to the call for evidence were keen to point out that cases of neglect and abuse, while receiving disproportionate levels of media coverage, occurred in a very small percentage of care settings. Many regretted the fact that Winterbourne view – perhaps the most famous abuse scandal in recent years – had damaged the perceptions of care homes so badly, although Winterbourne view was actually a private hospital (under NHS remit) providing assessment and treatment for people with learning disabilities rather than a place ‘to live’.

Recent data from the Health and Social Care Information Centre (HSCIC) show that there were 38,270 substantiated or partially substantiated cases of abuse in 2012/13 among vulnerable people of all ages.⁷² Of those, 39 per cent were perpetrated in a person’s own home, and 36 per cent were perpetrated in a care home setting. Not many of these were at the hands of care staff – 23 per cent of abuse cases in care-home settings were perpetrated by friends or family, 12 per cent by another vulnerable adult, and 20 per cent by staff. Care staff were responsible for around 7,654 cases of abuse in 2012/13.

These are 7,654 cases too many, but as 432,000 people lived in housing with care at the last count in 2012, the figure shows that less than 2 per cent of the population of vulnerable people in housing with care was abused. Such statistics should be further investigated, substantiated and released widely yearly so the public at large has a better understanding of the scale and trends related to neglect and abuse in the sector.

Several people commented that the overall state of the sector is actually very good – particularly its embracing of person-centred care – even though this is not how it is portrayed. Many commented that it is rare to come across places that are

‘not trying’ – more often they are preoccupied by overriding concerns about financial sustainability.

Yet many admitted the quality of care is very variable, and there are cases of substandard care, which needed to be tackled. Examples of very high-quality housing with care are often the more expensive ones, making them unaffordable for most people.

As an example, one expert referred to plans by Alan Milburn to introduce minimum standards for care homes, which were scrapped in 2002 when it was realised that 70 per cent of existing homes would not meet them.⁷³ The issue of ‘mediocre’ care homes was identified as a more widespread problem in the sector than abusive settings per se.

There is a clear need to dispel some of these enduring negative perceptions, not just for the sake of providers who are doing so well and for the morale of the staff working in the sector, but for individuals. We believe that negative perceptions are behind the tendency among professionals and commissioners to treat care homes as a ‘last resort’ even when it may be clear that an individual might thrive in a more collective setting, and for individuals to find the experience of moving into a care home so traumatic.

There is a need to repatriate residential care. For a lot of commissioners, it is almost something to move away from... The assumption is that really good things can only happen outside residential care.

Bella Travis, Policy Lead, Mencap

Evidence demonstrates that an unplanned and traumatic move to care is associated with poorer outcomes and inability to cope with the change in environment and circumstances. In short, dispelling the fear associated with care homes would benefit not simply providers and staff who may feel unfairly tarred with the same brush as a small number of extreme cases, but also individuals who might in fact thrive in housing with care settings, and their families.

More positive media coverage, more recognition of achievement in care homes (such as Skills for Care’s ‘Accolades’, which recognise workforce quality and development⁷⁴), and

increasing direct experience of homes among the public through care home open days might all help, as will undoubtedly the move by the CQC to make the promotion of good practice a more significant part of its function. This does not discount the need for more radical solutions, as we discuss in chapters 6 and 7.

Housing with care is so closely associated with old age, illness and disability, it is not possible to ascertain to what extent people's aversion to housing with care is actually an aversion to the concepts of illness and ageing themselves, rather than to any components of the housing with care offer. One of the experts we spoke to considered that these negative perceptions embody an underlying ageism, which sees older people as helpless recipients of care – and needs to be challenged:

People believe that old age is a time of decline and that nothing can be done to stop that decline and therefore no real efforts have to be made. That is an extraordinarily punishing cultural narrative and it is all around us and it is a major problem.

Dr William H Thomas, co-founder and president of the Eden Alternative

Interestingly, despite similar associations with illness and dying, hospices do not suffer from the same negativity that surrounds care homes, with public opinion far more favourable towards them. There are various possible reasons for this:

- Hospices get paid substantially more for care and have a higher level of skill mix.
- There is a more transparent offer with hospices, which commissioners and the general public understand.
- Hospices benefit by comparison with what else is on offer, while housing with care suffers from the same comparison.
- People perceive a choice between dying in a hospital or dying in a hospice, with a hospice considered the preferable option. For care homes, the choice is between staying in 'one's own home' or moving into 'a home' – 'one's own home' is seen as the preferable option.

A study by the Joseph Rowntree Foundation looking at how older people's care homes compare with other care settings reflects on another possible explanation for the difference in public perception between hospices and care homes:

This could be linked to the fact that hospice care has its roots within the third sector and delivers a single model of care focused on treating individuals' holistic needs: those that are clinical, emotional and spiritual.

In contrast, housing with care for older people expanded in the 1980s in response to the privatisation agenda. Although care homes are based on a similar vision and set of values to hospices, there is no central thread holding them together and public perception is very different.⁷⁵

Demographic change

This chapter has thus far considered the legislative and financial context in which the housing with care sector operates, and the wider public perceptions of housing with care, which underpins the challenges being faced. However, there is an even wider social shift on which all of these debates rest and which sets the context for the Commission's work – the inexorable increase in life expectancy of the UK population: numbers of older people are increasing rapidly relative to younger people.

This shift is due to a range of factors, including improved nutrition and public health, as well as improvements in healthcare and new treatments. This presents a range of new challenges, including the increased prevalence of complex and multi-morbidities in the very old, and exponential growth in the number of people with dementia. Disabled people, many who might have died in childhood just 20 years ago, are living longer – into adulthood and with a desire to live independent lives.

A shift in the housing with care population

Each of these trends brings significant challenges for the housing with care sector. First, demand for all housing with care options will increase as more older people seek suitable housing alternatives (including extra care and retirement village settings).

Second, demand for care homes specifically will increase, as the numbers of older people with complex needs (who may not be adequately supported by domiciliary care) rises. Third, as a corollary of the second point, the people living in care homes are likely to be older, with more complex needs, than in former years – creating a challenge for the majority of staff who are not well trained in health-related matters. Fourth and finally, demand for residential options among disabled people will increase, as more will seek to move away and live independently from their families. This will include supported housing options and other types of housing with support for those with different levels of need.

The experts consulted on behalf of the Commission had fully grasped the implications of an ageing society, including increasing prevalence of dementia, complex, multiple health conditions, and the number of frail elderly now in housing with care – and the increased training requirements for staff associated with this (particularly dementia training) and better partnership working with health services, including primary care (an issue we return to below). As a result of these changes care homes are no longer places where people live actively for longer, but more likely to provide dementia care or support for complex conditions, which could no longer be viably achieved in people's own homes. In some cases, activities and outings have been cut back, as people living in care homes were not really benefiting from them.

Our visits to three care homes to speak to people living and working there pointed to a similar trend. Those we spoke to in all three homes reported that new people were coming to them with more complex health conditions than in the past, and at the Beeches there was a noticeable increase in the number of people with dementia. The management commented that this is a particular problem as many staff do not have the medical expertise to be able to deal with the increasing needs of people moving there. Part of the reason for this trend was felt to be the shift towards 'care in the community', whereby people were being cared for at home for as long as possible and only coming into housing with care when their needs had escalated. This had the effect of increasing the training requirements for staff; one

carer reported to us that he needed specialist training to be able to look after people who were blind or visually impaired. Further, getting to know people is more difficult if they are admitted to care homes later in life, with a more advanced stage of dementia. This negatively impacts the care that can be given, as staff have not been able to form a relationship with the people they support nor were able to find creative ways of meeting their individual needs and understanding their behaviour.

Pressure from the NHS

Managers also reported increased expectations of residential care homes, particularly from hospitals, nursing homes and social services, and this had blurred the lines regarding which provider was responsible for what (particularly where residential care homes take on more nursing responsibilities, making the distinction between nursing and residential care homes less relevant). One care home reported having to turn people away because of inappropriate referrals (eg people with primary dementia) due to other health and social care professionals not being aware of the differences between different types of care homes.

It was felt that this was partly because of the pressure on hospitals to ‘free up beds’ – with patients being discharged with an inappropriate care package and then ending up in a care home when this collapses, or being sent to residential care homes straight from hospital as emergency discharges. One member of staff told us: ‘It’s essentially an offload system.’ This was exacerbated by poor communication between staff in care homes and hospitals – when people were being admitted to hospital, anecdotally it was reported that hospitals did not contact the care home for advice or to find out further information, nor did they provide any information about what hospital treatment or procedures had been undertaken when a person was discharged back to their care home.

One care home close to Stevenage noted that people were being referred to them from much further afield. Although their main commissioner is Hertfordshire County Council, around 40 per cent of people moving in came from the London boroughs.

This may well arise from decommissioning of care homes taking place without properly planning how to meet needs locally.

Other health-related pressures are also buffeting housing with care settings. For example, some settings have agreements in place with a single GP practice to register all people on admission, but this has prompted concerns about removing the right to freedom of choice and access to continuity of care.⁷⁶ Concerns over equitable access to primary and community health services have been substantiated by reports of GPs charging for services provided in care home settings, and evidence collected by the CQC has indicated that in many places access to a range of health care services for people living in care homes (including access to a GP) is inadequate and uneven.

In March 2010, the CQC conducted an online survey of primary care trusts (PCTs) about their commissioning of services to people living in care homes. The British Geriatric Society used these data to conduct further analysis, publishing their findings in their report, *Failing the Frail*. This reported that only in 43 per cent of PCTs were older people likely to have access to all the services they need; just 51 per cent of PCTs had enhanced service agreements with GPs for work in care homes and only 12 per cent of specialist community services involved a care home specific provider; and nearly half of services for which there were data did not meet the CQC's response standards.⁷⁷

Follow-up research led by the British Geriatric Society in collaboration with health care groups reported in June 2011 that ensuring effective healthcare for individuals living in care homes and effective support for care homes seems to be a low priority: 'Financial pressures have been a dominant force in the relationship between local authorities and social care commissioners.'⁷⁸ Observing the absence of a national policy that clearly describes NHS obligations and government expectations of local NHS services for people living in care homes, they concluded, 'It is unclear whether the previous lack of progress in this area is due to ignorance or ageism or the lack of appropriate incentives and sanctions to redress the situation.'⁷⁹

One GP told the British Geriatric Society that people living in care homes

get excluded from a lot of things. District nurses won't go into nursing beds. Physiotherapists are reluctant so [people living in care homes] get excluded from things that are available to people in their own homes. Bringing services in can be difficult.

Many interviewees reported clear inequality in the provision of services commonly available to older people living in their own homes, such as access to specific equipment like syringe drivers (nursing services) or modified seating (occupational therapy or combined equipment stores).

These conclusions were supported by a survey conducted in 2010 by the multi-professional Older People's Specialists' Forum, which is hosted by the British Geriatric Society. In the survey staff in care homes across the UK were asked about their experiences of accessing healthcare services for their residents, with the following findings:

- 68 per cent of care-home residents do not get a regular planned medical review by their GP
- 44 per cent were not getting a regular planned review of their medication
- 41 per cent could not access specialist dementia services such as memory clinics and community mental health teams⁸⁰

In 2008 the English Community Care Association reported that many of its members were paying retainers to GP practices to provide care, including 12 per cent of homes operated by one large care home provider, and these fees ranged from £897 to £24,000 per year, with £7,000 being the average.⁸¹ In 2014, Care England investigated this phenomenon and the prevalence of GPs charging for care delivered in care homes. They found that 30 of 34 care homes surveyed were charged 'retainer' fees, in one case £2,400 a month, to guarantee GP care for people living there. These fees have been justified with labels of 'enhanced care', which is beyond 'core' duties, but providers who ran several homes described the services of those not charging fees as 'equally good'. Other 'profit-motivated' behaviour has been reported by care homes, with GP practices

insisting that patients use the pharmacy run by their surgery as a condition of receiving care.⁸²

This situation is clearly not acceptable. Disabled and older people living in their 'own home' would not be charged for accessing the NHS according to how ill or frail they happened to be under the auspices of 'enhanced care' services, as this is entirely antithetical to a service free at the point of need. When someone moves to housing with care, their right to free NHS care and the proper equipment does not and should not change, and certainly care providers should not be paying the NHS for free services. In many cases the costs of these retainers may well be passed to individuals in the form of higher care fees.

Tensions between diverging needs

Because of the range of needs that housing with care is now meeting, it also seems that people with higher and lower levels of disability are increasingly living alongside each other. There are concerns that mixing the 'younger old' and the 'older old' (who may have dementia or end-of-life care requirements), people with physical disabilities and learning difficulties, or even disabled people in housing with care intended for older people, results in a worse experience for all parties. The potential tensions arising between 'the fit and the frail' was also identified in the review of existing evidence carried out by Demos on behalf of the Commission as an issue facing extra care and other village type settings, who may have people moving in at ages 55 or 60 and who then age in place.

On the other hand, the care homes Demos visited were grappling with whether or not people with varying degrees of dementia should be cared for separately from those who are physically frail but mentally fit. Grouping people with physical and intellectual disabilities together, or people at different stages of a degenerative disease such as Huntingdon's Disease, could also be a challenge for working-age disabled people. One woman we spoke to reported that it had taken her a little while to get used to living with other people who were not as able to communicate as she was, though she says she now 'speaks up for

residents that cannot speak up for themselves'. Nonetheless, this is a tension which may not yet be effectively resolved in the current system – in some extreme cases, disabled adults in their 20s and 30s are still being accommodated alongside much older, frailer people with very different needs and aspirations, because of the limited choice in some parts of the country of appropriate housing with care for disabled people.

The pressure point – need but not demand?

If I had to [move into a home] I would but it would be the last thing I do.

Member of the public, focus group

In the previous section we reflected on the context of an ageing population and changing demographics, and how this is increasing demand in the housing with care sector. However, demand for housing with care options is perhaps a misleading phrase. In reality, Demos' research found there was little 'demand' for much of the sector – while a move to an extra-care setting is often a positive choice, care homes are a different matter. People may *need* a care home, but may not *want* it – though evidence suggests views change with more experience of this type of care.

In the survey undertaken by Demos on behalf of the Commission, people were asked to select one location where they felt they would be able to achieve their priorities for later life. Demos did not include 'at home' as an option, in order to encourage people to consider alternatives. It is likely, however, that 'living with family or friends' will be taken to mean 'living at home', or as close to home as feasible, by most people. The locations chosen are listed below in order of popularity:

- living with family or friends (25 per cent)
- in supported/adapted housing (21 per cent)
- in sheltered or warden assisted housing (20 per cent)
- in a retirement village (15 per cent)
- in a care home or nursing home (2 per cent)

- none of the above (7 per cent)
- don't know (10 per cent)

Sheltered and supported housing grew in popularity with age, and living with family or friends fell in popularity. This may well be as a result of older people having a better understanding of their needs in later life and therefore having a more realistic view of where their needs would best be met. Nonetheless, the care-home option came a distant last place across all age groups. A wide body of evidence suggests that such opinions are linked to people associating care homes with frailty and dependence, and that people's aversion to the prospect of this is a root cause of their aversion to the concept of living in a care home.

Demos asked the same question about people's priorities if they were a disabled person or in poor health, but younger, again, excluding 'at home' as an option. The locations chosen are listed below in order of popularity:

- in supported/adapted housing (42 per cent)
- living with family or friends (33 per cent)
- in sheltered or warden assisted housing (10 per cent)
- in a care home or nursing home (2 per cent)
- none of the above (6 per cent)
- don't know (7 per cent)

These findings were confirmed in the focus groups Demos hosted. People in the focus groups could only see themselves moving into care homes as an absolute necessity – for example, if they developed dementia or were otherwise no longer safe in their home. However, they felt it might be a positive choice for people who are very isolated or lonely – this was the only reason people gave for actively wanting to live in a housing with care environment.

This will prove a challenge for the sector – being positioned as needed but not wanted is a demoralising position from which to innovate or proactively reflect changes in preferences and tastes, and may well be linked to the 'shame' or

‘embarrassment’ some of the experts reported was part of the psyche of the care-home workforce.

The sector’s response

Increased need (if not demand), increased expectations and more complex and challenging conditions – against a backdrop of under-appreciation at best, aversion and fear at worst, and dwindling resources – combine to create nothing short of an impossible situation for housing with care. Under the status quo, it seems the best providers might hope for is to be seen as a necessary inconvenience in an otherwise forward-thinking sector, underpinned by the Care Act’s vision of holistic wellbeing and support. This is an intolerable situation and one which does a disservice to the life-changing role the sector can play in enabling people with otherwise isolating support needs regain their independence, reconnect with their communities, and provide invaluable support to people with complex needs, dementia or in requiring support at the end of life.

That is not to say that all housing with care settings are achieving their potential. While there are a small number of pioneering housing with care settings pushing the boundaries of risk management, activities in the community and so on, and a larger number of good settings where highly dedicated and skilled staff are delivering personalised, relationship-centred care, this may not be enough to respond to the challenges outlined above. There are still many housing with care settings, often care homes, whose staff need to update their offer and think more proactively about empowering people living there. All of those we spoke to living in housing with care settings (including care homes and extra-care villages) were positive about the homes they lived in, but some also commented that they had moved away from their friends, and were less able to keep in touch with them, and that although they were generally grateful to have fewer responsibilities, they also missed having ‘jobs to do around the house’, and felt purposeless.

Complaints about room size, food, routines, and so on reflect the fact that people felt they were being forced into an

unfamiliar environment and were not able to do things in the way they would choose to do them. One woman reported that she had ‘battled’ to get her room the way she wanted it (having her own phone, computer and broadband and kettle to make tea for her visitors), reflecting a wider tension between the interests of the resident and the interests of the home – something that staff we spoke to were working hard to overcome, by adopting a ‘your home, not ours’ mentality, while acknowledging that some conflicts of interest are inevitable in a communal living environment. We heard how some people living in housing with care settings were also aware of the staffing shortages and time pressures the staff and managers themselves reported. Many felt reliant on staff for a lot of things, and would consider their requests for (for example) escorted trips out to place too much pressure on staff and volunteers.

In the next chapter we provide some examples of how care homes and extra care and village settings are meeting some of these challenges in different ways, while juggling resource constraints. Nonetheless, the Commission is concerned that in response to the pressures outlined above, the housing with care sector is splitting into a dual system – where the innovative and pioneering examples of good quality care, like those explored in the next chapter, are increasingly becoming the preserve of wealthier self-funders.

A split in the market

People who have the resources to pay privately have a wider choice of housing with care options to choose from, and may well do so as part of an ‘aspirational move’ to an extra care or village setting. Providers who cater to self-funders – which are an increasing proportion of the market, given the dual trends of fewer older people being eligible for care funding and below-market fees provided for local authority-funded individuals – offer higher-quality service and design, and charge higher prices accordingly. Without outside intervention to fund the market properly and commission appropriately, there is a risk of a two-tier market developing – with higher-quality homes offering

more facilities, activities and opportunities for independence reserved for people who can afford to pay for it, while local authority homes remain underfunded and overstretched.

Future generations of people who may move into housing with care are not unaware of this split. The over-60s whom Demos consulted in focus groups felt strongly that the quality of housing with care was directly linked to price – so people who could afford to pay more could have a very comfortable life and a high quality of care, while people who had to rely on the local authority to fund their care would be stuck in a sub-standard home.

Several people mentioned ‘good’ examples of housing with care that they had experienced (‘good’ features mentioned included an outdoor cafeteria, people sitting outside in the garden, good quality of care) and it was felt that delivering ‘good’ housing with care was entirely possible. However, there was perceived to be considerable variation in the quality of housing with care – especially care homes – on offer, and the main factor affecting this was price. The high fees of the better quality care homes were viewed as prohibitive for most people, and made a considerable difference to whether people could picture themselves moving into housing with care in the future.

Unless the funding challenges outlined above are tackled, it is likely this divergence will continue to the point where the poorest quality homes, with the lowest paid, least qualified staff, are reserved for a dwindling number of state-funded individuals – reinforcing public perceptions of care homes as being places to be avoided and feared – while more modern, higher-quality settings become the exclusive preserve of people who can afford it:

The key factor in producing positive outcomes is around staff – ensuring they are well trained and share the organisation’s values around giving people a sense of belonging and ownership in their lives, creating positive communities and supporting people to make positive choices... a funding model needs to be identified to sustain this; otherwise there is a risk that the care settings with higher staffing ratios and more modern facilities will only be accessible to those with the means to pay for it.⁸³

Summary

In this chapter we discussed the political, legislative, social and financial context in which housing with care currently operates. We began by describing the vision of care presented in the Care Act 2014, and how increased expectations of what all care and support can deliver, combined with straitened resources in order to achieve this, is creating a difficult situation for housing with care providers.

We went on to explain in more detail the extent of the funding pressure on the fees paid by local authorities to housing with care providers, and the implications this had for the workforce on rates of pay and investment in progression and skills. We also reflect on the challenges of the housing with care business model in such a financial environment and the potential instability in the market.

In the second half of this chapter we discussed wider trends – in particular public perceptions of housing with care, the impact of recent abuse scandals, and the general confusion over what housing with care provides and the nomenclature used. We then discuss the impact of demographic pressures in relation to increased demand for housing with care from disabled and older people, and the increase in the number of people with dementia and complex needs among those living in housing with care and the pressures this places on staff and funding, as well as relationships with NHS services.

We have concluded by discussing the ‘need, but not demand’ for housing with care, recognising that providers need to work hard to dispel misconceptions of what they offer and can achieve for people. We also looked to the future, and warn of the bifurcation in the market between local-authority-funded and self-funded provision, which will continue unless the pressures outlined in this chapter are tackled.

5 A better way

In chapter 4 we explore many of the current challenges facing housing with care – increased expectations from policy makers and the public, demographic pressures and an extremely challenging funding situation – set against a wider social anxiety about poor health, disability and ageing, which has culminated in fear, even hostility, towards care homes.

It is an intolerable situation. Yet there are many excellent housing with care settings, providing life-changing support for disabled and older people throughout the country, delivered by passionate, committed and highly expert staff.

In this chapter we bring together some of the examples of housing with care Demos has visited on behalf of the Commission, as well as international examples which the Chair of the Commission visited. There is no one identikit model which makes a perfect housing with care setting. Great care is an art, rather than a science, and a diversity of housing options to suit different needs and preferences is something we must strive to deliver.

Nonetheless, as we described in chapter 3, there are some common features of different housing with care settings the Commission has identified as powerful levers for life-changing support and likely to be effective in meeting the needs and expectations of future generations of disabled and older people, include those who are very frail and in need of end-of-life care:

- supporting people to gain and maintain independence and autonomy (including being able to progress to greater independence)
- taking control and having a sense of ownership over one's life and one's environment

- having personalised and relationship-centred support
- being an active and visible part of one's community
- engaging in meaningful activity and a sense of purpose

The next chapter is loosely grouped into these themes, though great housing with care will deliver on all fronts simultaneously. We end with a reflection on how housing with care is looking to the future – considering approaches which are responsive to an increasingly diverse disabled and older population.

This is clearly not an exhaustive review, but it serves to illustrate that, at its best, housing with care settings, and the staff and managers working in them, are already delivering exactly the sorts of things that people say they want and expect in a long-term care setting, and provides a vision of what the sector might strive for in future.

Independence, autonomy and self-determination

Independence is a key theme arising in existing literature and the field work carried out on behalf of the Commission.

‘Independence’ can mean different things for different people – ranging from self-direction and autonomy to freedom of movement to being able to do things with minimal help and supervision, to privacy and being able to spend time alone when desired. For those with complex needs independence is more about interdependence – the ability to do more things with support. Whichever one's interpretation, having autonomy and a sense of self-determination is identified as a key factor to quality of life and highly prized in later life or if one is disabled.

Conversely, a loss of independence and autonomy is one of the primary concerns for those who resist the prospect of moving into a housing with care setting.

Personalisation

Initiatives to promote independence, autonomy and control over one's care and environment are central precepts of personalisa-

tion, or ‘person-centred’ care, a concept which has been the cornerstone of care and support for many years and a defining feature of the vision of care developed in the Care Act. For many, personal budgets are seen as the primary vehicle through which person-centred care can be delivered, and this can create a challenge for collective care environments, like housing with care. There is a risk that if we become complacent about personalisation – by assuming that personal budgets are the only means through which personalisation is achieved – we overlook some care settings where personal budgets are harder to implement but whose users are entitled to person-centred care all the same.

Personal budgets have been hugely important in making life-changing differences to people using care services, and driving a shift from a service-centred, paternalistic care system to one where the individual is in control. But even the greatest proponents of personal budgets recognise that they are not sufficient for personalisation. Several other factors have to be in place. While we would never suggest denying people the chance of using a personal budget, we must recognise that personal budgets may not be the most effective method of personalising services for some people, and in some situations.

In Demos’ earlier research, entitled *Tailor Made*, we looked at how personal budgets in housing with care might be used to good effect, but also considered alternatives – such as coproduction and codesign, backed up by robust democratic structures to enable people living in housing with care to gain ‘ownership’ of their care as an empowered group.⁸⁴ Personalisation in collective care settings is entirely possible and happening throughout the country, but we must remember that personalisation is not the same as individualisation. Personalisation does not always mean the achievement of one’s preferences in every aspect of life, irrespective of practical limitations or others’ wants and needs. Compromise is sometimes necessary – as it is for everyone in everyday life. This is an important aspect of relationship-centred care, explored further below.

The key in housing with care is to make this compromise legitimate and transparent, and based on negotiation and

discussion, rather than the ‘say-so’ of authority figures. Democratic structures in communal settings should enable people to negotiate with each other, and with the staff and management. A powerful aspiration in housing with care is to treat residential settings as micro-communities, run for *and by* people living there. This does not mean that housing care providers should not strive to ensure that each individual in a collective care setting can pursue their own interests and spend time doing things separately from the group – the best providers effectively balance individual priorities with opportunities to build social networks:

A key differential with residential care options as opposed to other care options is that it involves group living. This offers both opportunities and threats. For some people moving into a community of people there are renewed opportunities to develop friendships and to feel a new sense of belonging. However, for others the loss of own space that this entails can be devastating. Creative residential care options will inevitably involve some compromises when a group of people are sharing the same space for parts of the day, but good design and supportive staff can enable people to retain their individual ‘space’ and sense of self. A person’s own bedroom, for example, can become a place where personal belongings and objects connect to identity and life story and also offers opportunities to welcome visitors with mini private living areas to facilitate this.⁸⁵

Tailor Made explored several strategies which can help deliver personalisation in a financially sustainable way in housing with care settings, including the concept of providing ‘just enough support’ and risk management, developing social networks and peer support, and using volunteers and ‘enablers’ to bring the community into the home and people out into their communities.⁸⁶ In this report we explained how collective decision making and collective empowerment were being delivered even in large care homes by dividing homes into wings, floors or zones, and creating ‘small group living’ where personalisation is easier to achieve, because it relies on the negotiation of competing preferences between a smaller group of people.

The example of Dee View Court is described in *Tailor Made*, a Sue Ryder care home for people living with neurological conditions, which can support 22 people living in small, self-contained units in groups of four or two, with their own kitchen and living space, located off a large internal ‘street’, where communal facilities are located. As a result of this design staff have been able to achieve some of the benefits of small scale living and improved personalisation within a larger-scale facility:

*Breaking up large scale residential and nursing homes into real domestic ‘houses’ within a larger care home offers an alternative to large scale anonymised living. Mixing together a wide range of people and needs sets residential care up to fail resulting in large environments, depersonalised central services and staff overstretched and unable to focus beyond task orientation.*⁸⁷

Powerful residents’ associations are used in some homes, which have responsibility not only for deciding activities and the scheduling of treatments, but also the final say over the recruitment of staff. The manager at Dee View notes that a lot of effort has been made over a long time to embed personalisation and create opportunities for people to exercise choice and control over their day-to-day lives including making decisions about the way the home is furnished through to being involved in recruiting and inducting new staff.

People choose their own menu and have the option of cooking in their home or eating in the communal café. The gardens contain raised flowerbeds so that any resident who wishes can take part in tending them. The facility also contains a hydro pool, which people living there use but is also accessible to the local community. Residents’ meetings are held every month and any proposed changes to the home are always put to people living there first, which brings a sense of citizenship to the home, with people having a say over how the centre is run.

The Chair of the Commission visited Humanitas Bergweg in the Netherlands, an apartment-based care home. Here, the marriage of the personal and the communal has been made explicit. Hans Becker, the founder of Humanitas, described his

philosophy as moving from a focus on cure and care, which create ‘islands of misery’, to a focus on happiness.⁸⁸ He defined happiness as requiring two elements: the individual and the collective.

In individuals the focus is on agency and control. People living at Humanitas rent or buy an apartment for life, their own space, which is designed to adapt as your needs change. Allied to this is a ‘yes culture’ in which staff are not allowed to say no. Instead, they have to work through with the individual what is possible and what they really want.

The collective focus is on belonging, forming groups to reflect interests, creating common links that start conversations, eg dining groups with a real restaurant choice and quality using food to promote social connectedness. The prevailing philosophy is to support the self-determination, self-reliance, fun and community bonding among people living there, employees and families. This relationship-centred approach is explored further later in this chapter.

Humanitas deployed a set of innovations and policy measures to enable this:

- age-proof residential complexes
- the extended family concept
- supporting self-determination and self-reliance among people living there and employees – use it or lose it
- supporting fun, through a positive attitude, surroundings and atmosphere

In order to avoid the creation of ‘misery islands’, Humanitas also stopped clustering people together by need. Therefore older and younger, poor and rich, migrant and Dutch, and people with low and high needs live in mixed groups as a conscious effort to create as diverse a range of relationships as possible – a radically different approach from those in the UK who suggest separation by need is a solution to the tensions caused by the ‘fit and the frail’ living together (discussed below).

Many housing with care settings and their staff working hard to bring personalisation and greater autonomy and

Figure 9 Example of Helen Sanderson Associate's one page profile

One page profile	
Photo Each one page profile has a current photo of the person	Appreciations This section lists the positive qualities, strengths and talents of the person. It can also be called 'like and admire'.
What's important to the person This is a bullet list of what really matters to the person from their perspective (even if others do not agree). It is detailed and specific. This section needs to have enough detail so that someone who does not know the person can understand what matters to them. It could include: · Who the important people are in the person's life, and when and how they spend time together · Important activities and hobbies, and when, where and how often these take place · Any routines that are important to the person	How to support the person This is a list of how to support the person, and what is helpful and what is not. The information in this section includes what people need to know, and what people need to do.

Source: Helen Anderson Associates⁹⁰

decision-making powers to people who live there use Helen Sanderson Person Centre planning tools. This excellent framework, including teaching resources, training and follow-up materials, covers the central tenets of person-centred thinking and can be applied to a range of settings and groups (including children in schools). It spans concepts such as the 'one page profile' (figure 9), coproduction, futures and lifestyle planning, and using personal budgets effectively; it is certainly a valuable method for housing with care to integrate personalised approaches into practice and staff cultures.⁸⁹

Collective empowerment

Autonomy and decision making was very important to people living in care homes whom Demos consulted during this research. People wanted to be able to choose what they did, who they saw, where they went, and how they spent their money, to the fullest extent possible. Demos visited several care settings on behalf of the Commission and saw how this principle is being put into practice, with collective empowerment also being used to enable people living in housing with care to pursue individual interests and achieve personal goals.

At Whiteley Village – a 225-acre retirement village in Surrey (box 6) – self-determination is an important element of life. People are active in planning and running various clubs and facilities around the village, from restoring a shed for use as a clubhouse by the bowls club to moving the IT room to create a space for art lessons, to organising a Burns Night supper and dance. The warden told us that very few events are organised by staff – even if the staff have an idea, it is generally the people living there who get involved to make it happen.

Box 6

Whiteley Village, Surrey

Whiteley Village was founded in 1917, at the bequest of William Whiteley, who stipulated in his will that his money should be used to provide accommodation for older people of limited means. In addition to the 262 original almshouse-style cottages, where people live independently, the village contains 51 extra-care flats and a 110-bed residential and nursing home (known as the care centre), therefore offering multiple levels of care on one site. In addition, the village is well equipped with facilities including two churches, a village hall, bar and café, village shop, bowling green, hairdresser, post office, laundry and activity centre. The village boasts 22 social clubs and numerous events – all of which are run by the villagers.

The barriers between the different levels of care are fully permeable – villagers can move from one living arrangement to another as their needs change, and in both directions. Around 50 per cent of people living in the extra-care housing on site had moved there from one of the cottages, with the

remaining 50 per cent moving in from outside the village. It was not uncommon for people – after initially living in extra-care housing – to move out into one of the cottages to live more independently, as their health improves.

The barriers between the different facilities are fully permeable in other ways – once a week, the care centre hosts a ladies' breakfast and a men's breakfast, which people from the rest of the village come to. People living in the care centre and extra-care flats use the communal village facilities. It is clear to people that they belong to one community, and have the ability to influence what goes on within that community. Having a continuum of care options on one site has several benefits for the village, including cost-effective use of staff and facilities and a continuity of relationships and routines.

The four conditions for moving to the village were set out in the terms of Whiteley's will. People moving there must be:

- *over retirement age*
- *of limited means*
- *of sound mind*
- *able and willing to contribute to the life of the community*

These four criteria significantly alter the composition of the village – few people move there with dementia (though people who develop dementia stay on, moving into the extra-care apartments or nursing home, if appropriate) and people come to the home with an expectation from the outset that they will continue to live full and active lives, and this expectation is borne into reality.

Source: Demos study visit, January 2014

One reason why Whiteley has this culture is that being able and willing to make a positive contribution to the life of the community is a condition of entry to the village. Villagers are encouraged from the outset to get involved actively, and live as part of the community. The research team heard that people who moved to Whiteley and preferred to keep to themselves soon

found that this was not the place for them and moved away again – demonstrating that this lifestyle is not for everyone but nonetheless appeals to people who enjoy community activity. People are not just recipients of care but take an active role in running their village, and by giving something back, they are able to live more fulfilling lives and remain active for longer, which has a positive effect on their health.

Whiteley may well be a special case because of its age and the generosity of the original benefactor; to try to re-create it anywhere else might be prohibitively expensive. However, the principle of encouraging people to be self-organising, by providing facilities but not activities, and developing reciprocal relationships of support by allowing people the opportunity to give something back to the community, are all features that other housing with care settings (whether village-style or traditional care home) should certainly draw on. The flexibility of care offered on site is also an important theme, which we will return to later in this chapter.

Whiteley is to some extent a self-selecting community – people there all have a similar attitude towards life and growing older. This could be appropriate for people with lower care needs and sociable, outgoing personality types. Other communities might ‘self-select’ on different grounds, for example looking for those with a common love of literature or music, a shared professional background, religious or cultural identity, or sexuality (common interests and values were also rated as important by focus group participants). In these cases, people actively choose who they will live with, which automatically contributes to a sense of control, perhaps making them more inclined to play an active part in the residential community once they arrive.

Progression

More disabled people want to live independently when they reach adulthood, rather than living at home with their parents. This can require a very different style of support from that provided for older people – younger people will want to seek

employment, attend training and education, start families of their own, and so on. This may well require help with the transition to independent living, so that young people can learn the skills they need to live alone, such as cooking for oneself, paying rent and budgeting in general. Housing with care is flexible enough to provide such support, acting in some cases as a step-down service to eventually enable people to move to their own apartments individually or with friends.

Housing with care can deliver this well, providing a route to independence and social engagement even for teenagers and young adults (box 7).

Box 7 Step-down support for young people with physical disabilities

Leonard Cheshire Disability's Fethneys service is a residential transition service for young people between the ages of 18 and 25 with physical disabilities. Fethneys supports people to learn the skills they need for independent living with the intention that most people will stay at the service for between 18 months and 3 years.

Transition from childhood to adulthood can be a challenging time for young disabled people and the support provided by Leonard Cheshire Disability is geared towards supporting people to exercise full choice and control over the transition process, ensuring continuity and aiming for better long-term health and wellbeing, access to education, employment and improved social inclusion for all.

Leonard Cheshire Disability operates a key worker system based around the principles of person-centred care and support. People living at Fethneys record their plans and goals in a weekly diary and receive one-to-one support to achieve them. The aim is to give them the confidence and skills they need to direct their own care and support effectively. As one of the people living there commented "Having a key worker is really good – you can build trust and confidence with that person and they get to know your needs really well. This helps us to grow in confidence and work towards our goals faster."

Key workers and other staff support people to learn a wide range of life skills including managing finances, securing employment and voluntary opportunities and directing their own support as well as laundry and domestic skills, cooking, shopping and accessing public transport. To cement this learning, many people work towards a living skills diploma with a local further education college while they are living at Fethneys.

Sue Ryder's submission to the Commission gave an example of this in a description of Livingstone Court, operated by the Linkage Community Trust (box 8).

Box 8 Promoting and building independence for young people with learning disabilities

Livingstone Court is a registered care home, but looks and feels like a supported living setting. It consists of seven purpose-built flats, five single-person and two two-person flats with attached staff accommodation. It acts as a step-down facility for young people with learning disabilities offering independence skills training in a real-world environment. Each flat is equipped with single bedrooms and has its own kitchen, lounge and bathroom.

Over the last 10 years more than 50 people have moved successfully through the service and on to independent or supported living arrangements following a period living at Livingstone Court. Many of these Livingstone Court graduates now live in their own homes within a small community with neighbours whom they have known from college years living nearby. Less than 10 per cent of people who have been through the service in the last 10 years decided that they did not want to move into more independent living arrangements.

The home manager reported:

Generally people stay a minimum of a year. The majority of people need support with managing money, but together with the

college we provide a comprehensive package of practical skills training to cover whatever people need to be independent safely.

Source: Sue Ryder submission

But progression in care – gaining greater independence and autonomy – is not just a preserve of younger people. Many older people moving into housing with care regain some of the independence they lost when living a relatively isolated existence at home through becoming interdependent – ie older people who are very frail, or have dementia, find they are able to do more through the presence of more staff (and other people living there) on hand to support them. The work of staff in empowering people to do more on their own and with a ‘safety net’, the proximity of leisure facilities, and accessibility of buildings, support and social networks nearby can all lead to older people regaining opportunities to go out and socialise and take part in activity when moving to housing with care. Mixed model housing with care – which combine care-home or small-house settings and apartment-style accommodation – can provide an opportunity for disabled and older people alike to move to more independent living should their support needs reduce (or move to more supported living if their needs increase) while maintaining consistency in the staff supporting them and the culture of their surroundings. Even within single site care homes, which can be constrained by bricks and mortar, we have been told of rooms which are for ‘more independent’ individuals, where a small kitchenette had been built and where there are no night visits. We discuss such models at the end of this chapter.

Other less radical channels for achieving a sense of autonomy and control among older people have been provided through giving them a voice, which is embedded into care-home governance structures. This has been adopted in many traditional care-home settings – for example, holding monthly meetings with people living there and their families or starting a ‘wish tree’ for people, family members and staff to request ‘simple pleasures’ that they would like to achieve. Both of these have been implemented at Glendale Lodge in Deal, Kent (box 9).

At national level, My Home Life began a ‘Big Care Conversation’ with an online wish-tree for people to think about what good care ought to be, and to encourage care managers (through resources on the website) to use wish trees and similar approaches in their care homes.⁹¹

Box 9

Glendale Lodge, Deal, Kent

Glendale Lodge is a 32-bed residential care home for older people in the village of Kingswood near Deal in Kent. People living there have a wide range of physical and mental care needs, including for end-of-life care, and all move in from within 20 miles of the home. Glendale Lodge opened in 1996, and has since been extended to accommodate more people. It is owned and run by Extrafriend Ltd – which runs two other care homes in other parts of the country.

Over the past 15 months the home has been implementing some of the principles of My Home Life around building relationships and maintaining identity, including a ‘wish tree’ and a residents and relatives forum.

These principles are very much in evidence within the daily routine in the home, which has a very friendly, informal atmosphere. When researchers visited the home, people living there, family members and volunteers were enjoying a glass of sherry in the lounge before lunch. People’s books and personal belongings were scattered around the lounge, and Henry the cat was about. At lunchtime, everyone sat together to eat the same meal, giving staff an opportunity to chat to people living there and family members in a relaxed setting. The overall impression was of a ‘home’ in the true sense.

Source: Demos study visit, January 2014

People living in Glendale, their relatives and staff meet every three months to discuss any changes or improvements they would like to see. Recent issues to come out of these meetings have included ideas for outings and entertainment (which people

living there decide among themselves) and a complaint about the amount of mislaid laundry; past ‘wishes’ have included requests for home-cooked steak and kidney pie, and for more physical activity. Although modest in themselves, staff and people living there reported that introducing these things had helped change the ‘feel’ of the home: people felt they were being listened to and valued, and felt that they were sharing a homely space with staff and knew more about each other. Research in this field supports such findings, suggesting that having a sense of control over the ‘little things’ is part of a wider sense of ‘environmental mastery’ in care-home settings:

If residents are to have a sense of freedom and choicefulness, they need to be trusted to make at least some of their own important welfare decisions, eg choosing bedtimes, leisure activities, meal choices and seating arrangements. Enabling such choices helps ensure that those who reside in care homes feel in charge of their living space and are not controlled by it.⁹²

So far we have seen how housing with care settings help people maintain (and often regain) independence through creative use of space and provision of facilities, a strong cultural focus on self-determination, and governance procedures that ensure people living in care settings have an active say and decision making powers over how they live their lives and how their home is run. Research suggests that a staff culture of positive risk management is also vital to underpin this – the Joseph Rowntree Foundation’s recent research on ‘risk and relationships’ is informative in demonstrating how an obsession with eliminating risk by care-home staff can create a paternalistic, restrictive environment, which prevents activity and engagement, and undermines relationship-centred care.⁹³ Earlier Demos research on personalisation in care homes described in *Tailor Made* also found that a more positive approach to risk management in hospices might be one reason why these may have a more personalised offer than care homes. One hospice manager reported:

If someone in a residential home or acute medical ward kept falling every time they had been mobilised, there might be a restriction condemning the patient to a wheelchair... In the hospice – this is where the personalisation comes in – within reason, we take a guarded risk. We think it's part of this person's independence to have mobility if that is what they have chosen. It is possible that they may fall a couple of times in a day, but if it's safe and manageable and that's what they want to continue doing, we will give people that extra freedom. It may require a high level of staff, but we want patients to remain as independent as they possibly can. It's about calculating the risk.

A hospital may insist that a patient be washed every day even though they may not, in other circumstances, choose to. [In a hospice] we would aim to follow the patient's wishes, if they chose not to be washed; we would ensure that we check their pressure areas and ensure that they are comfortable, change their sheets, wash their hands and feet etc. But the main thing is what the patient really wants. It's what we all went into nursing to do, to be able to care for people properly and thoroughly and have the time to explore their feelings and psychological needs.⁹⁴

There are other more radical ways in which people living in care might maintain their sense of autonomy. People in one of the focus groups facilitated by Demos on behalf of the Commission were particularly enthusiastic about the prospect of having a financial stake in a residential community, suggesting some form of profit-sharing or cooperative ownership. One US retirement village visited by the Chair of the Commission – Fox Hill Village in Westwood, Massachusetts – was operating a cooperative ownership model, under which people buy a share in the scheme. This protects their investment (which appreciates with the market value of the property), and confers formal governance rights over the running of the community.

Currently, only 0.6 per cent of the UK's general housing supply is co-op or mutual housing (compared with 6 per cent in Germany and 18 per cent in Sweden), suggesting that there is still a lot of scope for expansion. Indeed, in its final report (published in 2009) the Commission on Co-operative and Mutual Housing specifically recommended housing for older people as a growth market for co-op and mutual

housing, as it provides the opportunity for mutual support and companionship.⁹⁵

Even without shifting to a fully cooperative ownership model, some form of profit-sharing (where people are paid a yearly dividend by the owners) would provide a much valued sense of ownership and control over people's surroundings – the loss of which is keenly felt by people averse to 'institutionalised' care-home settings.

Being embedded in one's community

It is a central part of the local community and people are used to popping in and out, and that there are things to do that, it is not just full of very frail old people but for the community at large to have the odd, I don't know, activity, theatre, music, all those sorts of things can take place there so other people go in and enjoy it, and get to know it, it must be a resource to everyone.

Baroness Greengross

Although the perception among the public is that care homes are 'shut away' from the 'community' – which is seen as a separate entity at some distance from the care-home gates, leaving people vulnerable and behind closed doors, the reality is that housing with care settings, including care homes, have always been extremely 'porous' places. People living in housing with care have always pursued their interests and seen their family and friends (and younger people living in housing with care have pursued employment and education), often with support staff to make it possible. Increasingly, volunteers, community groups and local services are coming into care settings and making use of facilities. The Commissioners see a fully porous housing with care setting as one that is fully integrated with, and a natural part of, the local community; when done well it clearly demonstrates how housing with care – including care homes – can be a valuable and highly visible community asset. Care Home Volunteers' submission to the Commission's call for evidence points out the link between

public perceptions and the relative openness of care homes. Nick Trigg, BBC Health correspondent, makes the point that one of the problems with safeguarding vulnerable adults in care homes is that the abuse is difficult to detect.⁹⁶ Unlike hospitals, where members of the public come and go, care homes are private spaces with limited interaction with the public. Opening them up through local volunteers helps them bond more strongly with their community, encourage a sense of belonging in their neighbourhood and help showcase their good work.⁹⁷ An example of this is given in box 10. How this is done needs to be sensitive not only to the needs of people living in housing with care, their relatives and staff, but also, the needs of volunteers. Once again, the focus should be on fostering positive relations between all parties involved.

Box 10

My Home Life Essex FaNS

Essex County Council is supporting a three-year community 'friends and neighbours' movement (FaNS) to leverage and foster the support of community relationships within care homes. My Home Life Essex Community Association (MHLECA), in partnership with Age UK Essex and Independent Age, manages the project, which is a collaborative effort centred around a common aim to maximise people's quality of life according to their individual needs and preferences. Drawing on a volunteer network from local community groups, school and college students and staff, members of faith groups and local businesses, FaNs are groups of people and organisations that wish to take an active interest in the wellbeing of people living in care homes in their area; FaNs promote the links between care homes and their surrounding communities. Spending time with people in a care home is not the only way to be a FaN; the Essex model embraces the multiple ways in which people may be a good friend and neighbour and reflects this in the expectations of their FaNs, which emphasise contribution over obligation.

Within the FaNs project, MHLECA has established a community visitor scheme, which has been running since 2012.

Based on a model of relationship-centred care, community volunteers take on a more permanent role in the care home and are engaged in regular acts of witnessing, caring, noticing and acting to support older people.

Visiting once or maybe several times a week, community visitors act as friends and informal advocates through developing better and more accurate communication and mutual understanding between people living there and their families and staff. Focusing on making connections, initiating activities, providing company, and liaising with friends and relatives, volunteers support the juggling act of care-home staff by providing practical help, such as accompanying people to appointments, or investing in quality time with them.

Community visitors are able to make an impact by making contact with older people, witnessing what matters to them, and taking action that is supportive, addressing the little things that may raise anxieties when left unaddressed – such as how a cup of tea is prepared or moving the flowers. Through the scheme, older people have an opportunity to have relationships with people who are not involved in their intimate physical care.

What is striking about this scheme is the broad range of roles provided, focused largely on befriending, but offering support to people living there, families and care-home staff, as well as forging new links to community resources and, importantly, acting as critical observers. In this way, they are both part of the home and external to the home, their time being used to listen and talk, but also to observe and act.

MHLECA provides training, supervision and support to volunteers. Structured support is provided via six-weekly meetings, and a volunteer ‘charter’ sets out core expectations and entitlements. Community visitors have access to the training undertaken by home staff. One or two community visitors are allocated to a home; MHLECA’s vision is to have two or three volunteers in each residence.

Early evaluation suggests that volunteers have felt limited by the open-ended nature of their role, and unclear about where they may intervene in areas of concern, such as

making medical referrals. Community visitors are not able to provide a safeguarding role and have experienced some challenges in establishing relationships with people living in care homes, often having to tread gently to build up trust and rapport. Volunteers' personal expectations have to be managed; relationships they work hard to establish may be forgotten by the time of the next visit. Nonetheless, overall, the volunteers have found the role rewarding and they look forward to their visits. It has built their confidence and sense of purpose, enhanced their appreciation of the lives of older people, and given them a greater understanding of the life of the care home.

In a report on preparing for ageing, the Early Intervention Taskforce has highlighted some of the limitations of traditional 'befriending' programmes, which 'offer a role only as passive recipient rather than an opportunity for meaningful participation'.⁹⁸ Instead of viewing contact between older people (and others using befriending services) and volunteer befrienders as an end in itself, some programmes are now looking towards more directed and participatory forms of volunteering, drawing different ages together around a common purpose or interest, for example completing homework or having cocktails.

The intergenerational charity Magic Me runs a variety of community arts projects spanning film, drama, photography and music, which bring together older and younger people to create artwork that explores their shared experiences.⁹⁹ Since 2010 it has run the project Cocktails in Care Homes, which hosts monthly cocktail parties at six London care homes, involving people living there, relatives, friends and staff.

The National Council for Voluntary Organisations (NCVO) is currently running a three-year pilot project supporting volunteers to share time and skills on a one-to-one basis with people living in care homes (box 11).

Box 11

NCVO's pilot Volunteering in Care Homes

Launched in December 2013, NCVO's Volunteering in Care Homes is a three-year pilot project fully funded by the Department of Health's Innovation Programme. The scheme allows greater cooperation between care homes and the local community – a key recommendation in the 2012 white paper Caring for Our Future.¹⁰⁰ The purpose of the volunteering activity is to enhance quality of life, build cohesive communities and enable active citizenship.

Volunteers are recruited via their local volunteer centre and will be able to participate in a range of activities, supported with training by the organisation Skills for Care. This might include anything from organising a reading group to taking part in knitting or playing board-games. The pilot will run across five areas of England.

The aim of the project is to identify a standard of best practice in volunteering in care homes. The work will be evaluated by the Institute for Volunteering Research through a series of biannual interim evaluations – interim findings will be shared at a series of 'sharing and learning' events across the country.

Source: NCVO¹⁰¹

In the US, a focused form of relationship building has taken the form of strong links developed between schools and care homes in some states, where people help children with their homework, and children are able to learn more about ageing and illness (box 12).

Box 12

The NewBridge on the Charles, Massachusetts

NewBridge on the Charles in Massachusetts is a retirement community with a school colocated on the site (the Rashi School), which has developed a multigenerational curriculum. The curriculum teaches children about ageing and interacting with older people (eg communication skills, patience). It is

built around a 'continuum of engagement' with different levels of interaction for each year group:

- *Kindergarten and 1st grade – a group of 25 independent living residents act as classroom assistants, helping with reading and Hebrew studies; older people commit to work with the children at least once a week.*
- *2nd grade – pupils visit the assisted living wing at NewBridge, where they learn to interact with older people who may be less physically or mentally able (eg people in wheelchairs, or with memory loss).*
- *3rd grade – pupils learn about immigration by speaking to people living there and staff who have immigrated to the US.*
- *4th grade – pupils interview people living at NewBridge about their Passover memories and traditions. The pupils then create a customised Passover story book for each resident.*
- *5th and 6th grades – children and people living at NewBridge take part in a modified fitness programme, including adaptive sports that all ages and abilities can take part in. Pupils also take part in an eight-week programme called Making Memories, where they learn about Alzheimer's and other progressive illnesses and complications associated with ageing, and visit NewBridge's memory support units.*
- *7th and 8th grades – pupils create and run activity programmes for the people living at NewBridge.*

The programme is mutually beneficial. A scheme manager told us:

At Hebrew Senior Life, multigenerational programming has enhanced the overall quality of life for many participating seniors who are energized by the spirit and liveliness of their young companions. For the Rashi community, this partnership has enhanced learning for students both inside and outside of the classroom. Students learn how to care for and respond to senior citizens in an authentic and meaningful way. More importantly, they learn empathy and how to extend friendship beyond age.

The school already had contact with the retirement village before moving onto the site, and extensive engagement between the school and the scheme's multigenerational programme manager led to intergenerational work being embedded into the school's curriculum.¹⁰² This was essential to get the buy-in of academic leaders who were sceptical and feared additional burdens on the school.

The programming is two-way, with people living at NewBridge offering one-to-one support for pupils, running book groups, providing lived experience to bring history and other lessons to life, eg lessons about the Great Depression.

The different elements of the village (independent and assisted living and nursing care) do not have much interaction with each other, other than when a husband or wife needs change requiring a move. The 'glue' between the different elements is provided by the pupils at the school.

Another example from the US is Sherrell House, a nursing home providing care for older people and short term rehabilitation for all ages, which offers music therapy to people provided by music students from one of the local colleges. The students receive credits for volunteering.

Although the programmes described above are mainly focused on fostering intergenerational relationships, similar initiatives have been and could be set up involving any groups with common interests. The principles of volunteering with a purpose, and reciprocal volunteering where both parties give and receive something, remain the same, and are an important feature of good housing with care.

Colocating with community facilities

Another important way to ensure care homes and other housing with care settings are an integral part of the community around them is to create shared facilities. Housing with care settings which are open to both people living there and people living

nearby were universally praised by the experts consulted during the Commission and the older and disabled people we spoke to. Commissioners believe that housing with care, including care homes, should be viewed as a community resource, and well known in the local area, offering facilities (eg hairdresser, café), activities, rehabilitation and respite, advice and expertise. Initiatives like care-home open days that bring people into contact with care homes may help to demystify them, but a community resource which brings people in regularly (such as a GP surgery) would normalise them.

The Commission is aware of some good examples in the UK of colocation, including Sycamore Hall, Housing & Care 21's extra-care scheme for older people, where the local library and local sub-post office – under threat of closure in this rural location – moved into the extra-care scheme, making it a central part of the town's amenities (box 13).¹⁰³ Whiteley Village (box 6) has a lot of facilities that are used by the wider community – including sports pitches and a fishing pond. A nursery group meets in the village hall, and the local police service uses the grounds for dog training, and has a small office on site. This ensures that there is always lots of coming and going.

Box 13

Sycamore Hall, North Yorkshire

Housing & Care 21's Sycamore Extra Care Scheme in North Yorkshire embodies the potential of extra-care developments to be community hubs. The housing with care development opened nine years ago in the small rural community of Bainbridge, and has become the hub of the village. Housing & Care 21 staff engage closely with the local community to ensure that the development is fully used, looking at innovative ways they can support the village to maintain its community resources.

In 2007, when the village shop was struggling, the manager invited the owners to move to Sycamore Hall, which ensured the village could keep their shop. After the closure of the village post office, a new post office was opened twice a week at Sycamore Hall, and North Yorkshire County Council moved the village library to the scheme; it now operates daily

through a self-issue machine overseen by a volunteer who lives in the village. The site has modern facilities, which are fully used by the wider community: a restaurant and hair salon; rooms for yoga, keep fit sessions and school meetings; a mental health support group; and craft fairs.

Many other countries offer village-style care homes (care homes arranged in small-house units, combined with on-site facilities open to the public; see some examples later on in this section) and this approach is now being adopted more widely for new-build care homes in the UK. Sue Ryder's submission to the Commission included a case study of The Belong Village in Wigan, which supports older people and people with dementia. It comprises a mix of six 11-bed residential households and independent apartments, which surround the central building, to cater to different and changing levels of need. In planning the build, Belong worked with Stirling University (see dementia section below) and a well-known architect to design a model inspired by models such as De Hogeweyk in the Netherlands, which we describe below. Each residential household in the main building has its own discrete staff team. Between 60 per cent and 70 per cent of people in households have dementia, and the entire site is registered for nursing and dementia care. A bistro-café, open to the public, is at the centre of the scheme, but there is also a hairdressing salon on site, an internet café, and a community room, which is regularly used by local groups and organisations to hold meetings and classes. This creates a complex set of interactions with local people, businesses and community groups that help give the Belong village a real community presence and something of value back to the local community.

Belong Village has won a number of awards and more villages like the one in Wigan are planned, but finding the right location in communities and with good transport links is a key requirement and takes time.

While the provision for community facilities (such as a gym, GP surgery or restaurant) may be more feasible in 'village'

style housing with care settings, which are often purpose-built, traditional (single building) care homes can and do also make creative use of their facilities. Many care homes have facilities and grounds which could be of use to community groups who need room to meet, rehearse, hold fayres and so on. As many third sector grants are being cut by local authorities in the face of budgetary constraints, and day centres and luncheon clubs are closing, there is likely to be more demand for such facilities. Partnering third sector organisations would be relatively cost neutral (or indeed, could generate income if meeting space was let) but hugely effective in bringing a wider range of activity into care homes. This is a common approach in the US. The Chair of the Commission visited Mount Pleasant care home, for example, which runs a weekly play group in spare meeting space, while college professors (eg from Boston College) regularly deliver one-off lectures and lecture courses at NewBridge on the Charles, on a diverse range of subjects. Mount Pleasant also used the opportunity of a recent refurbishment to offer a primary care practice (a new model called the medical home) new premises. The practice now provides services to people living at the home and the wider community and is directly linked to the residential home.

Not every residential setting is fortunate enough to have grounds and meetings rooms to spare to allow managers to invite community groups, schools and so on into their premises, but resourceful staff in homes might encourage one-off events, staging of school plays, still life classes, trainee hairdressers and a variety of other activities to take place in their premises. This can both demystify and overcome public misconceptions of care homes, as well as ensure people living and working in homes feel more integral to the community around them. Some warn against engaging in these activities, pointing out that a care home should primarily be a person's home, not a community centre. Nonetheless, the Commission is of the opinion that privacy, peace and quiet can be compatible with care homes being used as a community asset, as long as proper delineation of space (preserving people's 'private space') is maintained and ensuring people living there have the option to

engage and enjoy what is going on, or opt out, without disrupting activities and routines.

In its 2012 report on the care home of the future, the ILC concluded that in order to respond to the pressures of a lack of resources and demographic change, recruitment and retention difficulties and other future changes, care homes should think about becoming a ‘hub’ for community activity. The report explained:

The hub could provide housing for people who live in a care home, but importantly could offer a range of other services not necessarily just for residents but for members of the local community. These might include:

- *health facilities such as mental and physical health, and community hospitals, as well as advisory services*
- *the development of day services with an emphasis on exercise, healthy eating and activities*
- *more generic services and amenities, such as meeting rooms, hair salons, cafés, laundries, swimming pools, gyms and pubs, and open spaces such as walking areas and gardens, especially sensory gardens, which are particularly appreciated by residents with dementia. In one example, a home with a lake allows people to fish there as long as they also meet with a resident during their visit.*

Non-residents’ groups such as exercise groups and swimming clubs from the community could be allowed to use care-home facilities. This would help to normalise the care-home environment for non-residents and the local community and could go some way to bringing people together.

As a place that non-residents could use, the care home could effectively become a community centre, working closely with a number of agencies to operate as a drop-in and resource centre. Hence, the perception of care homes themselves would change and they could potentially become a more desirable housing option.¹⁰⁴

The Chair of the Commission visited many care homes in the Netherlands and Denmark that operated as hubs for their neighbourhood, providing access to day care, home care, advice

and information. These are some interesting examples of hub models and colocation:

- *Humanitas Bergweg* in the Netherlands (a large block with 195 supported apartments for older people needing care and a communal facility for people with dementia) has a central atrium on the ground floor, which acts a focus for community living for people living there and the neighbourhood. It is known as a 'sheltered village square'. A bar, a restaurant, space for clubs, information centre, a small library, meeting space and internet café are just some of the uses of a versatile space. The complex also acts as a service hub for people living in the neighbourhood who need home care and monitoring, with offices for different health services and a 'memory museum'. It incorporates day-care services, catering to a range of religious and ethnic groups. An interesting feature of this setting is that while it is more like a UK care home in design than a care village, it has decoupled its housing from its care elements – leasing and selling lifetime apartments where a mixed range of low to high needs are met.
- *Wiedervogelhof*, also in the Netherlands, provides nursing care in a mix of apartments and small shared units. The complex is spread over four apartment blocks with a mixture of 'house' living and apartments. The scheme is part of lifetime neighbourhood and deliberately blends into the neighbourhood. The home's restaurant (Pieters Brasserie) is designed to be open to the public, and the easiest way to locate the scheme, which operates a care hotel for recuperation, respite care, palliative and end-of-life care.
- In Denmark, *Peder Lykke Centret* is a large nursing home complex sitting in a residential area of flats. Within the nursing home complex itself there is a GP practice that serves the majority of people living there (although they can opt for other GPs if they prefer) and other people from nearby neighbourhoods. The complex includes an activity centre, which caters mostly for people who are being cared for in their own homes. People attend the centre two to five days a week and take part in a range of activities. The fee for attending is 105 DK per month (around £10). The centre caters for around 180 people aged 75–80.

The use as specialist hubs for home care, advice and health services – not just a place for restaurants and libraries – is similar to Heavers Court in Croydon, which Demos visited on behalf of the Commission. It forms part of a dementia ‘hub’ based at the Heavers Resource Centre, which includes a care and nursing home, advice services, community mental health teams and day care. We discuss this care home further below when we explore dementia specialism (see box 17).

Learning, working and activity

An interesting form of colocation is that of housing with care and learning environments, such as schools and colleges. As we have seen above, NewBridge on the Charles is a retirement community with a school colocated on the site (the Rashi School), which is a vehicle for reciprocal, intergenerational volunteering with a purpose. While the Peder Lykke Centret activity centre (mentioned above) caters to people cared for at home and some people living in the nursing home, there is also another activity-based service on site; this has no direct English translation, the nearest being a ‘folk school’. The school offers a range of liberal arts or adult-based education, including computer skills, art, sports, music and literature. The service is offered to around 320 people aged over 60, with an average age around of 75–80. The difference between the ‘school’ and activity centre participants is their level of independence and self-motivation. Many of the participants of the activity centre and/or the ‘school’ move into the nursing home at a later stage. The colocation helps to demystify the nursing home for people who might move there and their relatives, making the idea more acceptable as part of a transition.

A more intergenerational approach is Lasell College (www.lasell.edu/), outside Boston. The college built a retirement village (Lasell Village) on the college campus and has integrated the village into its operation so that the chief operating officer of the village is also a vice-principal of the college, and the two organisations have joint purchasing of goods and services.

The Lasell College–Lasell Village set-up is not unique in the US, as other colleges have provided land for such developments. However, Lasell College has integrated the village into its operation and put education at the heart of the Village's mission. People who live there must take part in at least 150 hours of education a year. The village has been designed to include classrooms and the people who live there can attend courses delivered in the village and elsewhere in the college campus. There is a strong intergenerational dimension with classes being taken by students and those living in the village.

The Chair of the Commission visited the village to see at first-hand how this arrangement functioned in practice. While sitting in the café, he overheard people discussing the latest things to come up in class. He noticed that the discourse among people who live there was not about 'ageing and ailments' but had a future focus relating to the educational dimension of the Village, creating a greater feeling of connectedness and purpose.

When the scheme opened in 2000 it filled within four months, confounding the sceptics who doubted there would be a demand for a scheme which set participation in education as a condition of residence. Today around 95 per cent of people who live in Lasell Village take part in the educational programme and 15 per cent are engaged in college courses sitting alongside younger students. Even people living in the nursing care part of the village continue to enrol and take part in courses as far as their physical or mental capacity allows. In addition, around 40 students are employed in the village in a range of administrative and catering roles to help pay for their tuition in term time and summer breaks, while students taking certain medical courses visit the village to learn about dementia and geriatric medicine.

In Denmark, Hinnerup Kollegiet provides a home and educational environment for children and adults with specialist needs including autism, self-harm, eating disorders, obsessive compulsive disorder and depression. The site consists of one-bedroom apartments centrally located in Hinnerup, providing housing with support in a community setting, offering individual practical assistance with everyday tasks and a programme of leisure activities, as well as group activities in the

neighbourhood. Staff work with people living there to develop individual action plans, with an emphasis on striving for the greatest quality of life. The programme of work is designed to teach compensatory strategies to increase independence, developing self-expression through contact and interaction, and boosting personal and social functioning and development, with the goal of enabling more people to be able to live outside a housing with care setting with less intensive support.

The College works closely with the Hinnerup employment and training service to support an individual's education and employment opportunities, developing motivation and work habits and routines. Training sessions are offered and support teams (psychiatrist, social workers) focus on the development of executive skills. Work plans are documented, and progress reports are used to manage performance and coordinate with support teams.

The range of examples here suggests the opportunity to learn appeals to younger and older people alike. For the former, it may well be linked to the prospect of future employment and progression, by learning independence skills – as we have described earlier in this chapter. For older people it may relate to the opportunity to stay mentally active and have a sense of purpose and focus.

The need for purpose and activity is a consistent theme in the research carried out on behalf of the Commission, with many care home managers in the UK and abroad commenting that only having 'ageing and illness' to focus on and talk about was not conducive to a positive environment. In Denmark, all four schemes the Chair of the Commission visited emphasised the importance of purposeful activity. The manager of Bryggergården (a dementia care home for younger adults experiencing early onset dementia, often through alcoholism) explained that the staff aimed to challenge people intellectually and physically. The first floor of the block is given over to a range of planned and unplanned everyday living activities, a 'life away from their health problems'. The predominance of men has proved challenging when it comes to identifying activities, but a room set up as a pub with pool table where

people meet and socialise has been particularly popular. Other activities include courses and activities run by an educator, with the aim of challenging people intellectually. There is a sensory garden; painters have been invited to lead painting sessions; and choirs have been invited into the care home to sing and lead singing with people living there. The Peder Lykke Centret also has volunteer educators working in the activity centre, mostly providing IT-related training. This results from the Danish Government's decision to move to a wholly e-Gov system, with everyone issued a PIN and having to access public services online.

In the UK most care village settings have leisure facilities and resident-led clubs on site to cater to a range of interests and hobbies, while care home staff work hard to provide a range of activities by engaging with community groups and volunteers. For example, a review of arts activities in National Care Forum (NCF) care homes in 2011 found 82 per cent of NCF members engaged in some arts activities, including singing, dancing, arts and craft. Some of the best examples the Commission is aware of are those housing with care settings that offer people long-term activity 'with purpose', for example through active learning, employment support, continuous engagement in cultural activity, and so on.

In box 14 we describe the living well through activity in care homes toolkit developed by the College of Occupational Therapists (COT).

Box 14 Living well through activity in care homes, toolkit of the College of Occupational Therapists

The living well through activity in care homes toolkit was developed by COT in consultation with people living in care homes and key stakeholders. It is a free online resource of practical ideas to support people living in care homes with the day-to-day activities that are important to them. Training materials and audit tools are available and designed to review and evidence aspects of care, such as personalisation and

choice. The list of activity ideas range from exercise and physical activity to cognitive stimulation, arts, food and drink, gardening and relaxation, household tasks such as laying the table and self-care.

The toolkit has been supported by 1,700 care home managers and staff via the Living Well in Care Homes online network set up to champion dignity, choice and independence for older people in care homes. The toolkit promotes dignity and respect, mental and physical wellbeing, inclusivity and integration in the wider community.

Recognising the diverse needs of those involved in supporting older people, the toolkit is divided into separate resources directed at people living in care homes, their family and friends, care home staff, owners and managers, inspectors and occupational therapists. The individual guides can be viewed online or downloaded, and are available from the COT's website at www.cot.co.uk/living-well-care-homes.

Occupational therapists are experts in enabling occupation, understanding how dementia, long-term conditions and the effects of ageing impact on activity participation. An overarching aim of the project is to draw on occupational therapists' skills to support a cultural shift in care homes required to meet the standards related to activities of daily living, choice and care planning, and a move to person-centred outcomes. Clear statements of the expectations of quality standards and how these can be met are provided, in a way that acknowledges the constraints of those involved. For example, to address the mental wellbeing of older people in care homes, the section for staff provides suggested actions for 'when you have less than five minutes'. A helpful tips section provides practical suggestions for dealing with common difficulties when working in groups. The residents and families section provides a description of what it means for staff to be person-centred, relating this to their day-to-day interactions with staff.

The location of new builds

If people living and working in housing with care are to continue to play an active part in the life of the community, new care facilities will need to be built in locations where they are visible and accessible. Several of the experts who gave evidence to this Commission stressed that having access to local shops and amenities was important in allowing people living there to be as independent as possible and felt that new care homes in particular needed to be centrally located wherever possible.

This can be challenging when land is scarce and costly, although examples of former pubs and hotels being converted into care homes are an interesting development, which could enable new housing with care options for older people to spring up in central and accessible locations. Building care homes on the sites of colleges and hospitals, as the Commission has seen in other parts of the world, would also help make care homes more visible and centrally located, and overcome the shortage of land that can cut off valuable additional supply of housing with care.

It is easier for housing with care settings that operate with smaller, apartment-based living to locate in town centres and be distributed among other housing, as we describe in box 15.

Box 15

Eden Square, Greater Manchester

Eden Square consists of one- and two-bedroom supported living apartments in a new town centre shopping development, supporting 12 adults aged over 18 with physical and/or learning disabilities, requiring 20 or more hours of support a week.

Eden Square was developed following feedback from people in Leonard Cheshire properties, who said that they wanted better transport links and more accessible properties. The flats are located above shops – six are fully accessible and adaptable, the other six are regular flats distributed among 50 or so privately owned flats. Leonard Cheshire has an office on site, and staff are available 24 hours a day, if required, but because of the scheme's location it is safe for them to go out to local shops and cafés unsupported, and become part of the local area.

Most of the people living there use direct payments – the scheme is not directly commissioned from the local authority. This can present a challenge in planning staffing levels, so the service relies on a bank of part-time and occasional staff, in addition to a core staff employed on permanent contracts to ensure continuity. Thus it is possible to increase and decrease support levels, as determined by the people who move there.

The service manager reported to the Demos research team that traditional supported living (shared apartments) was not always the most suitable option for disabled people, as not everybody likes to live in a shared environment – there need to be more options available for people who prefer more privacy, which is what this scheme offers. She explained that what is classed as ‘housing with care’ is largely defined by the regulator. For example, Eden Square is not registered as housing with care because people rent their flats separately from the housing association, and only the personal care is provided by Leonard Cheshire. The scheme is intended as a long-term residential option, and does not offer respite or reablement services.

The service focuses on developing and maintaining independence, by providing support with all activities of daily living. This involves a lot of work on life skills (eg cooking, cleaning, shopping), health, work and volunteering, and friendships and relationships.

There are a number of benefits to living in Eden Square:

- The service that Leonard Cheshire offers is very discreet – the flats are not visible from the outside as ‘supported living’ flats, the carers do not wear uniforms, and unlike other supported living arrangements, they are not a constant presence in people’s homes, but are on site and available when needed.*
- Privacy is the norm rather than the exception – people at Eden Square can be left on their own, and have control over who they let into their homes and when.*
- It is easier to maintain family life and friendships at Eden Square than in a traditional housing with care setting – people*

can have friends and family over to visit and stay whenever they like.

- It is cheaper to run for the local authority than providing domiciliary care in private homes, as there are economies of scale (eg providing night cover to several people at once, rather than individually) because of Eden Square's geographical proximity. This allows peoples' personal budgets to stretch further.*
- The support can also be much more flexible and responsive, if people want to change the times and length of visits, for example. People have a lot more control, as carers support a smaller group of people all in one place.*

Overall, a scheme like Eden Square balances the benefits of a traditional care home (economies of scale, support on hand when people need it) with the benefits of living in one's private home (having your own front door and furniture, privacy and independence). The service manager felt that the model itself was reasonably 'future proofed', as it was demonstrably delivering economies of scale for the local authority, while also providing more of what people want in a responsive way. For example, if in the future 24/7 care is no longer required, the service would rethink its function and perhaps scale down its offer.

Fostering relationships

The review of existing research and the field work carried out during the Commission's work is unequivocal – rewarding, respectful relationships with other people and the staff who support you is key to quality of life for people living with support needs. As we describe in chapter 2, relationship-centred care is seen as a central tenet of good quality care and part of the evolution of personalisation. Building more positive relationships within and around care homes is one of the key aims of the My Home Life programme. The concept of 'relationship-centred care' places emphasis on the importance of positive relationships between the different parties involved in

care – people needing support, their families, and care staff, as well as the local community and wider health and care systems – first and foremost. The phrase was first coined by a task force established in the US in the 1990s to review the ability of the American healthcare system to meet future demand.

The *My Home Life* programme draws on Nolan et al's Senses Framework for its definition of relational care, which highlights the importance of fulfilling six senses in residents, relatives and staff in order for them to be in good relationship with each other:

- a sense of security
- a sense of continuity
- a sense of belonging
- a sense of purpose
- a sense of fulfilment
- a sense of significance¹⁰⁵

Commissioners believe the incorporation of MHL principles into housing with care settings, for both older and disabled people, provides a valuable practice framework through which organisational culture and process can be shifted to create a relationship-centred, personalised and enabling environment. However, Essex County Council has also begun to use the MHL framework for the commissioning and support of their local care home market, replacing the previous Quality Monitoring team in the council with a small Quality Improvement team, changing its relationship from a 'hands-off' punitive approach to monitoring, to working in a supportive way with care homes to achieve better outcomes for older people.

The MHL themes have become part of the council's contracting and procurement processes, meaning that funding and contractual decisions are based on quality outcomes, rather than traditional measures such as numbers of people or beds. Essex also repeatedly commissioned the MHL Leadership Support and Community Development Programme to help facilitate a support network for care home managers in the local authority to learn from each other and share ideas for best

practice. The early evaluation of the approach, entitled *Commissioning Relationship-Centred Care in Essex*, has found that:

*There are signs that through modelling relationship-centred care, managers have begun to shift the power dynamics between staff and older residents. In some homes, there is a concerted effort to move away from too much focus on physical tasks towards more positive relationships and individual outcomes for older residents.*¹⁰⁶

In other parts of the world, relationship-centred care takes other forms. Public perceptions of nursing homes in the Netherlands is, like the UK, fairly negative; however, the philosophy of care is holistic, promoting a normal life and encouraging people to maintain independence and enjoy everyday things, the goal being to promote wellbeing and happiness. Whole staff teams – domestic, care and medical – are united by the common purpose of enabling people to lead a good life and some care providers train all their staff in hospitality and rely significantly on volunteers to achieve this; they are recognised as part of the care team.

As we described above, Hans Becker, the founder of Humanitas, explained to the Chair of the Commission how he avoided ‘islands of misery’ through concerted efforts to forge relationships across people living, working and visiting Humanitas Bergweg. The manager at De Hogeweyk, a Dutch dementia care village described below, said that hospitality was an important consideration when training staff and volunteers. She described the nursing care aspect of the scheme as being a ‘backstage function’; supporting people to lead everyday lives is what everyone sees ‘on stage’. The Mariënhorst and Mariënhoevel apartments – independent living apartments built in the vicinity of a nursing home – have a similar philosophy, looking at the needs of people living there as a whole rather than simply focusing on tasks. Again, the idea of hospitality featured and the importance of the staff being involved in people’s lives reflects the central role of relationships. In addition to the staff being engaged in people’s lives, emphasis was placed on involving families in the care of their relatives

Relationship-enabling environments

Although relationship-centred cultures can and often do operate independently of physical setting, it is also true that the physical environment of care can have a determining effect on the relationships formed. Many of the sites we visited in Denmark and the Netherlands operated with a central hub and avoided long corridors, creating ‘houses’ (small group living) within larger care homes. All of these steps were taken actively to foster community or ‘family’ life, with strong relationships formed between people living there and between them and staff.

The Commission is aware of an innovative approach taken by Glendale Lodge in Kent, which demonstrates that innovative use of space to create small group living can be achieved within a traditional care-home model (box 16).

Box 16

Glendale Lodge, Deal

The care home Glendale Lodge has been divided into four colour-coded ‘zones’, with care staff in each zone wearing correspondingly coloured uniforms, so that they are easily identifiable to people living there and visitors. Staff always work in the same zone, supporting the same group of eight people. Care staff run their own zones, with minimal interference from the manager. Carers in each zone organise their own trips and other activities at the request of people living there, and keep track of what is happening within their small group of people in dedicated handover books.

Reorganising staff into smaller teams in this way required no extra training, as it was simply making better use of skills that were already there, and many of the suggestions (such as the handover books for each zone) had come from staff themselves. ‘Staff’ include not just care staff, but also cleaners, laundry and kitchen staff, all of whom get to know people’s preferences.

Although none of these features is radical in itself, they have changed the ‘feel’ of the home as a place to live and work as they have been introduced. Smaller group living and consistency of staffing provides greater opportunities for developing meaningful relationships. This has brought a number of benefits in a very short space of time:

- *Improved wellbeing – including health, mood and mental health symptoms, and reduced visits to the GP.*
- *People report they are listened to and valued.*
- *Better quality care – the smaller teams and higher level of autonomy make staff more accountable for the care they give.*
- *Smaller teams enable staff to be quicker and more responsive in helping people, allowing them to have their own routines as far as possible.*
- *The effect of all of these things is ultimately to give people a more fulfilling life, and to create an atmosphere that feels more homely.*
- *Staff sickness has fallen drastically and staff report higher job satisfaction and morale.*
- *Staff reported feeling as if they were working as part of a team, knowing the people they were supporting better, and feeling more positively towards them.*
- *There was improved ability to negotiate with people and relatives because of better relationships.*
- *Staff felt they had more freedom to problem-solve and make decisions without referring to the manager every time, while the manager recognised the system made better use of staff skills, aptitudes and compassion.*

Another approach to a relationship-centred environment is the ‘green house’ model founded by Dr Bill Thomas.¹⁰⁷ Ten to 12 people needing support live in a green house setting, where the kitchen is at the heart of the house, with a communal living room, no long corridors, and none of the usual items of equipment that medicalise the setting. Staff do not wear uniform and are trained in hospitality; they carry out a range of support and coordination roles while linking to a clinical support team. Sitting round a table and eating together is an important part of life in a green house, with the express purpose of creating a family-style environment.

The Chair of the Commission visited two green-house-style care settings in the US – the White Oak Cottages at Fox Hill Village and the Florence Leonard Centre for life.

The Florence Leonard Centre is a block of specially designed flats, where each floor has two green house model wings that are home to 10–15 people. The centre has flexed the model to cover rehabilitation, long-term nursing care and specialist support for MS and MND. Staff turnover at Leonard Florence is around 10 per cent, achieved through a combination of paying higher wages than nursing homes and providing a range of staff benefits, including insurance cover, a company-matched pension scheme, company grocery store providing free groceries, and a flexible spending account. The issue of wages and staff benefits is an important finding, as it supports our evidence in chapter 6, and subsequent recommendation in chapter 7, that giving the living wage to housing with care staff has a positive impact on recruitment and retention.

Fox Hill had built two cottages and set them up on the green house model to provide assisted living. At the heart of the model is the way the staff are organised and trained. The idea is to have versatile workers who undertake a variety of roles, and there is a very flat management structure. The quality of the relationships between the workers and the people living there is crucial. Staff retention at White Oaks has also been very high – since they opened in April 2012, no members of staff have chosen to leave (seven have been fired). The feeling was that the green house model helped attract and keep staff, but that the novelty was beginning to wear off, and they were now looking at ways of re-energising and re-inspiring staff through team building exercises, social gatherings, increasing the frequency of team meetings, giving staff more of a voice and consulting their views more.

The green house movement has given rise to variations in the US; one is known as the ‘small-house’ model. It adopts some of the same design principles, but does not apply the philosophy to the whole redesign of the service. The green house model has been imitated to varying degrees in other countries, borrowing either the household scale element, the versatile-worker element, or both. For example, Flintholm care home in Copenhagen has been specially designed with dementia in mind. The building is oval in shape and the apartments are

on the outside with a central space on each floor, which includes a kitchenette, where food is plated, and dining tables and seating. The appearance is very similar to the design approach used in the green house model in the US, but the staffing model is more conventional – while it uses staff in a flexible way, there is a hierarchy of qualifications and competencies. The housekeeping team is supported by nurse practitioners and social workers who act as consultants and coaches. The nurses make judgements about involving the doctor, and the social worker does the same with the psychiatrist. The scheme was a prototype for a new generation of homes being built by the local municipality.¹⁰⁸

The Chair of the Commission also saw the small-house and versatile-worker approaches used in the Netherlands, though in both countries the green house approach is not mainstream. In De Hogeweyk, a dementia care village in Amsterdam, people live in a ‘house’ with six or seven others who share similar tastes and outlooks on life. These matches are very important to the model of care and to supporting people to lead as normal a life as possible. The village is designed around a network of ‘houses’, which have been dressed to reflect a range of different lifestyles. Every ‘house’ has a front door to the outside, albeit within the village. In contrast, Wiekslag Krabbelaan is a Dutch house-style care home on a much smaller scale, with two purpose-built ‘houses’ connected by a common room and colocated with the more recent addition of a day centre. Weidevogelhof, another care home, operates a mixed model with some ‘house’ schemes and a more traditional nursing home but with larger two-room apartments.

The common features of these Dutch care settings are a living room and kitchen at the heart of the scheme, with individual rooms or apartments and shared bathrooms. Even in large multistorey blocks, the internal design aims to maintain a more homely feel and the philosophy of care was reflected by the design of the buildings. It was common for staff working in these small, ‘homely’ environments to eat meals with people living there and not to wear uniforms, creating a family atmosphere and engaging with people.

A new initiative is under way to bring the green house model to the UK. Evermore, which aims to create a household environment for people aged over 80, was formed recently and has started building its first home.¹⁰⁹ The Evermore model is like the green house in that people live in small households of between 10 and 12 people, with each person having a one-bedroom apartment with its own living area and kitchenette. The apartments open into a communal space with living area and hearth, open plan kitchen and large dining table. Staff operate on the versatile-worker model, and people purchase care packages when they need them. Evermore's first home, with 60 apartments grouped into houses, will begin construction near Burnley in autumn 2014.

Responding to social and demographic trends

So far we have explored how housing with care settings, including care homes, can deliver the outcomes we identified in chapter 2 as being important for people if they were disabled or older and in need of support. A sense of autonomy, control or ownership over one's life; the importance of focused activity and purpose (or perhaps learning) and community engagement; prioritising meaningful relationships; an active home life and having the right support if one is frail or near the end of life are all vital to people's quality of life. The way this can be achieved in different settings varies, with village layouts, individual apartments and traditional care-home models all finding their own ways of delivering on these fronts. In addition, what people think of as self-determination and autonomy, community life and relationships also varies. Younger people are more likely to prioritise access to employment, training and raising a family while older people might prioritise the ability to remain physically and mentally engaged, pursue hobbies and overcome isolation.

While it is important to think about how housing with care delivers the outcome disabled and older people want now, it is also vital to think about how the sector meets emerging needs and preferences in coming years. As we discuss in chapter 4, the

older population is becoming more diverse, and people are likely to grow old with more complex needs. Dementia, in particular, will be far more prevalent. The numbers and diversity of disabled people living into adulthood and seeking greater independence from their families, wanting support to work and have families of their own, will also increase; the need for opportunities for progression for younger people, and to step-down support providing independent living skills, has already been described. Good practice in housing with care must adapt to these emerging and changing needs. We explore how some housing with care settings are already future-proofing their offer in this section.

Dementia care

*Given the prevalence of dementia in care homes is so high, providing good quality care to people living with dementia must be the core business of homes.*¹¹⁰

Research on dementia care and design in residential settings is patchy. The Dementia Services Development unit, based at Stirling University, offers some very useful guidance for care homes, with the ‘virtual care home’ tool providing a range of design plans and room layouts to help care homes reconfigure rooms and public areas, making them easier for people with dementia to navigate. It also offers a series of guides on the use of lighting, colour, applying design to kitchens and bathrooms, and so on.¹¹¹ Several of the experts we spoke to referenced this work and felt this should be standard practice for refurbishment and new build for housing with care.

However, practical advice on how care itself (rather than care environments) can be tailored to support people with dementia is more limited. It is instructive that Barchester published a report about how staff in one of their homes changed their practice to improve quality of life for people with dementia; the project required staff to observe people closely rather than provide care (see, not do).¹¹² The insights gained prompted staff to re-organise their work processes so that they

could concentrate on small groups of people in designated parts of the home. As a result, people received more consistent staff attention and a smaller physical territory to manage. They became less distressed, regained their appetite, and so on. This suggests more pioneering providers are improvising and responding to the specific needs and behaviours of people they support, rather than copying an ‘off the peg’ dementia-friendly care style per se.

With this in mind, there is much to learn from care homes and villages around the UK and abroad in the types of design and styles of care they have developed to ensure the increasing numbers of people with dementia they support remain independent and enjoy a good quality of life for as long as possible. The Commission is aware of the good work undertaken by the Social Care Institute for Excellence, the College of Social Work’s communities of practice, and charities like Alzheimers UK in ensuring this good practice is shared and disseminated, and hopes the CQC’s increased focus on sharing good practice as part of its inspection role will boost the rate at which innovation and new insights are spread across the housing with care sector.

Examples of good practice are described in boxes 17 and 18.

Box 17

Heavers Court and the Croydon Memory Service, Croydon

Heavers Court dementia hub is an excellent example of dementia specialism that Demos visited on behalf of the Commission, demonstrating colocation and integration with other health and care services, providing a service to the wider community, innovative dementia-friendly design and technology.

It is a residential care home with one wing of nursing care. The building also accommodates two day-care centres, Croydon Alzheimer’s Society, NHS community mental health teams, and the Croydon Memory Service. There are up to 60 people living in Heavers Court at any one time, most of whom have some degree of dementia.

Heavers Court forms part of a dementia 'hub' based at the Heavers Resource Centre, which includes a residential care and nursing home, advice services, community mental health teams and day care. The idea of the 'hub' is to build links between different parts of the health and care system (who may be unused to working together – particularly GPs and voluntary sector), and spread dementia expertise, so that it is not concentrated in one place. This has the effect of smoothing the transition into housing with care, and stopping people from coming into the system either too early, or at crisis point. By managing capacity throughout the whole system, dementia can be detected earlier, more hidden dementias can be picked up, and appropriate low-level support can be provided to help people manage at home for longer.

Having services colocated in the same building helps to facilitate this by increasing familiarity among service users (who may come in to use the day centre before they move into the care home), and by acting as a centre for excellence, allowing best practice to be disseminated into the community (eg dementia discharge nurses, dementia-friendly wards in hospitals).

The Croydon Memory Service is a new model for early diagnosis and care for people with dementia, formed in 2003. The multidisciplinary team includes social workers, occupational therapists, nurses, psychologists and psychiatrists. Any member of the team can make an assessment, and the multidisciplinary team as a whole makes the diagnosis and forms a treatment plan (eg involving day care, aids and adaptations around the home), which is then reviewed by the team every six months. The Croydon Memory Service is intended to be a low-cost, high-throughput service to ease pressure on the health services, and provide extra capacity for assessment and diagnosis.

The service has had a number of positive outcomes – diagnosis of dementia in Croydon has increased from around 25–30 per cent to 65 per cent as a result of the extra capacity.

Box 18 West Hall Anchor care home, West Byfleet

West Hall was last year's winner of the Dementia Care Awards care-home category. Using colour coding, memory boxes outside people's rooms and no mirrored surfaces in lifts enables people living there with dementia to make their way around their home and back to their rooms with little assistance.¹¹³

Every member of staff is trained in working with people with dementia and care is guided by the Helen Sanderson person-centred care approach (mentioned earlier).¹¹⁴

An interesting aspect of how West Hall is designed is that each of its floors is reserved for different stages of dementia – so people at earlier stages do not live alongside people at the more advanced end. The manager of Heavers Court, a dementia 'hub' care home in Croydon (box 17) told us that people living together with and without dementia, and people with mild and more advanced stages of dementia, often caused frustration and distress on both sides, but it was often unavoidable. This is a similar problem in care villages, where people age in place at different rates, creating a division between 'the fit and the frail'. Some studies of life in extra care find this can cause social tensions.¹¹⁵

Dividing care settings into floors, wings or other 'homes within a home' are innovative uses of space the Commission is aware of that can help ensure people do not need to move from their home (whether a care home or in a village setting) when their needs change, catering to different levels of need and being sensitive to group living dynamics. The Belong Village in Wigan, mentioned above, with its mixed model of apartments and 'house-style' care homes on one site, is a good UK example of a more purpose-built approach to this issue.

In the Netherlands divided care settings are used to great effect for people with dementia. For example, Wiekslag Krabbelaan consists of two 'households' for people with dementia, as well as upper floor apartments for older people still living independently and therefore allowing for transition.¹¹⁶

Weidevogelhof creates a ‘lifetime neighbourhood’ providing rented sheltered housing for a mix of care needs.¹¹⁷ This includes sheltered apartments, some for people needing nursing care, apartments for people with dementia and some that can be reconfigured to accommodate more dementia care, as well as a ‘care hotel’ providing rehabilitation and hospice care. We describe these ‘continuum of need’ approaches in more detail in the next section.

In the De Hogeweyk dementia care village, 152 people with dementia (average age 83) live in one of 23 ‘households’, each of which is designed to re-create one of seven lifestyles that people were accustomed to when they were younger (eg urban dwellers, culture-lovers, Christians).¹¹⁸ Every ‘house’ has a front door to the outside, albeit within the village. The village feel is created by a series of interconnected named ‘streets’, which includes its own shop, theatre, restaurant, café, hairdresser and social activities; people can move about the village safely, as they wish, and keep up their normal routines. The building was purpose-built in 2010, on the site of a more ‘traditional’ nursing home. The village concept was a deliberate rejection of the traditional nursing home model on the grounds that they do not reflect the normal rhythms of a person’s life, and therefore can be disruptive to a person living with dementia.

Another interesting feature of De Hogeweyk, also found in Anchor’s West Hall and something which Commissioners believe should be a central tenet of all housing with care catering to older people, is that all staff at the village (domestic and care staff) and volunteers are trained in hospitality, dementia, lifestyles and the vision and values of the organisation. Everyone is expected to facilitate the people living there in having a good life. For example, we heard how the bar staff keep an eye out for people who order drinks but leave before it has been poured, and remind them of why they came. De Hogeweyk employs a full multidisciplinary team of doctors, psychiatrists, nurses, social workers and care assistants. They develop a life care plan in conjunction with a named member of the family or with an advocate. The emphasis is on a holistic approach to the person’s needs.

Another approach to dementia that seems specific to the Netherlands is that local authorities place a shared duty on care providers to locate and operate an information and advice centre in their schemes – at least one per town – so providers share the responsibility for funding them. Each centre offers information and signposting and is aimed at being the place people concerned about early signs of dementia and concerned family members can be referred.

In Heavers Court in Croydon and the dementia centres in the Netherlands the purpose of the ‘hub’ model is to support people with dementia living in the local area. However, the idea of housing with care acting as a coordination point for other services is not just relevant to dementia care. Commissioners believe is an important and fruitful avenue for care settings to explore. Several of the schemes seen by the Commission around the world include work space for welfare officers, district nurses and consultants, as well as advice services for disabled or older people. We explore this further in the next chapter.

Specialisation

Commissioners strongly believe that housing with care providers should do more to claim their rightful place in a modern care system. Housing with care staff and managers have invaluable expertise in supporting disabled and older people with a range of conditions, and this could and should be shared with the neighbouring community. They are under-recognised and under-used but they, and the care homes and villages they work in – are valuable assets. Not just, as we explain above, as a place where facilities like GP surgeries or libraries might be based – but where specialist advice and expert knowledge can be accessed by those supporting people at home. In the same way as hospices provide hospice-at-home services, training and support for family members, and advice about end-of-life care, so too should housing with care staff offer information and advice, and provide expert outreach, training and family support for people caring for older or disabled relatives or friends.

Heaver's Court Dementia Hub is an excellent example of how a care home can become associated with a specialism and benefit the wider community by pioneering new approaches and spreading expertise regarding a particular condition. Care homes that tend to specialise in one condition, like Sue Ryder's Dee Court, can become beacons of expertise in how best to support those in a similar situation – in this case, with neurological conditions. More generally, staff in care homes and villages that support older people can provide advice for older people, and expertise on geriatric conditions, dementia and end-of-life care, and be a centre for consultants and other specialists. Their staff should be able to offer outreach and 'care home at home' services, helping families feel more comfortable with frailty so as to support their older relatives for as long as possible in their own homes.

The housing with care specialism could take other forms – for example, offering rehabilitation and reablement, short-stay and respite care are all avenues worth exploring for care homes and villages looking to diversify the types of services they can offer. Engaging with local health and care commissioners will be vital in achieving this, but housing with care must also work hard to promote themselves as centres of excellence in dementia and end-of-life too, highlighting their expertise and investing also in their staff and facilities accordingly. To reflect a more diverse disabled and older population, housing with care settings are further specialising their offer, with some homes dedicated to cultural or linguistic groups, but more can and should be done.¹¹⁹ For example in Copenhagen, one care home, Bryggergården, catered to the relatively recent phenomenon of supporting people with early onset dementia and underlying health problems caused by alcohol abuse. Another in the same city – Peder Lykke Centret – has recently been designated a centre for meeting the care needs of ethnic minority populations so that the immigrant populations of the area – including Chinese and Turkish older people – can be cared for alongside older Danes.¹²⁰

There are groups currently underserved by the housing with care market, for example people with Down's syndrome living beyond middle age who develop dementia, and older

people with HIV and Aids. There are opportunities for specialism by providers to cover these groups.

Creating a continuum of care

If you go into some level of residential care and then if your health deteriorated – or these homes don't give 24 hour nursing for example – you'll have to move again and move again and it's all very stressful and upsetting.

Member of the public, focus group

Demographic change and medical breakthroughs allow disabled and older people to live longer with support needs, which are likely to change over time. This could necessitate moving from one care setting to another as needs grow and later life lasts 10 or 20 years – for example, a move to retirement housing might be following by a move to sheltered accommodation, and then a care home. However, some housing with care settings are now developing mixed models to allow multiple needs to be supported on the same site without people having to move. Many of these have been mentioned throughout this chapter already in other contexts; several of the housing with care settings visited in Denmark and the Netherlands combined apartments with 'house-style' group living and a traditional care home on site to allow transition between these as people's needs progress (or as they regain independence). Several of the experts interviewed on behalf of the Commission talked positively about models that combined 'intermediate' and 'full' care on the same site, catering to different levels of need, but warned that this kind of model posed challenges for regulation, registration and inspection, as homes are operating under more than one framework. Regulatory, commissioning and funding systems will all need to adapt to accommodate these emerging mixed models, which are being led by people's needs and preferences. Some housing with care settings in the UK which have successfully developed mixed models include Whiteley Village, Surrey (box 6) and Hartrigg Oaks, York (box 19).

Box 19

Hartrigg Oaks, York

Hartrigg Oaks in York, opened by Joseph Rowntree Housing Trust in 1998, aims to offer a 'home for life' by providing different housing options on one site, suitable for young retirees through to older people who need specialist nursing care. The site combines modern bungalows, designed with easy access and to accommodate adaptations with a care centre, providing short- or long-term full residential and nursing care. People living in the bungalows may move into the care home when their needs progress, or, more frequently, stay for a short period for recuperation after a hospital stay. People living as couples in the village also stay for short periods to give their partner respite. There is a care team on site providing support and personal care to people in their own home (the bungalows) and a range of leisure facilities and social activities. The model operates with pooled finance, so people may purchase their bungalow and pay into an insurance scheme of sorts, so when they need care (even in the care centre) this does not lead to an increase in fees.

Using technology as an enabler

The housing with care sector today has access to a wider range of technology than ever before and housing with care providers hoping to stay abreast of the future needs of disabled and older people, and to become more efficient in providing relationship-centred care and community links, need to embrace it. In its report *Care Home Sweet Home*, ILC-UK argued that care homes should make the most of the technology available to improve the quality of care – not least through better communication between health services and housing with care settings.¹²¹

The potential for technology to be used in this way was shown by Heavers Court care home in Croydon (box 17). Heavers recently started using a tele-health system developed by Tunstall called 'myclinic',¹²² as a way of reducing emergency hospital admissions by targeting medical interventions before a situation reaches crisis point. The technology allows staff to recognise and communicate early warning signs, so that

appropriate medical action can be taken. The software uses a handheld tablet device for patients – so it can be used in a more informal setting (eg in people's own rooms) and integrated into daily routines. In addition to monitoring vital signs, myclinic asks sets of questions about symptoms that staff can edit. Different responses have different associated levels of risk, which flag up to carers (as well as a remote triage manager) what action (if any) they should take.

The system has proved very popular with care staff, residents and relatives. Staff feel reassured that any concerns about people living there will be picked up through the triage manager, making better use of their intelligence about them. The technology has also provided a tool for better communication between carers and people living there – particularly people with more advanced dementia – which helps carers respond to people's needs better. It has served its purpose of keeping people away from A&E – and making better use of clinical staff time – by helping staff to manage conditions better in the care home. The technology is still in its 'trial' stage, and staff at the home are thinking about more creative ways of using it, eg engaging with community pharmacists to incorporate questions about medications and potential side-effects.

The ability for telecare to monitor people's activities and conditions leaves staff freer to focus on relationship building, and other features that improve people's quality of life. At the same time, people maintain greater independence as they are less reliant on staff actively to monitor them. In Broadacre's Rivendale Extra Care facility, each apartment has a door entry and intercom system, enabling people living there to contact staff and control access to their homes. Everyone has personal triggers to enable them to request assistance at any time, and a range of telecare sensors are in place to support people according to their individual needs, including smoke detectors, flood detectors, fall detectors and door sensors.¹²³ Similarly, in St Cecilia's dementia care home in Scarborough, a range of sensors are used to ensure falls, floods in people's rooms, incontinence in bed or people going out in inclement weather is detected immediately and without the constant watchful presence of staff

or frequent checking, which (compared with quality one-to-one interaction) was shown to increase people's anxiety. The technology was trialled in 2009–2010 and 20 of the 21 people living there still have their telecare in place today.¹²⁴ Another innovative use of telecare can be found in Hull, where the Telecare Team supports the Council's intermediate care units, such as Thornton Court, which houses 14 semi-independent flats in a similar 'step-down' approach as we describe above. All flats are fitted with a full range of telecare to enable patients to become familiar with telecare as they rehabilitate. This helps to build their confidence and prepare them for using telecare in their own homes. Joint funded by Hull City Council Social Care and City Health Care Partnership, Thornton Court has been at or near 100 per cent capacity since its inception. Results show that 77 per cent of people staying at Thornton Court returned home with a reduced package of care, and 74 per cent returned with telecare in place.¹²⁵ An example of a larger scale roll-out of technology in care homes can be found in Calderdale (box 20).

Box 20 Calderdale

NHS Calderdale CCG is working in partnership with the local authority and Foundation Trust to deliver telehealth and telecare solutions supporting 1,000 people across the region, including 271 in care homes – the largest single deployment of telecare into care homes and the first to offer telehealth at the same time. The objectives of this strategy was to better manage the risks of everyday living for local care home residents, improve privacy and dignity in care, enabling staff to spend more quality time with people living in care homes, and increase their independence. Telehealth is also in place to encourage self-management for people with long-term conditions and reduce unnecessary hospital and GP visits.

Out of 50 care homes in Calderdale, 25 are now using telecare and telehealth to support people living and working in the homes, with 271 residents supported by 581 telecare devices. All of the care home residents said they like the telecare, with 90 per cent of care home staff said telecare improved the residents'

safety, 80 per cent reporting that since telecare has been introduced, hospital admissions and ambulance call-outs have been prevented, and 80 per cent of staff believed that telecare has increased the residents' quality of life and dignity.

In addition to technology being used in a care capacity, the Commission also came across examples of technology being used in housing with care to maximise people's enjoyment of life, and give them equal access to opportunities that they would enjoy in any other housing environment, such as wi-fi access for computers, tablets and smartphones, accessing Skype, online learning, puzzles and other games.

Conclusion

In this chapter, we have drawn together examples of a mixed range of approaches – across care homes, apartment living and village models – which are delivering the outcomes older and disabled people want and need. This includes personalised, relationship-centred support, engagement in purposeful activity and community life, autonomy, independence and interdependence for those who find themselves mainly dependent on others due to their frailty at end of life.

What many of these models are trying to do is create a sense of everyday life, which is not qualitatively different from everyday life outside a housing with care setting. People living in housing with care should be no more “separate” from the communities they live in – either physically or psychologically – than any other person. This is reflected not just in the physical environment, but also in the cultures and staffing models that operate within it. Housing with care needs to support both the living and dying: help people return to independent lives, facilitate meaningful lives for those who are partly dependent, and support good end of life.

It is clear, in reviewing this evidence, that although we know in general terms what older people ‘want’ and ‘what works’ (My Home Life’s evidence-based and relationship-centred vision

for best practice), there is no single model for its delivery – nor should there be. There is a need for diversity, to meet a range of housing needs and preferences, and for people to have the freedom to choose the model that best suits them according to the lifestyle they want. How to create a flourishing market of supply that can offer this range of options is something that we address in more detail in the next chapter; but it is clear that best practice is only good practice insofar as it can be actively chosen and embraced by the people using it. Every individual is different and has their own personal needs, which are dependent for their delivery on there being positive relationships between people using housing with care services, their relatives and staff and also positive relationships between housing with care services and their local communities and the wider health and social care system.

Summary

In this chapter we have explored the many ways in which housing with care is delivering outstanding, life-changing support for older and disabled people. Using examples from Denmark, the Netherlands, the US and the UK we demonstrate some of the best practice that exists across a variety of housing with care models, including care homes, village-style settings, mixed provision and supported living apartments.

We divided this chapter into sections that discussed some of the most innovative and promising practice, but recognised that the best housing with care will deliver on all fronts simultaneously:

- independence, autonomy and self-determination, including delivering personalised support, methods of collective empowerment and progression
- being embedded in the community, including a discussion of colocating with community services and acting as a hub, interesting examples of housing with care collocating with learning environments, and the need for prime locations for new-build housing with care

- building relationships and relationship-centred care, including a discussion of how environments can facilitate this
- responding to emerging trends, such as the need to address the increased prevalence of dementia, the opportunities for specialisation (such as rehabilitation and step-down and step up support), creating a continuum of care with mixed provision (such as combining a care home with apartments), and making the most of technological advances

6 What needs to change?

Just because you or I want it to change that is not going to be enough. It will change when we finally overthrow narrative of helplessness and embrace this concept of life and growth and change across the life span.

Dr William H Thomas, co-founder and president of the Eden Alternative

The research undertaken and evidence gathered to support the Commission demonstrates what good housing with care can achieve, what people want when it comes to support following frailty in old age or a disability earlier in life, and how to recognise good care in specialist residential settings. But we have also heard about the challenges the sector faces and the need for commissioners, regulators, the NHS and national governments to help overcome them. In this chapter we consider what might need to change in order to ensure that the residential sector fulfils its potential in a modern care system.

We have identified four priorities for action that we feel could have the biggest impact for people who need support over the next decade:

- build on what we have
- create a flourishing market of supply
- tackle how we think about housing with care
- decide how to fund care

Step 1 Build on what we have

The NHS is not fit for purpose in supporting disabled people, older people, or those with complex needs over the longer term. This is not its principal goal, and though it does much great work (including prevention), its principal purpose remains to fix

and cure. While the NHS has an important role in supporting people with long-term conditions, in many instances it can achieve better outcomes, more cost-effectively, where it works in partnership with those working in social care. Step-down, post-discharge care is just one example of this. With demographic change and medical and technological advances, there are more and more people who live with complex needs who do not need to be in hospital, but equally who cannot be (or do not want to be) supported in 'general needs' housing (often their own home for older people, or for disabled people, perhaps their family home).

In this context, if we consider care and support on a spectrum, it is essential that we increase the stock of disabled-friendly housing available so that people's homes can adapt to their changing needs as well as improve and adapt the range of housing with care options available. In this way, everyone will be able to make a real choice about where they live and how they receive care and support.

Around 30 per cent of acute hospital beds are filled with people who don't need acute care – many of whom could be better supported by either adapted housing or housing with care options. It is also estimated that levels of functioning reduce in hospital by 2–3 per cent per day – hardly the place for people with long-term conditions who wish to improve or maintain their independence.

Housing with care is already providing a route to independence, community and social activity for many, as well as vital support for people with complex needs and a good place to die, but it is also true that the options are fairly narrow to cater for the hugely diverse range of people who want to live somewhere between their family home, which can leave people isolated and struggling to cope, and the hospital ward. It is vital that the range of options available can meet the variety of outcomes and preferences of people who need support, and are recognised as a form of flexible housing for people whose support needs may increase over time. Looking ahead to the next cohort of disabled young people hoping to leave home, the physically frail older people currently in hospital

unnecessarily and the dramatic and challenging increase in numbers of people with dementia, many of whom need round-the-clock care and support, it is evident that the sector will have to meet a wide variety of needs and expectations in the next few years.

There are many instances of good practice in the sector already. Commissioners believe we must take an asset-based approach to the sector and build on what we are already achieving and where we are already excelling – whether pioneering care and support within ‘traditional’ models of care homes or in innovative newer models.

Purpose-built, dementia-friendly design may look like the future of housing with care, but we must remember we are not starting with a blank slate. Around 450,000 people of all ages currently live in some form of housing with care and building enough new stock just to cater for these people, let alone meet increased demand, would require substantial capital investment. Perhaps more importantly, we must not focus entirely on bricks and mortar and the need to embrace or abandon particular models. Failures in care delivery are rarely a function of the physical environment. They are more often caused by poor culture, where a lack of empathy, kindness, good leadership, staff support and staff development are often contributory factors. While particular environments may facilitate better or more personalised care, they do not guarantee it.

It is essential that we emphasise that it is ultimately the quality of care provided by the housing with care workforce and the relationships and care they foster, rather than physical buildings, which defines the quality of a person’s experience. Ensuring great leadership, supportive cultures, high-quality training, the strategic use of telecare to promote personalised and relationship-centred care, effective supervision and good management across the board – working towards a shared vision of what ‘good housing with care’ should be – is vital to good quality of care and quality of life in housing with care. The Commission recognises the talent and capacity already exist in the sector to achieve this, but also that this is not yet the ‘norm’ across all housing with care settings.

How we might ensure that the sector improves and that the best we have seen in the sector becomes the standard to strive for and, eventually, the typical offer is the focus of this and the next chapter.

Creating new opportunities in the sector

You could still have residential care offering an outreach package with nursing or care staff going to stay for a period. I think we need to open our minds up a little bit so we are less fixated on the location of a building and much more focused on business models that respond to people's needs.

Bill McCarthy, NHS England

It has become apparent through the course of this Commission that the housing with care sector has much more to offer to help complement the statutory health and care systems. It is an under-used resource and as a source of specialist support, expertise and hub for related activity it is, sadly, frequently overlooked. Current housing with care services could prove an excellent resource for step-down and step-up care and reablement services for people leaving hospital or at risk of entering acute care when moving straight back to their usual home is not feasible; as a provider of rehabilitation services for people with a serious physical or cognitive injury; as a short-stay or respite care setting for family carers; and as an outreach service to provide 'housing with care in the home' just as 'hospice in the home' is currently available in supporting family carers looking after terminally ill relatives at home. These are just some of the potential complementary services that housing with care providers can offer, if engaged more systematically by informed and innovative health and local care commissioners, building on relationships that often already exist. It is worth bearing in mind, for example, that CCGs need to consider out-of-hospital options as part of their five-year strategic 'place-based' plans – investment in housing with care settings as one of these options by health commissioners is an important avenue for growth for the sector and delivering better outcomes and efficiencies.

Commissioners in health and social care underestimate the potential uses of the independent residential sector, with care homes seen as a ‘last resort’ and extra-care villages often only as an alternative for the better off.

The Commissioners believe that internal and cultural change within the sector needs to be supported by an external shift. The pervasive negative public attitude towards housing with care settings and the underestimation of housing with care by health and care commissioners will stymie attempts to resolve sectoral issues of training, leadership and the culture of care, and dampen innovation. The next sections focus on this external context, considering not just the ‘bricks and mortar’ but how it is commissioned, regulated, built and ultimately perceived.

Separating the housing and care components – choice over the ‘what’ and the ‘where’

In the current care system, when a person’s support needs are assessed, a decision is usually taken about whether these needs can be met in that person’s current location (often their family home) or, failing this, in a care setting (usually a care home). This move is often seen as ‘forced’, as (for state-funded individuals at least) a decision made by local care commissioners – a corollary of a person’s needs becoming too complex (or costly) to be met in their ‘own home’. It is hardly surprising that such a move is also closely associated with failing health and a loss of independence in the public psyche.

Having reviewed the evidence gathered and consulted experts on this matter, the Commission has concluded that each person’s care and housing requirements should be considered separately. Individuals should have their care needs assessed as distinct from any presupposition as to where this might be delivered. In turn, housing with care options need to be diverse enough to cater to a range of different housing and lifestyle preferences, as well as care needs, so that when a person has an assessment of their support needs, they have a real and valid choice over where they might live to have these needs met along a spectrum of care settings.

The Commission feels that at the moment, the entire concept and popular understanding of ‘housing with care’ is driven by a sense of place – most usually a care home. The ‘what’ of housing with care is so closely tied to the ‘where’ of care that they are almost indistinguishable, and we believe that it is often the ‘where’ aspect which fills people with dread.

Teasing the ‘what’ and the ‘where’ apart so that a certain location does not entail a certain level and type of care (and vice versa) will enable people to make separate decisions on the basis of what they want to achieve and what they need support with and where they want to live – having an active choice over both, without having these packaged so that people’s care needs dictate where they must live and turning this into an emotive and traumatic move. There is no reason why this should not be the case for state-funded and self-funded individuals.

As we have seen in chapter 2, there is an economic case for using collective settings when delivering care that requires specialist equipment, multiple staff or round-the-clock support. It is essential that we recognise that ‘traditional’ care homes, particularly nursing homes, predominantly provide care for people with the highest and most complex levels of need, for whom care may, in the staff’s view, be optimally provided in a residential, non-hospital setting. Nonetheless, this certainly does not imply there is a binary choice between care ‘at home’ or ‘in a home’ with a cliff edge dividing the two and no variation in the latter. The infrastructure, skill and innovation exists in the current provider market to create an effective continuum of care within a variety of different settings to cater for different people’s preferences about where and how they live, but as we explain below, housing with care is buffeted by funding, commissioning and policy decisions that span health, social care, housing, planning, pensions and beyond. These systems can either help or hinder a flourishing housing with care market.

It seems that while personalisation in care and support services has been growing apace (and facilitated by legislation, guidance and a cultural drive by organisations such as Think Local Act Personal (TLAP) and *My Home Life*), diversity, choice and personalisation of the location in which that care is delivered

has not had the same encouragement. Indeed, changing one's care without changing one's setting, and decoupling the two, would be very difficult within the existing bounds of the commissioning, funding and regulation of care. We reflect on these in turn below.

Box 21

TLAP

Think Local Act Personal (TLAP) is a national partnership of more than 30 organisations committed to transforming health and care through personalisation and community-based support.

Its tasks are to drive improvement, enable improvement, exchange knowledge and model coproduction in action. It does this by delivering a work programme, agreed with partners and funded annually by the Department of Health, with a number of specific commissions from other agencies. The work programme is delivered through work streams by a small team reporting to the Programme Board. The work streams are:

- advice, information and brokerage
- self-directed support and personal budgets
- workforce development
- integrated care
- quality
- making it real
- building community capacity
- coproduction

How people pay for housing with care

The proposed 'care cap' funding system has the potential to support an approach which separates the what and the where of care by separating care from 'hotel' costs and providing greater transparency of what fees people are actually paying towards both. Long standing but controversial practices such as the cross-subsidisation between self-funders and state-funded individuals, and the use of top-ups, will also be made clear. The

Commissioners hope that the cap model will lay the way for a more transparent and equitable fee structure in housing with care models, but also one that actually reflects the real cost of care. This is vital and we revisit this in our recommendations in the next chapter.

Perhaps a better funding strategy is the tripartite system in use in Denmark, whereby charges are split into three distinct components – rent, service charges (for cooking, cleaning, laundry, etc) and care costs. Some providers in the UK already operate a similar cost system – though people may prefer to opt for an all-inclusive fixed cost. The challenge with any such system is to ensure that people making a move into housing with care have enough information and understanding of the ongoing and long-term costs of living in a residential setting to allow them to make the correct financial decisions to give them the best choice in their circumstances. Care fees, rent and service charges need to be balanced against a person's preferences for the sort of lifestyle they would like, their existing or likely future care needs, their mobility, and so on. Such a decision – as with all housing moves – needs to be weighed up against possible life events and adequate advice will be critical to making a reality of this choice.

The tripartite system has the benefit of bringing with it something that is currently absent from the housing with care sector in the UK – an equivalent concept of 'tenants rights'. Scope commented in its submission to the Commission's call for evidence, 'Currently when a person becomes a resident of a care home, they lose all their rights to a tenancy and therefore they are denied a fundamental right of citizenship.'¹²⁶

The National Development Team for Inclusion produced useful guidance in 2010 in *The Real Tenancy Test* to help ensure people with learning disabilities in supported living did not have their tenant's rights eroded.¹²⁷ A similar approach might be taken in housing with care settings – laying out a tenancy framework appropriate for care homes, extra care and other care-village-style schemes, which enshrined such tenants' protections. These are some areas that might be addressed in such a framework:

- People should not be moved from their homes based on a care commissioning decision, but through a natural process and personal decision of wanting to move location, a change of lifestyle, or (though we expect not in the vast majority of cases) if that particular setting is not flexible enough to cater to a change in support need.
- It would formalise current good practice whereby the front door to a person's room or apartment would be the threshold of their private space, so (unless safeguarding or mental capacity is an issue) it would not be breached by staff without seeking permission to enter, and people would have shared ownership of the communal space and make decisions about decoration.
- Resident-association-style committees, which we have seen in some housing with care settings already – would give a feel that care homes were being run not 'for' but 'by and with' people living in them, with people having decision-making powers and rights of consultation about the running of the scheme in which they live.
- It might lay out information about how to complain and access advocacy services. Personalised care that respects people's physical space and personal boundaries within the care home environment is vital. A 'tenancy agreement' of sorts would enshrine this approach and culture in each care setting, and give people moving into residential settings and their families a better understanding of their rights and protections.

Putting such a lens on care homes provides answers to some complex issues. For example, CCTV in people's bedrooms – often discussed as an issue of safeguarding – would be a matter of personal choice (as is the case already in some care settings) as it would if a person chose to have CCTV in their own home.

There are wider implications of this change. For example, with tenants' rights also – potentially – comes the right to claim housing benefit. As the English Community Care Association (ECCA) pointed out in its submission to the Commission's call for evidence:

If the relative merits of different care packages in different settings are to be comparable on both costs and benefits, then all forms of social care should be assessed on the same footing. As such, it will be necessary to separate care and accommodation costs in care homes. Indeed, we would argue that in order for any individual to make a choice they would need access to robust comparable costs across differing settings and services. The disaggregation of the care home fee will enable individuals and families to make informed choices about alternative models of accommodation and care. People can then plan how to fund the separate elements.

Currently, housing benefit is not payable to care home residents. Given the disaggregation referred to above, it would be logical for it to be paid to people who lack the means to finance the accommodation elements of the care home service. Doing so would remove the funding anomaly between residential care and supported living and enable like-for-like comparisons.¹²⁸

The Commission feels this is a logical and reasonable argument. If people choose and fund the ‘what’ and ‘where’ of their care separately across the housing with care spectrum, such choice should be applied equally to all settings. A care home is a home, first and foremost, and there is no reason why people eligible for housing benefit should not receive this to pay for their housing in care-home settings.

ECCA also proposes that an equity stake might be purchased by people moving into care homes, recognising that people want to maintain ownership over their home – regardless of whether that home happens to be a private property, an extra-care apartment, or a room in a care home. Some form of stake, in the form of a deposit, or the purchasing of a lease, would certainly provide a stronger legal underpinning for the conferral of tenants’ rights to people living in care homes. As mentioned earlier in this report, the idea of a cooperative or mutual model in housing with care proved popular with the members of the public we consulted.

Commissioning

Commissioners believe the separation of ‘what’ and ‘where’ should also be applied to the commissioning and regulation of

care. While health and care commissioners and regulators do need to help secure and improve the quality of care and support according to the outcomes each person wants to achieve, where that occurs should be a matter of personal choice.

Camphill Scotland stated in its submission to the Commission's call for evidence:

People are not always able to exercise choice and control in choosing to live in a residential community. We experience local authority 'gatekeepers' who, often due to a misunderstanding of what support in a residential setting looks like, do not support individuals or families who might wish to explore whether or not Camphill is right for them. There is a sense in which, for some local authorities, residential care/shared living is seen as being a last resort, suitable only for people with the most complex needs, and we would very much like to see this focus change to looking at the individual (regardless of their level of need) and whether or not living in Camphill is something that they would like and from which they would benefit.¹²⁹

No commissioner should look to commission a 'bed' or a 'room' – but a package of support based on outcomes each person wants to achieve. Once that package has been developed with the individual and their family, where best to achieve those outcomes should be a matter of preference – facilitated by commissioners as part of their market shaping responsibility (underpinned by a shared vision of what good housing with care looks like), but not driven through their own purchasing decisions.

We recognise that when care needs become more acute, cost issues may make having one-to-one care visits in one's private, family home untenable, and also perhaps impractical. Even so, when this is the case, the specialist options – from individual supported living through to village communities and larger communal settings – should provide a wide choice for individuals to consider in the light of their support needs and personal preferences. Most people make these choices at different times in their lives, moving into a flat share at some points, living alone at others, living with their families at others. We should all have these choices – and the chance to change our

minds when our circumstances, hopes and abilities change. Making this a reality for everyone with care and support needs is vital if we are to tackle the publicly perceived trauma associated with the ‘institutionalisation’ of a forced move to a care home.

Regulation

Similarly, regulators need to inspect and set standards for care and support, based (like commissioning) on an appreciation of outcome-based support and a shared vision as a society of what good care should be achieving. However, when it comes to the inspection and regulation of care homes, the inspection of the ‘where’ alongside and entirely tied up in the ‘what’ being delivered is unnecessary and unhelpful, for several reasons.

First, the statutory definition of a ‘care home’ as a location involving ‘the provision of residential accommodation, together with nursing or personal care’¹³⁰ ties the ‘where’ and the ‘what’ so closely together as to prevent the development of more flexible, innovative models. The primary difference between what is deemed to be an ‘independent living unit’ (an adapted apartment where care is provided on site) and a care home is that the former is fully self-contained, while a care home is more usually conceived as a private bedroom and bathroom with communal living space. But this is by no means always the case and there is overlap: some housing options registered as care homes (for example, Leonard Cheshire’s Springfield care home) are in effect clusters of bungalows around a communal living space. However, and while innovative services exist, current regulations can limit the ability of providers to create a varied living environment to meet specific needs outside the traditional care-home model.

Second, it makes little sense that people’s ‘own homes’ are not inspected by regulators when inspecting domiciliary care, because this is seen as a ‘personal choice’, while the home of someone living in housing with care is, simply because they are living in a housing with care setting. On the other hand, the housing provided by extra-care settings are not inspected, but the care they deliver is. The CQC has decoupled care from accommodation in this instance, but combined them in care

homes. A quirk of the definitions used in registration of these residential services creates two very different inspection regimes, even when often the people living in both settings have very similar care and support needs. We would argue that all housing with care should be approached like extra-care inspection – where the ‘what’ is inspected while the ‘where’ is identified as people’s ‘own home’ and an issue of choice.

The Alzheimer’s Society response to the Commission’s call for evidence is informative on this point (box 22).

Box 22 How do you define residential care?

This is the Alzheimer’s Society’s response to the questions ‘How do you define residential care? Do you see extra care, retirement villages and other ‘housing with care’ options as different by definition? What makes them different?’:

In practical terms there are two key distinctions between residential care and housing with care:

- *Individual accommodation in housing with care schemes is made up of flats with kitchens and greater living space, while residential care accommodation tends to be just rooms.*
- *Residential care tends to be more communal than housing with care schemes as options for, eating alone, for example, are much more limited.*

However, these relatively simple distinctions are made significantly more complex because of regulatory and legislative differences in the way these forms of accommodation are treated. These differences are largely the result of historic divisions in care provision and regulation. Examples of differences include:

- *While residential care homes have to be registered with the CQC, this is not the case for housing with care schemes where registration is only required for any domiciliary care agencies who work on site.*

- *Residents in care homes are ineligible for housing and other benefits which those in housing with care are entitled to. This raises questions over the financial comparison and viability of housing with care over residential care.*
- *People in residential care occupy premises under licence, a less secure form of occupation than tenancy or leasehold agreements which are common in housing with care.*

As a result of such legislative and regulatory differences, residential care and housing with care are treated as distinct systems, with different staff, providers and representative bodies.¹³¹

Scope's submission to the Commission's call for evidence also considered that existing definitions stifled innovation, from their point of view, in preventing care homes from becoming places of reablement and places where disabled people could progress from:

Currently residential projects which are set up specifically to enable people to develop their independence are still required to be registered as residential care homes. This places certain restrictions on how they can be run and the activities that residents can undertake.¹³²

We believe that inspections and regulations on registration of such places must be changed so that they can more closely mirror what it is like for a person to live independently, with support if necessary, in their own home.

An additional theme which arose from the Commission's research was that almost everyone we consulted – practitioner, commissioner and other experts alike – considered the distinction between 'residential care home' and 'nursing home' for regulatory and inspection purposes had become less meaningful and unhelpful, because it suggests that the presence of a nurse (24 hours a day, 365 days of the year) is what makes the difference between nursing and care homes. Some experts suggested the distinction should be scrapped – with the general

population of people living in residential care homes and nursing homes becoming older and frailer, or with increasingly complex support needs, some argued there was now a need for a nursing presence in every care home to help assess and ensure people get access to appropriate healthcare. Without the presence of nurses in every housing with care setting, the NHS would need to work in much better partnership with the independent sector to ensure healthcare needs are assessed and appropriately met.

Ideally, the Commission would like to see a new regime where the ‘what’ of care is regulated and inspected by the CQC, while the ‘where’ falls within the variety of quality standards used for housing. This regime should be underpinned by a commissioning regime that occupies itself with the ‘what’ through needs assessments and funding (or the element which counts towards the care cap in a new funding system) while leaving the ‘where’ a matter of free personal choice in a local market of housing options where care can be delivered on site.

Step 2 Create a flourishing market of supply

Housing with care in the future will not be the same as that of today – services will be different and the location of care and support will change. As we discuss in chapter 3, having a better idea of what future generations of disabled or older people will need and want is key to the development of the sector. But this is not a one-time activity. New ideas about physical design and operating models are always evolving, and there is a need for ongoing collaboration between providers, facilitated by local commissioners and indeed the CQC and other organisations, to continually update the common understanding of ‘good practice’ and embrace the evolution of design, techniques and technology.

If we are to create such a system, which is responsive to future demands, and where people express a free choice over where they live when they need care, rather than it being a mandatory extension of one’s care package, we will need greater diversity of housing where care can be delivered on site to cater

for a range of different housing preferences. This includes care homes (as currently defined), supported living and improved homecare provision. Ideally all these services will work together on a spectrum of care and moving between them (in both directions) will become the norm.

Much of the infrastructure for this is already in place and so we do not need to start from scratch (which, in any case, would be neither affordable nor desirable given the variety of good practice that already exists). However, we need to ensure that all our housing with care settings are places of choice, not an inevitable part of a care package. Part of that is related to how care is commissioned and regulated, as explained above, but part is about what is on offer from providers. As we describe in chapter 5, much can be done within the confines of existing bricks and mortar (for example with strategic use of space and technology, and a focus on staff cultures) to personalise care, including for people with dementia and end-of-life care needs, provide opportunities for reablement and help regain of confidence and independence, link with other services and so on. While we might want to stretch the existing boundaries of some care settings to ensure they are 'places of choice', we also want new facilities to be built – which requires exploring how to reuse former care buildings as hotels or other such facilities and replace them with new, built for purpose residential schemes. If we see the current stock as an asset to be used, rather than a fixed cost which cannot be changed, there may be an opportunity to think more innovatively. For example, old sheltered-housing schemes have been bought and used by providers of other housing-based services (student accommodation, key workers etc).

Housing with care does not operate in a vacuum – it is influenced by funding, commissioning and policy decisions that span health, social care, housing, planning, pensions and beyond. These systems can either help or hinder a flourishing housing with care market by creating different incentives and disincentives, and these need to be tackled if we hope to stimulate greater and more diverse supply of housing with care options.

The evidence gathered for this Commission suggests that housing with care is frequently hindered by the structures around it. For example, we heard that local commissioners were asking providers of independent living for disabled adults to build independent living units (small shared flats with communal kitchens and living space) with larger numbers of bedrooms and additional facilities for on-site care. These were described to us as ‘care homes in all but name’. As outlined above, the statutory definition of a ‘care home’ as a location involving ‘the provision of residential accommodation, together with nursing or personal care’ can prevent the development of more flexible innovative models. The existing lack of regulatory clarity and flexibility leaves providers facing a number of challenges when they want to innovate, and this will need to change if we are to increase the ‘where’ of residential-based care into a diverse range of options.

David Rees, chair of the Health and Social Care Committee, Welsh Assembly, stated in his submission to the Commission’s call for evidence: ‘Our [the Welsh Assembly’s] inquiry suggested that flexible registration would reduce the need for older people to move home when their needs change, eg when they develop dementia.’

Planning also plays a part in dampening the ability for care providers to innovate. Local plans often do not recognise the need for housing with care, nor are they obliged to ensure there is adequate land for such developments to serve the local community. With a focus on first time buying and affordable housing, ensuring housing is adequate for disabled or older people can be less of a priority. In addition, the C2 and C3 use classes, C2 referring to care homes (eligible for CQC inspection) and C3 referring to extra-care developments (subject to s106 planning obligations regarding affordable housing), cement the distinction between these two forms of housing with care and preclude variations that might fall between or around these. A ‘housing with care’ use class could help provide the flexibility needed for providers to innovate with new models of support.

If commissioning and inspection were to be limited to the commissioning, regulation and inspection of care, and if planning were more conducive to the provision of housing with care and allowed for greater flexibility, then the diversity of housing models suitable for care delivery would become almost limitless, allowing for more mixed tenure models in a wide range of housing with care types – giving people more choice and linking more readily to the property market. The Commissioners are aware of many exciting and innovative models in the UK and abroad. We have described some of these in chapter 4 but feel that the housing models that should be developed are those that not only offer greater choice over housing options, but also are conducive to providing high-quality care and support. As the current sector expands to provide a wider range of services, looking further into the future it is possible to envisage a system where people seek ‘housing with care in the home’ and a full range (from domiciliary care through to concierge services) of options being available, perhaps using a local housing with care setting as a hub for services and support. The Commissioners are aware of a model in areas of Spain similar to this, which has been successful in providing integrated services across health, care and lifestyle services within a home ‘care’ environment.

Technological developments are the source of a wealth of new possibilities – on the one hand, evidence suggests telecare in people’s family homes can delay the need to enter a housing with care setting by more than 12 months. On the other, technology in residential settings is being used as an outlet for leisure and connectivity for people living in housing with care – with a marked increase in people using Skype and more portable tablet devices for gaming and news consumption – as well as to remove the need for staff to undertake basic administrative or monitoring tasks, leaving more staff time for relationship-centred care and activities people value as enhancing quality of life, while preserving greater privacy.

These are some of the housing with care models we feel might be particularly valuable for the sector to explore:

- different models within models, allowing people with more acute needs to live alongside those able to live more independently without so much support; this will allow us to support intergenerational living and ageing in place, provide flexibility of moving up and down a need spectrum, and offer continuity of relationships and personalisation
- ‘teaching’ models where gerontology, dementia or condition-specialist placements could take place
- ‘green house’ style models, with apartments and communal kitchen areas to encourage social networks
- ‘smart’ models – bringing in technology so that those working in a housing with care setting have more time to concentrate on quality of life, activity and relationships
- ‘smart homes’, which enable the home to evolve with the needs of individuals and to delay or remove the need for a move to a different care setting, while increasing their connectivity with the local community
- housing that is colocated with general use community facilities such as children’s centres or learning environments
- for working-age adults in particular, housing with greater linkages (even colocation) with employers or training sites, and opportunities to start families within a care-on-site model
- ageing hub models, where housing is colocated with advice and health services for older people
- housing offering specialisms in rehabilitation, reablement, step-down and short-stay facilities on offer

Step 3 Tackle how we think about housing with care

A question of labels

A separation of ‘what’ support someone needs and ‘where’ this is delivered would provide a step-change in the housing with care sector, its regulation, funding and commissioning. But it would also be revolutionary for people’s perceptions of the sector, where the ‘care home’ looms large as a place of frailty and vulnerability, and challenge many assumptions held by some local health and care commissioners and other professionals. Yet

as with widespread perceptions on any issue, change can be slow to achieve. We therefore believe we need to be equally bold in how we discuss and think about housing with care, and change the terminology used, in order to lead the way in changing public and professional mindset.

Camphill Scotland's Submission to the Commission's call for evidence explained how 'residential care' had become an unhelpful term:

In our experience, the term residential care has unhelpful and out-dated connotations. Camphill communities which are registered as care homes find that people make incorrect assumptions about the support that they provide if it is defined as residential care, and communities who provide accommodation-based support registered as care at home/housing support do not believe that the term residential care conveys the sense of ownership and individualised support that they provide..... All too often, the term residential care seems to be used in a pejorative sense, conjuring up images of large scale institutions and poor standards of care. This is a view which we still encounter on occasion, particularly from placing social workers, and so we very much welcome a public debate which considers residential care on its merits.¹³³

While St Anne's commented:

We would like to see the names residential care and supported living phased out and replaced by something which better describes the model i.e. a phased approach to people with intermediate, low, middle, high needs. The use of the term residential care is a derogatory one and one that was going out of favour up until recently.¹³⁴

Such responses and the Commission's research with members of the public is, almost by itself, a good enough reason to consider carefully the changing of terms and rebranding of housing with care. But it is also the case that new terminology might cut through some of the current confusion and ambiguity.

It was clear from the Commission's research that while one's 'own home' and hospital are both known and understood environments, the offer available in between these two ends of

the spectrum is often unclear, and the proliferation of different names to describe the different models of housing and housing with care services only adds to the confusion.

For example, when we discussed this issue with members of the public, many were unclear about the differences between different models of housing with care (care homes, nursing homes, retirement housing, sheltered housing, extra care, etc). The terms ‘care home’ and ‘residential care’ were often used interchangeably, even though the latter clearly should describe something broader. The term ‘retirement housing’ was felt to be something distinct from care homes – and something that there was a considerable appetite for, as it was felt to deliver more of what people wanted – principally independence.

The proliferation of terminology to describe a variety of different ‘residential care’ models may in part result from the negative connotations of ‘care home’ and ‘residential care’: many innovative spin-offs from the traditional care-home model have been renamed and rebranded, perhaps to differentiate from the ‘care home’ label, but this has only served to cause confusion. One expert explained to the Commission that the ‘extra care’ label had lost some of the negative connotations around care homes precisely because it is viewed more like a type of housing (‘your home’) rather than a type of care (‘a home’), and this makes a difference to how personalised the environment feels, even if many of the options available are in fact the same in both settings and most extra-care villages now provide a considerable amount of care on site. A lot of this comes down to how the model is promoted – which is invariably as a positive, alternative to housing with care.

The Commissioners feel that to reflect a sector which separates the ‘what’ and the ‘where’ of care as described above, the term ‘housing with care’ could replace ‘residential care’ to describe a spectrum of different housing options where care is delivered on site. It is a more explicit and transparent term, and better reflects the proposed separation of the accommodation and care component outlined above. By placing ‘housing’ front and centre in the term, it suggests that moving to housing with care is making a choice about where you live, based on one’s

preferences, as is the case with any other move during one's life. As a housing decision rather than a care decision, this carries with it fewer emotive associations of physical or mental decline and dispels the idea that moving to housing with care is a move from 'staying in my own home' or 'selling my home' to pay for care.

While housing with care is a more appropriate overall term to refer to the entire continuum of specialist housing options, the sub-categories within it should remain so that people can recognise the variety of options available. Removing the nomenclature of 'residential care' does not necessitate reducing the variety of housing options available, and we cannot create an unintended consequences of supported living-style settings morphing into more traditional group-living, care-home models.

The primary difference between housing with care options is often where one's personal space – one's front door – starts. In care homes, one's personal space is usually a bedroom with an en-suite bathroom, although some registered care homes have 'apartments', which include a small sitting area, and sometimes a small kitchen. Dining and living space is communal. In extra care and care villages, private space is more extensive, usually including all the amenities one would find in a standard house or apartment. There may be communal living in and dining space, but these are understandably optional and usually sit alongside leisure and health facilities.

When considering the range of options in this way, it becomes more obvious for people choosing between them which will suit them best, based on their care needs, abilities and preferences. Someone unable to cook (or without the inclination to do so) need not opt for (and pay for) a living space with a kitchen, for example. The Commission feels more transparent and meaningful terminology can be created if it is based on describing these differences – talking to the public about their options for what they actually are: private bedroom homes, apartment-homes, shared apartments, care villages, and so on, along with a discussion of the size of the setting, the culture of care and location, rather than attempting to create a new brand each time a slight variation on an existing model emerges.

Commissioners, regulators and inspectors across health and care must also adopt this approach, using a common criteria and language which is shared with those building, working and living in these housing with care settings to minimise the confusion and duplications of terms which currently exist.

In 2010 the Joseph Rowntree Foundation produced a very useful overview of how older people in housing with care schemes could achieve a ‘better life’. This report looked at all aspects of housing with care encompassing extra care and assisted living. While the researchers recognised there was no standard definition, they took housing with care to mean:

*developments specially designed for older people, which offer self-contained accommodation together with 24-hour care and a wide range of leisure and other facilities on site with some meals provision.*¹³⁵

The authors of the Joseph Rowntree Foundation study clarified that housing with care is:

*a housing model, not residential care – its stated ethos is to support and promote independence, occupants have security of tenure and should have the right to control who enters their property and to choose the form their support should take.*¹³⁶

The Commission assumes the authors are using ‘residential care’ to mean ‘care home’ in this instance. The Commission feels the promotion of independence and choice of support is a feature of any good care home, while some also provide greater privacy by giving people their own ‘front doors’ (with bells, etc) into bedrooms while maintaining open communal living rooms. The only real distinction, therefore, between the Joseph Rowntree Foundation’s definition of ‘housing with care’ and ‘residential care’ (care homes) is security of tenure. In such a confusing sector, where different definitions are used and often conflated, Commissioners believe that security of tenure and tenants’ rights are perhaps the distinguishing feature separating care homes from other housing with care options. If ‘housing with care’ is to become a preferred term for **all** housing with care

options (including care homes) then this particular difference would need to be resolved.

Bringing the public into the sector

While changing how we talk about housing with care can do much to help us change how we think, it is clear we face significant and serious public concerns about care homes in particular. The sector has certainly recognised this, and the recent proliferation of care home rating and user review websites, and initiatives like the National Care Home Open Day, demonstrate an impulse to open up the sector to people who might move to them, their families and friends.

The use of volunteers is also becoming more widespread, a very welcome development as a way to encourage more people into care settings and to expand the range of activities on offer by supplementing the work of care staff. We could go further than this, however – housing with care might do more to become more ‘porous’ – open and engaged as part of the local community, as we describe in chapter 4. This may include encouraging local groups to use spare rooms for practice and meeting spaces and seeing housing with care facilities as a community asset, or indeed colocate with other community facilities such as GP surgeries. The *My Home Life Essex Friends and Neighbours* scheme is a more concerted effort to achieve this across the local authority by systematically bringing recognised ‘outside’ volunteers into care homes to get to know and spend time with the people living there. Commissioners and inspections might also use family and friends as lay assessors themselves:

*The care and inspection process should better capture the lived experiences of care home residents and should include the use of lay assessors, a process already under way in Wales. We believe that inspection reports should be fully accessible and available to prospective care home residents.*¹³⁷

Getting the facts straight

There is much to be said for addressing misconceptions head on. Bad practice and abuse must be highlighted and we must have a system, and most importantly a culture, where it is driven out. However, facts regarding the actual prevalence of cases of abuse and neglect in the sector are thin on the ground, leaving much space for alarming stories of particular cases. It is unsurprising how it may seem that such failures in care are rife, even if they in fact affect a tiny proportion of the hundreds of thousands of people living in residential settings across the country – as we describe in more detail in chapter 4. We need a verifiable source of intelligence on this issue in order to set individual cases in context, and figures should be collected annually to monitor trends. We also might consider a ‘friends and family test’, often used in the NHS as a way for the public to understand how care staff would use, or recommend their relatives use, housing with care options.

Therefore in the next chapter we recommend the introduction of an annual CQC survey of people using all housing with care services to run alongside the CQC’s existing surveys of people using acute services, outpatient services and community mental health services. This would sit alongside an annual workforce survey and both would help to construct a more accurate picture of how the sector is performing. Transparent, readily available data are vital to change public and media perceptions.

Thinking ahead

There is a vicious circle that needs to be tackled. People are ill-informed, suspicious or outright fearful of a potential move into housing with care – which almost inevitably means the prospect of such a move is not considered or discussed until a person reaches crisis point (eg they have a fall, or their informal care or domestic arrangements break down). This may make the move traumatic involving a distressed purchase, poorly planned, perhaps not moving to a setting best suited to the individual’s choice and needs. Research by Bradshaw and Playford suggested that a positive attitude on entering a care home was linked to

emotional resilience and better outcomes in the longer term and ability to cope with the change of lifestyle.¹³⁸

Commissioners believe that reframing a move to housing with care as a housing choice first and foremost, with a care package attached (rather than, as is often the case now, a care package with an obligatory location attached), will do much to ease some of the emotion associated with the transition. The whole approach to housing with care must consider both the individual's family home and a range of housing with care settings when designing and providing services. But to achieve this, health and care commissioners and care providers will need to work hard to make sure that this housing choice is viable. Housing with care providers also need to ensure they – and the people who live in their schemes – become a more visible part of the surrounding neighbourhood, bringing local groups and volunteers in as much as reaching out to people who are supported in their family homes. Other steps might be taken to 'normalise' a move to housing with care – such as ensuring schemes are advertised in estate agents – so that when people have a care assessment they and their family can undertake a review of the housing options capable of delivering their care in a more 'normal' way, as well as relying on the advice and guidance provided by their local authority, CQC reviews and other TripAdvisor-type websites.

Step 4 Decide how to fund care

Much has been written on the subject of care funding over the past decade, and every expert we spoke to mentioned funding as a serious issue preventing innovation and development within the sector. Yet more has been said and written on the issue of care funding than done. While we may feel closer to a funding settlement following the Coalition Government's intent to use a new capped-funding regime – based on Andrew Dilnot's 2011 plan – Dilnot was not asked to address the most crucial question in his review: how much funding would actually be needed to deliver the volume and quality of care outlined in the Care Act. This is a crucial issue. We have a potential answer as to how the

responsibility for care funding can be divided between the individuals and the state, but we do not know how much we will need nor where the resources will come from.

Commissioners believe this will undermine the successful implementation of the Care Act and jeopardise the future of the care system. For example, it seems impossible that the duty of wellbeing, delivery of prevention services to reduce or delay care needs in the future, and other provisions of the Care Act can be implemented if eligibility for state support is reserved for people with substantial needs and above.

The current sector is also beset by poor wages and training levels, a direct result of a lack of available resources to invest in staffing. This has an effect on the quality and consistency of care provided, and on public perceptions of the workforce and housing with care more generally. The Commission feels it is high time there was a minimum level of training, with independently accredited certification, applied across the housing with care sector. This certification would need to be in place before staff were able to support people unsupervised in housing with care settings. This would in effect create a 'licence to practice', linked to this minimum training level, which would enable people to have their licences granted, renewed or indeed withdrawn and prevent them from working in the sector if the circumstances required. This would improve the quality and consistency of care across the sector, provide opportunities for staff mobility between settings and progression, and help improve public confidence about the competence and accountability of housing with care staff.

Such a step would come at a price, making proper investment in adequate care funding vital. Alongside better training must also come better wages. We have seen in chapter 4 how average wages, barely above minimum wage level, are rife across the entire sector, but also that those working in housing with care settings seem to be more poorly paid than their domiciliary and day-care counterparts. It sends out the wrong message of housing with care as a vital part of the health and care system, an economic growth area, and one requiring a highly skilled and dedicated workforce. Again, this comes at a price. As the

Resolution Foundation explained in its study of the living wage and the prospect for implementing it across the economy:

Costs in some areas, particularly social care, will be high. Here, there is an urgent need for a sustainable funding settlement covering better pay, status and qualifications for care workers, as well as funding arrangements for service users. Ultimately, better pay in social care will require national leadership.

It is also important to remember that around 200,000 care workers – one in five of the workforce – are currently paid below the minimum wage (Hussein 2012). This is not just morally unacceptable but also illegal.¹³⁹

Research commissioned by the Joseph Rowntree Foundation this year concluded that “there is no conclusive evidence that increased pay improves care quality, but research shows the importance of making staff feel valued; chances for progression; managerial support and proportional human resource management.”¹⁴⁰ However, evidence from other sectors where it has been introduced suggests that implementing the living wage is linked to improved morale and retention. Retentions and continuity of staffing is particularly important in care settings to foster positive relationships and personalised support. For example, a 2012 survey of 17 London employers (largely outsourced cleaning) by Trust for London found that the calculated savings from reduced rates of labour turnover varied from 0.1 per cent to 2 per cent of the non-living-wage comparison contract or time period, while the average wellbeing score for those employed in a living-wage workplace was 4.5 units higher than those employed in a non-living-wage workplace. A 2009 GLA-commissioned survey by London Economics of 11 employers that had adopted the living wage found improved retention rates (reducing the costs of recruitment and induction). On average, rates of labour turnover went down by 25 per cent, although actual rates varied greatly. Barclays Bank had seen a cleaning staff retention rate of 92 per cent, compared with the industry average of 35 per cent, and KPMG had seen turnover of cleaning staff fall by 50 per cent; 80 per cent of employers and 75 per cent of employees surveyed

reported improvements in work quality.¹⁴¹ The report also cited evidence from the US identifying similar trends, for example San Francisco Airport found that turnover among security staff fell from 95 per cent a year to 19 per cent a year once the living wage was being paid. The costs of higher wages have been found to be partially offset by the reduced costs of absenteeism, recruitment and induction.¹⁴²

The Commission feels that despite such evidence, the vast majority of care providers would be unable to afford to boost wages or training levels in any significant way given the current funding constraints placed on them. This is becoming more obvious as those providers that remove themselves entirely from the local-authority-funded market and set fees at rates which only wealthier self-funders can afford do have the resource to pay better wages, invest in training, and provide better care facilities. The Commission feels strongly that adequate funding from local health and care commissioners, plus additional resource from government, are necessary to halt the growing division of the market where high-quality care, delivered by better-trained, better-paid staff, is becoming the preserve of wealthier self-funders. Unless a decision is made to fund the care system adequately, we will not simply see the entrenchment of the status quo, but the emerging two-tier system become the norm, with local-authority-funded individuals receiving a far poorer service and generation of unacceptable health inequalities and, inevitably, unsustainable costs for the NHS.

We know, for example, that cost of falls to the NHS costs around £5 million per day, £6 billion per year, and that ‘up to one in three [3.4 million] over-65s suffer a fall each year’.¹⁴³ We also know that delayed discharge costs the NHS around £360,000 per day, or £130 million per year (with the total costs of £526 million over the four-year period of 2010–14). Age UK observed,

Patients waiting to be transferred to a residential home in 2013/14 wait an average of 30 days, while someone who needs grab rails or ramps fitted at home waits 27.3 days. An NHS bed costs around £1,900 a week compared to about £530 for a place in housing with care. There is no age breakdown

*available for patients affected by delayed hospital discharge but we know that many are older people.*¹⁴⁴

We also know that the cost of treating pressure sores to the NHS amounts to £4–6 million per day, or £1.4–2.1 billion per year. An article in *Age and Ageing* concluded: ‘It has been shown that older persons with pressure ulcers have a longer overall hospital stay and a higher excess length of stay compared with similar cases without a pressure ulcer.’¹⁴⁵ While treatment of cold-related illnesses and conditions costs the NHS approximately £1 billion per year; cold conditions affect circulation and around half of excess winter deaths are circulatory in cause. The number of excess winter deaths in England and Wales is estimated as 25,000–45,000¹⁴⁶ per year.

Such costs are clearly just the tip of the iceberg. A poorly functioning offer for people whose support needs cannot be met in general housing is a recipe for financial disaster, and there is a case to be made that both the NHS and housing budgets need to be directed towards improving the provision of housing with care. With demographic change and increased demand for care and support services, housing with care is a growth employment sector (the workforce grew by 15 per cent just between 2009 and 2012, while estimates suggest it will grow by between 20 per cent and 60 per cent in the next 20 years¹⁴⁷) and source of regeneration for local communities. Where a housing with care development is built, it generates employment for a range of industries, can reinvigorate declining town centres and provide stimulus to local housing markets where older people downsize into housing with care. It also supports families juggling work and caring responsibilities, offering both temporary and permanent substitute care. And yet most of these economic benefits are overlooked, with social care funding often viewed as a ‘cost’, with no benefit – a chronically underfunded regime in need of an injection of resources no government seems willing to part with.

Summary

In this chapter we have presented a strong plan for change for housing with care. We identified four priorities which are crucial for housing with care to survive and flourish in a twenty-first-century care system:

- Build on what we have – recognising that the housing with care sector and the workforce are an asset, and needs to fulfil its potential with new opportunities for specialisation and outreach as well as the vital step of separating the ‘what’ from the ‘where’ in housing with care so that care needs and preferences for accommodation and lifestyle can be two distinct aspects of decision making. This separation would have implications for how housing with care is paid for, its commissioning, regulation and inspection.
- Create a flourishing market of supply to ensure that there is greater diversity of choices for people and that new build can develop according to an evolving understanding of best practice and innovation. This will involve providers, commissioners, inspectors, regulators and planners sharing an evidence-based and continually updated vision of what good housing with care ‘looks like’ and facilitating this.
- Tackle how we think about housing with care – this section included a discussion of the terminology used and the need to adopt new terms to better describe the market and to cut through confusion of what it can offer. It also reflects on the need to bring the public into the provision and inspection of housing with care, to tackle misconceptions of housing with care with a more transparent, fact-based approach, and the need to encourage people to think ahead and make a move to housing with care more aspirational.
- Decide how to fund care – the chapter concluded by reflecting on the financial pressures faced by housing with care, the impacts it has on staffing, facilities and quality of care, and a stark warning of the implications of the growing bifurcation of the housing with care market on health inequalities and NHS resources.

7 Recommendations for change

In the previous chapter we discussed what steps were needed to help ensure that the housing with care we have now is a prominent and valued part of a twenty-first-century care system for disabled people and older people in need of support. We discussed four steps – making what we have better; creating a flourishing supply of housing with care; changing how we think about housing with care; and deciding how to fund care. The uniting theme of these steps is to separate – in provision, commissioning, inspection, regulation, funding and public perceptions – the housing and the care elements to improve choice, transparency and tackle public fear of housing with care. We set out below specific recommendations needed to implement such an approach, with the recognition that the health and care systems vary markedly in each of the four nations. In this regard, this report has primary application in England. Nonetheless, the Commission believes the recommendations made with English commissioners, inspectors and regulators in mind will be of interest and have transferable value to their counterparts in Scotland, Wales and Northern Ireland, all of whom are facing similar challenges in ensuring housing with care can fulfil its potential in a twenty-first-century care system.

A note on tackling perceptions

The Commissioners are at one in recognising that housing with care is a vital and valuable part of a future care system. It can be transformative for people who live there, and in the face of demographic change will become more important and more in demand – not less.

All good housing with care providers regard anything less than good, person-centred care as intolerable, and the moment

that any slippage from that standard is brought to their attention they act swiftly to put it right. To be treated unkindly – let alone abused – in one's own home (as this is what housing with care is) is a peculiarly intrusive and cruel invasion into one's place of safety. Improvements in personal care when it does not reach a good standard must always be made swiftly, by which we mean within hours and days not weeks or months.

But it has been made apparent throughout the course of this Commission that a small percentage of shocking and unacceptable scandals and other negative judgements of care homes have tainted the entire care sector. The potential for care homes to ensure a great quality of life for people living in housing with care settings is currently being undermined by stigma and mistrust linked to these scandals, which not only creates a situation in which care homes are misguidedly viewed as an option of last resort, to be feared and avoided, but also isolates and stigmatises people currently living and working in care homes and makes the moves to such settings unnecessarily traumatic.

The Commission has concluded that while we might recommend greater effort to cover positive news stories about care homes, instead of the unrelenting coverage of where failure has occurred, and suggests there need to be many more initiatives to celebrate the good, such as National Care Home Open Day, and so on. However, these incremental changes may take years to have an impact on public opinion.

We need to be much bolder. We have to tackle the impact of abuse scandals and people's fear of care homes head-on if housing with care is to fulfil its important role in a future care system. National and local government, the CQC and providers each have a role to play in achieving this.

With this in mind, the CQC's recent announcement of a 'special measures' regime – where care homes are subject to an intensive period of monitoring and support to tackle failings (whatever they might be) – is welcome in principle.

However, the proposals raise many questions regarding the implementation of such a regime. Details are sketchy at the time of writing, but news reporting suggests the special measures

phase for care homes is 'likely to involve less external support and instead rely on shorter deadlines to shock the providers into action' when compared with the special measures system used for hospital trusts, which includes 'buddying' with a successful trust and parachuting in an improvement director.¹⁴⁸

Differentiating the system used in care homes from that used in hospitals is an unwarranted and wholly unhelpful step – reinforcing public opinion that failure in care homes is rife and somehow more serious than in hospital settings, thereby justifying a more severe process. At the same time undermining the entire purpose of 'special measures' – to provide an intensive period of external support to enable care homes to turn themselves around while safeguarding people living there.

The CQC should create a system where care homes are helped to maintain high standards of care and improve where they might be in difficulties. This could include advice and sharing of good practice, long before they reach 'special measures'. In this regard, inspection should be preventative in nature. A system where care homes deemed to be failing are given a short period of time to turn themselves around, and no real support to do so, risks the rapid closure of many settings, which we must remember are people's homes. The failure in question may well be a resolvable issue with the right help, entirely unrelated to neglect or abuse, but the communication of this new, harsher form of 'special measures' for care homes seems both a reaction to, and a reinforcement of, misplaced public perceptions of abuse and neglect being endemic.

The Commission also hopes that as details of this approach are developed in due course, the role of local commissioners in care home failure needs to be recognised in the new special measures regime. If a home is placed in 'special measures', a proper investigation of why that happened needs to be carried out to recognise that local commissioners can exacerbate or entrench failure through funding pressure or lack of support through commissioning practice (as well as help keep homes out of special measures, with the right support). The Commission feels the CQC should have the ability to inspect

commissioning practice where their provider inspections suggest it may be necessary.

In its submission to the Commission's call for evidence, ECCA felt there was a lack of oversight over local authority commissioning practice, in particular in reference to below-market rate funding regimes:

Many authorities have resisted the idea of an agreed formula for determining fair, economic rates for care homes... preferring instead to exploit their monopsony power by imposing on providers the lowest possible prices, regardless of the quality of care provided or the prevailing economic conditions... Since responsibility for monitoring local authority commissioning was removed from CQC, there has been no effective oversight of performance in this dysfunctional system, a deficiency that has also been noted in the NAO [National Audit Office] report.

The replacement for CQC monitoring – the LGA [Local Government Association] model of peer-reviewed self-regulation – is not an effective preventive mechanism. We ask if the 'democratic mandate' of local authorities is sufficient reason for the government to permit a situation that would not be tolerated in the NHS.¹⁴⁹

If the funding practices of local commissioners are impacting the quality of care being delivered in housing with care settings, it seems reasonable that the CQC should investigate such issues.

Our recommendations related to tackling the poor perceptions of housing with care services are woven throughout the following sections. We believe these will change not only how the public perceives housing with care but also, crucially, how some commissioners and professionals in the health and care sectors view this form of support. Some of the recommendations (such as CQC surveys of the workforce) deal with poor perceptions head on, others, such as the establishment of tenants' rights in care homes, have a wider purpose but nonetheless support the Commission's mission to see a sea-change in how housing with care is perceived.

Recommendations

Leading from the front

The Government must recognise the important role housing with care plays in this reformed system. It provides a vital middle way between the care delivered in people's (general needs) homes and the type of acute care that people received in hospital – one that, if it were not there, would lead to many more people being hospitalised unnecessarily (at huge cost and with significant negative impacts on their quality of life) simply because their private homes were no longer fit for their needs. Living for longer with more complex needs (including dementia) will be more common, and local authorities and central government will be unable to discharge their duties as laid out in the Care Act 2014 without using the full spectrum of housing with care services properly.

Housing with care should not be seen as a last resort. It must be embraced, encouraged and supported to fulfil an ever-wider range of support needs in a modern care system, and must be recognised as a vital part of the housing offer for older people too. The chronic shortage of housing across the housing chain is certainly felt in the dearth of adapted and adaptable property for older and disabled people. Housing with care – housing with care delivered on site – is one way that this gap in supply can be filled for some. Housing with care services are also a major driver for local economic development by providing employment, infrastructure and capital investment. Health and wellbeing services will be major growth areas for a significant number of communities; this needs to be recognised by local enterprise partnerships.

The Government should lead from the front on this issue. We recommend:

- The Government establishes a shared vision of what role housing with care plays and what it should achieve for people it serves in a twenty-first-century care system. This should recognise the important contribution it makes to the housing market and the wider economy, as well as the huge savings it generates for the NHS. To acknowledge housing with care's prominent role in the

- health and care system, the Government should include housing in the planning and guidance for the second year of the Better Care Fund after its notable absence in the first year's guidance.
- The Government should also promote a shared evidence-based vision for what we know people needing support, relatives and staff want from housing with care and what we know works. Unless all stakeholders are agreed about what best practice looks like in housing with care, commissioners, providers and inspectors will all look for different things.
 - The term 'residential care' should no longer be used in government policy and guidance; instead the sector-wide term 'housing with care' should be used to encapsulate all forms of care delivered in specialist housing settings.
 - The Government should investigate and develop proposals (alongside the new care funding system) for tenancy in care homes so that people do not pay 'hotel costs', but rent, service charges and care fees. The viability of a tenancy framework, adapted for care home settings, should be explored. This would set out people's rights and entitlements and enshrine a culture of care that preserves and respects personal space and autonomy. Commissioners believe this would be revolutionary in imparting rights and protections for people moving into care homes and help fulfil the duty of promoting and protecting wellbeing as laid out in the Care Act 2014. People living in care homes should have the same security and rights as people moving into supported housing and apartments in care villages – equal status across the entire housing with care spectrum.

Working in housing with care

The Commission recognises that the future of housing with care is reliant on a highly-skilled, motivated and respected workforce. Most of those working in housing with care are dedicated, expert and experienced in their jobs, but are not invested in – through training and wages – nor respected or recognised for the vital and life-changing role they play.

Successful housing with care relies on relationship-centred care, rather than a time and task culture, and one that can deliver

the outcomes people want. Versatility and flexibility to cope with changing needs is crucial as well, as is the need to become more expert and knowledgeable in complex health needs, dementia and so on, to take into account the growing demand for more specialist care settings. Working in housing with care is becoming ever more demanding and it is vital we invest now to ensure the workforce is prepared for these challenges.

Commissioners believe housing with care requires a unique skill set for its staff, including the best of the health and social care and housing disciplines (such as personalisation and encouraging independence, and the specialist knowledge to help people with complex needs, dementia and in need of palliative care) but also bringing in the ability to deliver personalised support within a collective setting, providing hospitality like services, encouraging social networks, engaging with a wide range of community organisations, and ensuring specialist care is brought in as needed.

With this in mind, we recommend:

- The care sector should become a living-wage sector through a combination of changes in the personal tax and national insurance allowances and higher wages. In turn, higher wages must be made feasible through a transparent and fair funding formula developed by national government, local commissioners and providers, so that contract prices set by local commissioners adequately cover the costs of housing with care delivery at living-wage prices. While some care providers pay above the minimum wage for specialised trained carers, at the moment, the 78 per cent of the care workforce in the housing with care sector in ‘direct care’ roles earn on average £6.45 per hour – barely more than the minimum wage. While progression, skills and status all play a part, the minimum wage status of many care jobs sends a signal that this is not a well-respected or valued profession.
- The increase to the living wage – £7.65 per hour outside London – would cost around £1.1 billion per year extra for the 526,500 direct carers in housing with care currently being paid less than this on average. This would need to be delivered via additional funding from central government and administered

locally via a fair funding formula. An alternative approach would be to spread this cost with the Treasury by increasing the personal tax thresholds and national insurance contribution allowance. If these workers were exempted from both, their pay would only need to increase to £7.14 per hour for take-home pay to be the equivalent of the living wage – at a cost of around £654,000 extra per year in direct salary increases. There would also be further costs to maintain pay differentials, which is necessary in order to recruit care workers to important leadership roles such as team leader. Nonetheless – and as we explained in chapter 4 – the Commission feels housing with care will not be viable – financially, operationally or culturally – if it remains a minimum wage – indeed, below minimum wage, sector.

- Skills for Care should become the national professional organisation to represent housing with care staff and promote excellence in housing with care practice. Professional registration should be linked to qualification and training, not simply as a result of being employed in the sector. We strongly support the proposal put forward in the recent Kingsmill review into working conditions in the care sector that care workers should be awarded a licence to practice. We believe such licences would be highly powerful in that they could be revoked if necessary. Having a dedicated body would do more to promote excellence in the profession and in housing with care practice and provide a forum for staff and housing with care managers to share good practice, network and provide peer advice.
- There should be a minimum level of training and development introduced across housing with care based on the proposed care certificate. The Commission welcomes the concept of the new care certificate currently being trialled,¹⁵⁰ but it is particularly concerned by the prospect of a lack of independent validation and accreditation of these certificates, which may significantly undermine their status as a quality marker, not to mention render them not fully portable across the care sector. The Commission urges that this is addressed before the certificate is rolled out. Given the specific competences required for good quality housing with care, the Commission also feels a dedicated ‘housing with care worker’ qualification – which is externally

accredited, recognised and portable between providers – would be an important addition to the general certificate. In the longer term, we recommend the development of a two-tier ‘standard’ and ‘advanced’ certificate to allow for career progression and to recognise that the current certificate is suitable for all and does not differentiate between addressing day-to-day care needs and people with more complex requirements.

- Management of housing with care should be recognised as a distinct skill set, vocation and career path, and specialist training, qualifications and pay should be offered accordingly. Salaries should be published in the same way head teacher salaries are published to improve transparency of the position.

I know from personal experience because my wife works in a Jewish care home. She's one of the volunteer's co-ordinators in charge of the volunteers department. It's the management and if a particular home goes down it's because the manager or the manageress has either lost interest or has gone elsewhere and they have replaced her, her or him. It is definitely the management.

Member of the public, focus group

- All housing with care settings must have a registered manager. At the moment, 12 per cent of care homes do not have a registered manager in post,¹⁵¹ but it is clear that strong and coherent leadership in housing with care is vital to tackle many of the challenges outlined in this report, including the poor public perceptions of abuse and neglect in care homes which can be helped with clear and transparent accountability. The leadership qualities required of a housing with care manager are highly prized in housing with care, balancing as they do the demands of local commissioners, inspectors and regulators, the expectations of people living and working in that care setting and their families, while maintaining a central mission and culture unique to each scheme. Such skills and personal qualities need greater recognition if we hope to teach and encourage those from within the existing workforce and outside it to aspire to such roles. Again, a licence to practice, linked to a minimum set of competencies and a professional responsibility for quality,

should be instituted, similar to the ‘administrator licence’ used in many states in the US.

- Develop paid internships and apprenticeships sponsored by housing with care providers for those interested in working in housing with care. This will lead to a greater consistency of service and hopefully a more robust pipeline of potential employees, plus greater awareness across health and social care of the value and skill of the work undertaken in these settings.
- Skills for Care and the Department of Health should work with providers and other key stakeholders such as the Royal College of Nursing and Nursing and Midwifery Council to develop a vocational nursing role that allows nurses to be trained while working in care settings, mentored by qualified nurses, outside the traditional hospital or university learning environment. A vocational nursing role of this type would provide practical and affordable career development options for care workers wishing to progress into nursing roles while also tackling the immediate growing shortage of nursing staff in care settings, driven by the prevalence of more complex needs among people needing support. As we recommend the distinction between nursing and housing with care be removed, we would expect nurses to be used more widely across housing with care, recognising the changing demographic of people living there and based on their requirements, rather than according to the guidelines associated with particular registration.

Commissioning and assessment

- We recommend that consideration of the ‘what’ is decoupled from the ‘where’ in the assessment and subsequent local commissioning of care services.
- We also recommend that local commissioners across health and social care develop integrated commissioning models that are driven by outcomes rather than specify ‘how’ or indeed ‘where’ these outcomes are achieved, using personal plans and the aspirations and requirements of the person and their family. Assessments of needs and the codesign of personal care plans

with older people and disabled people should start with what people want and value, without presupposing a location in which this should be delivered. Assessments should focus on outcomes, not service types,¹⁵² and the subsequent discussion of preferences for the ways in which these outcomes might be achieved, the style of living the person is looking for, the adaptation, equipment and technology that could help should be based on offering information and advice of the options available, rather than making a choice on a person's behalf. Outcomes will inevitably need to be negotiated according to what people want, and will take into account what can be realistically achieved within the resource allowed and restrictions of collective living. Nonetheless, this negotiation needs to be just that – a two-way process where a person's preferences are put first, rather than assumptions made regarding the type of care or setting needed.

- Local commissioners should use their market shaping duties, and the advice they give to people making housing with care choices, to encourage existing housing with care providers to deliver an evidence-based, shared vision of good practice, including good practice related to staff pay and conditions (underpinned by a fair funding formula); as well as only engage with providers that can demonstrate that all their staff have attained a mandatory minimum standard of training (the care certificate or equivalent), which can be universally applied throughout the sector and effectively monitored by regulators.
- Local authorities must also encourage the widest possible range of housing options where care can be delivered on site, as well as partnerships between housing with care and other local facilities – such as children's and community centres, health or advice services. This will need to be undertaken in close partnership with planning authorities (see below) and with people using these services themselves. Working closely with local populations to ask them about their housing preferences – not just their care needs – will be vital. Local authorities must ensure that domiciliary care and specialist (retirement or adapted) housing for people who do not need care per se are both available locally alongside housing with care options to create a real range of

choices across the spectrum of need. This is a less direct form of pressure exerted than through the traditional system of direct commissioning of ‘care beds’. However, the inevitable move to a system where each person is a self-funder under the care cap, or is like a self-funder through personal budgets, should be embraced, and influence exerted on providers through market shaping (a person’s ‘choice architecture’ when making a choice regarding the ‘what’ and the ‘where’ of their care), rather than through direct (and often block) purchasing of places in housing with care.

- Local authorities should ensure their duty to provide advice and guidance under the Care Act 2014 does not simply provide advice regarding the range of housing options open to a person with a particular support package, but also includes practical and emotional support for people and their families moving to housing with care, to minimise the sense of upheaval and loss that can be associated with such a move.
- The statutory right to a social care assessment should always include a consideration for technology-enabled care services, appropriate to need. Like the dementia-friendly technology charter, this recommendation ensures that a basic awareness of the types of technology services available is in place, such as telecare, which can have huge potential benefits for people with support needs and their families.¹⁵³
- The Commission urges health and local care commissioners to do more to ensure people living in housing with care settings have access to the proper equipment, primary care and other health services, and that an NHS ‘free at the point of need’ is preserved. Housing with care must be seen primarily as a form of housing. GPs and therapists, mental health and reablement teams and other services needed by disabled and older people should come into housing with care settings as frequently as they would someone’s ‘own home’ (or indeed more so, given the demographic) and commissioners in health and care must ensure this is the case – and end the inequality of access that persists between people living in care homes and ‘in the community’.

Providing housing with care

- We recommend above all that housing with care providers, the Government, local commissioners, regulators and the people using their services work together to develop a shared vision for their sector and do their part to achieve this.¹⁵⁴
- There is substantial evidence on what good housing with care ‘looks like’, some of which we have described in chapter 5. In particular, the Commission would like to see a much stronger focus on relationship-centred care, valuing people at the centre of how we define and deliver excellence. We also feel there is much to be said for the ‘porous care home’; the creation of working–learning environments; embracing technologies to improve quality of life; democratic structures for people living in care homes and governing boards made up of people needing support, families, and lay independent members; partnerships with a wide range of local support, activity and advice services; and the use of community visitors and volunteers to provide greater connection and meaning for people living in housing with care and advocates to have their voices heard. This cannot be a short-term initiative. We must embrace the evolution of design by continuously reviewing what we understand by best practice and innovation.
- We recommend the introduction of government-sponsored grants for innovative redesigns, refurbishment and the implementation of enabling technology for care homes seeking to pioneer new approaches; as well as the launch of a design competition and a call for new designs and new ideas in housing with care to stimulate innovation, such as the Design Council’s Design for Care programme. The Commission also recognises that to deliver more substantial change, and to meet demand in 20–30 years hence, housing with care would benefit from more disruptive innovation – bringing in insights from other fields of design or from other countries. Such pioneering activity should be given more direct government backing in recognition of the potential gains to be made in investing in future-proofed health and care design.
- We recommend that care home providers work with national government and local commissioners to explore the possibility of

the aforementioned tenancy framework applicable for care-home setting, as well as look into new models (eg cooperative, mutual or profit-sharing ownership models), which give people living in housing with care a greater sense of ownership over their environment.

Building housing with care

To build more innovative models of care, health and care commissioners will need to work with local planning authorities to ensure the planning regime in each area recognises the needs of the local disabled and older populations so that there is sufficient supply to meet the housing with care preferences of local populations.

- We recommend that local plans are coproduced with care commissioners and those responsible for drafting local JSNAs. While local plans are intended to look to the housing needs of local populations over the next 15–20 years, too few specifically consider the needs of an ageing population or a population where more disabled people are living longer and want to live independently.
- We recommend that local plans must include an assessment of the population's future housing with care and retirement housing needs alongside an assessment of need for general accessible (disabled-friendly) housing. These changes taken together should help developers of housing with care compete for land and planning permission on a more level playing field.
- We recommend that local planning authorities also reflect a preference in planning permission guidance set out in the local plans for colocated facilities, those embedded with the wider community, and innovative and diverse design based on the robust evidence that already exists regarding dementia-friendly design and tech-enabled housing. We believe this will align with local care commissioners' market shaping duties to encourage as diverse a range of housing with care models as possible.

- The Commission also recommends a review of CIL charges to establish whether housing with care providers are disproportionately disadvantaged by this regime. CIL is applied per square metre and it seems likely that developments with large amounts of communal space (like housing with care) will be charged high amounts relative to mainstream housing. Yet housing with care providers will have limited ability to recoup these charges through sales of property (compared with a general needs housing developer, whose square footage is mostly likely to fall into private apartments). This could be passed to individuals through high service charges, but local authorities should bear in mind these people will be older or disabled and an argument can be made for a lower CIL rate or exemption, as currently exists for social housing developments. This would particularly be relevant if incentives were put in place to encourage housing with care providers to contribute to services or housing for people with care needs whose support is funded by the local authority – see below.
- We recommend exploring the use of incentives – including expedited planning permission; reduced purchase price on land from local authorities, hospital groups, national government or the NHS; and reduced CIL tariffs, in return for providers who are willing to build housing with care that:
 - reserves a percentage of space for people whose care services are funded by the local authority or contributes financially to services for people funded by the local authority
 - demonstrates best practice in design and is tech enabled
 - offers outreach services to the wider community (such as support for informal carers), and exhibits best practice in relation to quality of life, quality of care and quality of management along the lines of the shared national vision of relationship-centred care (described in more detail in chapter 5).
- We recommend a change in planning-use classes to reflect the reality of ‘housing with care’, and make it easier for providers to be more flexible and innovate and build multi-use developments.

The use of C3 use classes in the existing planning regime (subject to affordable housing charges) or C2 (subject to CQC inspection) creates a variety of incentives for developers running counter to the delivery of a flexible model and reduces colocation or mixed use.¹⁵⁵ A new use class should be created for all housing with care, which would be:

- subject to CQC inspection of its care (not accommodation)
 - a reduced CIL rate (recognising that its communal space directly supports the quality of care for people living there)
 - subject to s106 agreements not (as is mainly the case for general needs housing) to contribute to the provision of affordable housing, but to reserve a set percentage (quota) of places in each development for state-funded older or disabled people or to contribute to services which support these groups.
- We recommend the relaxed change of use measures introduced in 2013¹⁵⁶ to help local authorities convert offices to housing should be extended to enable the NHS, MoD and university land banks, and appropriate office buildings to be converted into housing with care models more easily. Repurposing and refurbishing existing stock, alongside new build, is important if we are to create a diverse range of housing with care options without relying on substantial levels of new capital investment from developers. It will also provide opportunities for housing with care to be built in town centres and other well-connected locations, so important for disabled and older people, where new building is not always feasible.
 - Over the longer term, the Commission would like to see all housing being built on an adapted or adaptable model so that the line between mainstream housing and specialist housing is blurred. We recommend that a way forward would be for all homes to be built to Lifetime Homes standards, and that a proportion (say 10 per cent) is built to be fully wheelchair accessible.

Regulation, registration and inspection

The CQC is a vital partner in tackling poor perceptions of housing with care and can help challenge public misperceptions.

- We recommend the introduction of an annual CQC survey of people using all housing with care services to run alongside the CQC's current surveys of people using acute services, outpatient services and community mental health services. This would provide a more effective means of highlighting thematic issues across the sector which need to be addressed at a regional or national level. In addition, it would support the CQC's efforts to become more data-led and focused on customer experience as well as helping to address the current gaps in adult social care data. One way in which the CQC could do this is to introduce a standard set of questions which providers are required to include in their annual customer experience surveys and report to the CQC on. Transparent, readily available data are vital to change public perceptions.
- We recommend that the CQC conducts an annual workforce survey to monitor staff engagement across the sector, and to validate the level of abuse and neglect in housing with care. There is strong evidence that staff engagement and motivation is linked to people's experience and quality and safety of care provision, and it is vital that this is recognised with regular monitoring. The survey should include direct questions about whether members of staff have themselves witnessed care that they would regard as neglectful or abusive. This would help by creating a sense of accountability and confidence in a sector which has long been mistrusted through greater transparency and better communication.
- The Commission recommends that providers should be required to publish standardised feedback reports from their customers and their families (along the lines of Your Care Rating) on their website, alongside whistleblowing and complaints policies and data relating to complaints (including response times and lessons learned) so that these are accessible to and comparable by services users, regulators and the general public. This would ensure that all providers have adequate policies and procedures in place and are operating openly and transparently in this

respect and the CQC should provide guidance for providers in how to fulfil this duty. In order to ensure that these data are useful and accessible a comparable methodology should be used by all providers and it should be made easily available in a variety of formats.

- The Commission would like to see the consolidation of several review sources on the CQC website, making it easier for prospective customers and their families to review their choices from a range of independent sources in one place. At the moment, several TripAdvisor-style websites have been set up to enable people to post reviews of housing with care services. While it is likely – as with other review markets – that these websites might consolidate to one or two large operators, in the meantime another method of consolidation is needed.

The Commission welcomes the fact that the regulator is increasingly seeking the views of people needing support and relatives in care homes to help monitor quality and drive service improvement. Under the new inspection framework recently developed by the CQC, inspectors will not look at compliance alone, but also at a service's ability to learn and correct mistakes. Inspectors will be more explicit about encouraging homes to improve than they have been in the past, by being clear about what good housing with care is, and providing homes with the tools to improve. This is to be welcomed but more needs to be done to differentiate between the care being delivered and the location in which this is occurring.

We recommend:

- The CQC should carry out outcomes-based inspections and inspect the quality of care delivered – and its ability to deliver a good quality of life – in all housing with care settings, including supported living, extra care, village models and traditional care and nursing homes.
- The role of the CQC should be expanded under the powers in the Care Act 2014, so that it has responsibility to evaluate the effectiveness and quality of commissioning, alongside care

provision. This would include conducting regular, ongoing reviews of local authority commissioning to ensure that it is delivering high-quality outcomes for disabled and older people in receipt of care and support, and to conduct reviews into local authorities immediately when there is a concern about a risk to safety or welfare for people using services.

- While an assessment of whether the housing in which the care is delivered is conducive to the care needed for each individual should be made (particularly for people with dementia and sensory impairment), the CQC should not remain responsible for inspecting the accommodation of people who need care in housing with care settings, including care homes. In practice this led to care home and nursing home inspections being aligned with current extra-care inspections. Other levers – through commissioning, planning and central guidance regarding a shared vision of good practice – will encourage housing with care settings to innovate and develop good practice in environmental design.
- To reflect this change, we recommend a single category of housing with care be used in CQC registration, called housing with care. This will encapsulate every form of housing where care can be delivered on site, including small independent living units for disabled people, extra-care villages, and care and nursing homes. The distinction between nursing and care home should no longer exist. The CQC would inspect the quality of care (based on a wider definition of quality of life and outcomes achieved) of all housing with care options in the same way, with the ‘bricks and mortar’ of the accommodation outside its remit. This is not just to deliver a sense of normality and send a message that people’s own home (whether their family home, adapted apartment, or tenancy in more communal housing) is their private choice, but also about creating a regulatory system that recognises that the quality of care is not defined by accommodation.
- We recommend building inspection for communal care settings (eg traditional care-home models where all space outside one’s bedroom, apartment or ‘bedsit’ is communal) is increased to

match the level seen in other communal establishments, such as hotels, alongside the standard housing, fire, safety and other standards currently in place in extra-care settings.

Funding

Adequate funding for housing with care is vital – it is the foundation stone on which the wider vision set out in this and previous chapters must be built. It is a prerequisite for the successful implementation of all of the recommendations made in this chapter.

As we explain in chapter 5, much has been written on the subject of care funding over the past decade, but we cannot be complacent in thinking that the funding of social care has been ‘resolved’ with the planning introduction of the Dilnot-inspired care funding cap. Dilnot was not asked to quantify how much funding would actually be needed to deliver the volume and quality of care to meet current demand, nor future demand. Nor indeed was he asked to provide a definitive conclusion as to the level of demand the state should be met. Yet these questions are crucial. The fact the Coalition Government has proposed to set the national eligibility for state-funded care at ‘substantial needs’ and above could render the implementation of the Care Act almost impossible.

The Government must adequately fund social care so that the vision for care and wellbeing laid out in the Care Act can be fulfilled, enshrined at local level by a fair funding formula.

The Commissioners strongly believe that the Government, providers, local health and care commissioners and the public need to understand how important good care is to the everyday happiness of hundreds of thousands of people, and how much quality care costs, and – importantly – how much it saves other services and contributes to the economy. This transparency should filter down into all elements of the care system so that people understand the costs of housing with care, and what they are paying for, after years of such costs being obscured by local authority commissioning. We recommend:

- HMT should commission the OBR to conduct a five-yearly, 20-year projection of demand for care services, considering health status, demography, technology and so on, and the financial drivers of different models. This will help us answer how much the care system as envisioned in the Care Act will cost now and in the future.
- Open book accounting and a fair funding formula should be implemented for the care provided in housing with care settings, and the cost of accommodation. This formula must recognise the true cost of care; as staffing costs are the major driver of care costs, this must be reviewed annually in line with inflation and changes to the minimum and living wages. It must also recognise that, like rental charges for any general needs accommodation, providers need to make a return on their capital investments.
- As part of open book accounting, housing with care providers should adopt the tripartite funding system, separating out rental charges, service charges and care fees and making these transparent. The term ‘hotel costs’ is unhelpful in suggesting that people living in care-home settings have no rights over their accommodation nor living in ‘their home’, but rather are a sort of temporary guest.

Summary

This chapter presents the Commission’s recommendations for the provision, commissioning, inspection, regulation and building of housing with care. It is the culmination of over a year’s research and discussions and provides a clear means by which the plan for change, outlined in chapter 6, can be implemented through a joint effort by all the relevant stakeholders – including central and local government, the CQC, care providers, Skills for Care and other umbrella bodies.

The Commissioners feel strongly that these recommendations hold the key to the future of housing with care, which cannot just survive, but should grow and flourish, and claim its rightful place as a crucial part of the vision of care presented in the Care Act 2014.

Summary of recommendations

Leading from the front

- 1 The Government should establish a shared vision of what role housing with care plays and what it should achieve for people it serves in a twenty-first-century care system.
- 2 The Government should promote a shared evidence-based vision for what we know people needing support, relatives and staff want from housing with care and what we know works.
- 3 The terms ‘residential care’ and ‘care home’ should no longer be used in government policy and guidance; they should be replaced with the sector-wide term ‘housing with care’ to encapsulate all forms of care delivered in specialist housing settings.
- 4 The Government should investigate and develop proposals for tenancy in care homes so that people do not pay ‘hotel costs’, but rent, alongside service charges and care fees.

Working in housing with care

- 1 The care sector should become a living-wage sector, with a transparent and fair funding formula developed by national government, local commissioners and providers to make this viable.
- 2 Skills for Care should become the national professional organisation to represent housing with care staff and promote excellence in housing with care practice.
- 3 A minimum level of training and development should be introduced across housing with care and linked to a licence to practice.
- 4 Management of housing with care should be recognised as a distinct skill set, vocation and career path, and specialist training, qualifications and pay should be offered accordingly.

- 5 Paid internships and apprenticeships should be introduced, sponsored by housing with care providers, for those interested in working in housing with care.
- 6 A vocational nursing role that allows nurses to be trained while working in care settings, mentored by qualified nurses, should be explored by Skills for Care, the Department of Health, providers and other key stakeholders.

Commissioning and assessment

- 1 Consideration of the 'what' should be decoupled from the 'where' in the assessment and subsequent local commissioning of care services.
- 2 Local commissioners across health and social care should develop integrated commissioning models that are driven by outcomes rather than specify 'how' or indeed 'where' these outcomes are achieved.
- 3 Local commissioners should use their market shaping duties to encourage existing housing with care providers to deliver a shared vision of good practice, including good practice related to staff pay and conditions.
- 4 Local authorities must also encourage the widest possible range of housing options where care can be delivered on site.
- 5 Local authorities should ensure their duty to provide advice and guidance under the Care Act 2014 includes practical and emotional support for people and their families moving to housing with care.
- 6 The statutory right to a social care assessment should always include a consideration for technology enabled care services, appropriate to need.

- 7 Both health and local care commissioners must do more to ensure that people living in housing with care settings have access to primary care and other health services.

Providing housing with care

- 1 Housing with care providers, the government, local commissioners, regulators and the people using their services should work together to develop a shared vision for housing with care and do their part to achieve this.
- 2 The Government should sponsor grants for innovative redesigns, refurbishment and the implementation of enabling technology for care homes seeking to pioneer new approaches; as well as the launch of a design competition and a call for new designs and ideas in housing with care to stimulate innovation.
- 3 Care home providers should work with national government and local commissioners to investigate the possibility of the aforementioned tenancy framework applicable for care home setting, as well as look into cooperative, mutual or profit-sharing ownership models.

Building housing with care

- 1 Local plans should be coproduced with care commissioners and those responsible for drafting local JSNAs.
- 2 Local plans must include an assessment of the population's future housing with care and retirement housing needs alongside an assessment of need for general accessible (disabled-friendly) housing.
- 3 Local planning authorities should reflect a preference in planning permission guidance set out in the local plans for colocated housing with care facilities, those embedded with the wider community, and innovative and diverse design.

- 4 The CIL should be reviewed to establish whether housing with care providers are disproportionately disadvantaged by this regime.
- 5 The use of planning incentives should be explored for providers willing to build housing with care which contributes to services for people funded by the local authority, and other related conditions linked to good practice in design.
- 6 There should be a change in planning-use classes to create a dedicated use class covering all housing with care.
- 7 The relaxed change of use measures introduced in 2013¹⁵⁷ to help local authorities convert offices to housing should be extended to enable NHS, MoD and university land banks, and appropriate office buildings, to be converted into housing with care models more easily.
- 8 Over the longer term, all new housing should be to Lifetime Homes standards and at least 10 per cent of new housing should be built to fully wheelchair accessible standards.

Regulation, registration, inspection

- 1 The CQC should conduct an annual survey of people using all housing with care services to run alongside the CQC's current surveys.
- 2 The CQC should also conduct an annual workforce survey to monitor staff engagement and instances of abuse and neglect.
- 3 Providers should be required to publish standardised feedback reports from their customers and their families on their website, alongside whistleblowing and complaints policies and data relating to complaints.

- 4 Several review sources should be consolidated on the CQC website.
- 5 Outcomes-based inspections should be carried out by the CQC in all housing with care settings.
- 6 The CQC's role should be expanded to the inspection of local authority commissioning practice.
- 7 The CQC should not be responsible for inspecting the homes of people living in housing with care settings, including care homes.
- 8 A single category covering all residential care should be used in CQC registration, called housing with care.
- 9 Building inspection for communal care settings (eg traditional care home models where all space outside one's bedroom, apartment or 'bedsit' is communal) should be increased to match the level seen in other communal establishments, such as hotels.

Funding

- 1 HMT should commission the Office for Budget Responsibility to conduct a five-yearly, 20-year projection of demand for care services.
- 2 Open book accounting and a fair funding formula should be implemented for the care provided in housing with care settings, and the cost of accommodation. This must be reviewed annually in line with inflation and changes to the minimum and living wages.
- 3 Housing with care providers should adopt the tripartite funding system, separating out rental charges, service charges and care fees and making these transparent.

Concluding thoughts

The Commissioners began this year-long investigation into the future of the housing with care sector with the view that housing with care has the capacity to change lives for the better, help people gain independence and participate in community life where they might once have been isolated in their family homes, provide the best form of support for people with complex needs and dementia, and be a good place in which to die.

The research undertaken and evidence gathered to support the Commission certainly demonstrates what good housing with care can achieve, what people want in support following frailty in old age, or a disability earlier in life, and what good care ‘looks like’ in specialist residential settings. But we have also heard about the challenges the sector faces and the need for commissioners, regulators, the NHS and national governments to help overcome them. Commissioners believe that without a joint, sustained effort on the part of housing with care providers and these other stakeholders, the future of housing with care and the life-changing role is at risk. The risk is not just that instability and unviable business models will see many otherwise excellent providers leaving the market, but also that the market will be split into two, entirely separate markets – one for self-funders and one for local-authority-funded individuals. The former will maintain good quality care with larger homes, focusing on higher needs, and charging higher fees to recruit better paid and better skilled staff; while the latter will see an entrenchment of poorer standards of care and facilities, delivered by low paid staff. This is already happening and needs to be remedied as a matter of urgency.

Local and national government play their part in providing housing with care, alongside market forces, wrapped in social norms and cultural responses to disability, ageing, frailty,

dementia, disability and dying. The issue of providing support in some form of specialist setting cannot be separated from our deep-seated caution, perhaps fear, at the prospect of becoming old or impaired in some way and needing support 'away from home'. Nor can we ignore the impact of the prevailing financial climate and the shifting policy sands on which funding for care currently sits.

With this in mind, there are many aspects of housing with care and its reform we simply cannot explore in sufficient detail. Our review of existing evidence identified at least 40 well evidenced, important reports since 2009 exploring various elements of housing with care and its improvement, and we have no ambition to replace them, nor add to this body of work without inspiring any actual change.

Much has been said and written, but less has been done. Through this report, therefore, we want to create a powerful action plan for change – identifying what needs to be done and who needs to be responsible for these actions, with a view to inspiring a joint effort. We are confident that, with this effort, housing with care can claim its rightful place in a twenty-first-century care system.

Appendix 1 Glossary of abbreviations

ADASS	Association of Directors of Adult Social Services
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
ECCA	English Community Care Association
LGA	Local Government Association
MHL	<i>My Home Life</i>
NAO	National Audit Office
NCF	National Care Forum
OBR	Office of Budget Responsibility
PCT	Primary Care Trust
TLAP	Think Local Act Personal

Notes

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The Commission on Residential Care was formed in July 2013 to explore the future of residential care in its broadest sense – from care homes to extra care villages and supported living, for older and disabled people. Chaired by former Care Services Minister Paul Burstow MP and composed of a group of academics, experts and practitioners related to residential care, it has two main objectives. First, to create a vision of ‘housing with care’, not bound by existing definitions but based on the outcomes that people want and value.

And second, to set out how the existing offer could change to deliver this vision, across financial, operational, governance and cultural aspects of care. This is the final report of the Commission, which draws on evidence gathered over the course of 12 months by the Demos secretariat. This includes surveys, interviews and focus groups with experts, care staff, disabled and older people and members of the public; site visits and international trips; and two calls for evidence.

One of the most striking findings is the sheer impact of negative public perceptions – the public broadly see care settings as places of illness and frailty, where you would only go as a last resort. But despite these perceptions, the sector is full of innovative and excellent examples of high-quality, personalised and empowering care for people with diverse and complex needs.

The Commission recommends a number of measures to embed good practice and challenge public perceptions. These include enshrining a broader, more accurate definition of ‘housing with care’ throughout government policy; greater co-location of care settings with other community services such as colleges; the expansion of CQC’s role in inspecting commissioning practices; and promoting excellence in the profession through the introduction of a license to practice and a living wage. The Commission concludes that these measures, among others, could help build a housing with care sector fit for the twenty-first century.

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