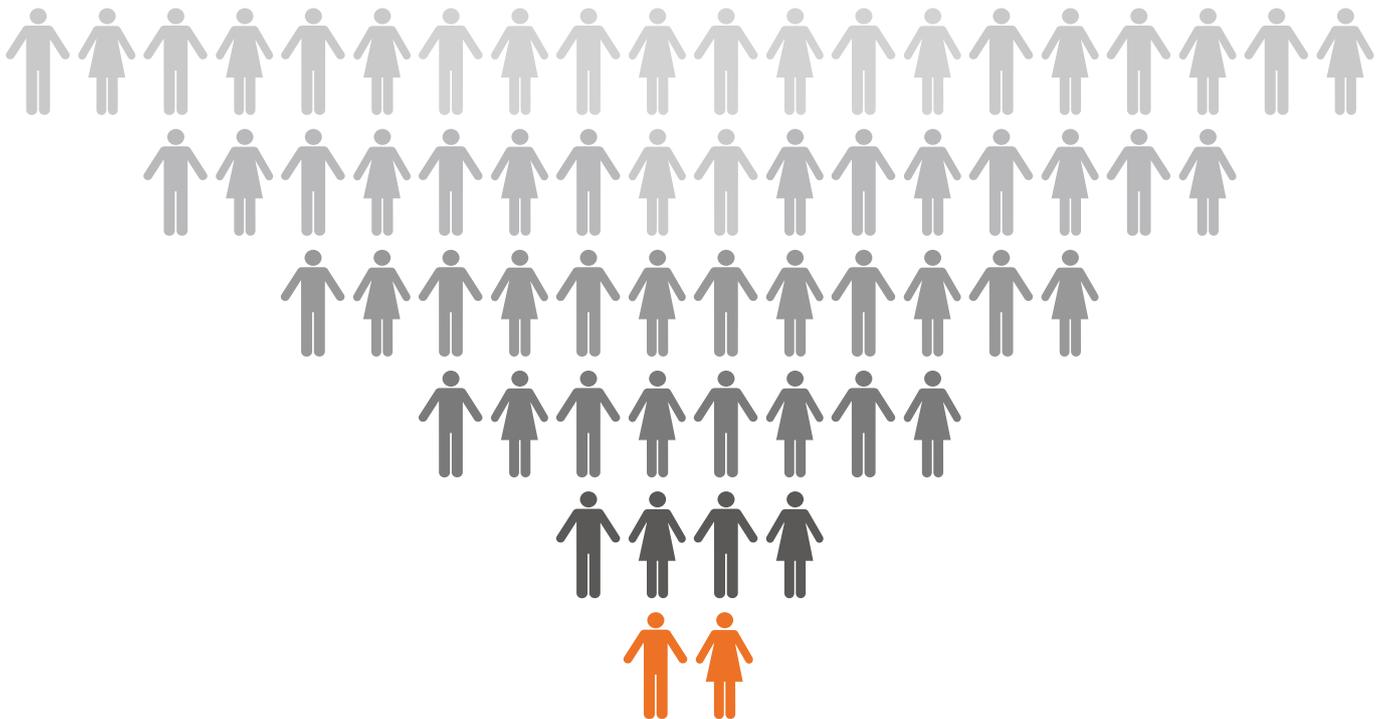


REPORT

# THE GENERATION STRAIN

COLLECTIVE SOLUTIONS TO CARE IN AN AGEING SOCIETY



Clare McNeil and Jack Hunter

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## ABOUT THE AUTHORS

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The views expressed in the report are those of the authors alone.

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The Calouste Gulbenkian Foundation is an international charitable foundation with cultural, educational, social and scientific interests. Based in Lisbon with branches in London and Paris, the purpose of the UK Branch in London is to bring about long-term improvements in well-being, particularly for the most vulnerable, by creating connections across boundaries (national borders, communities, disciplines and sectors) which deliver social, cultural and environmental value. In 2008, the Foundation launched an initiative on ageing and social cohesion. Since then, we have supported a number of partnerships and initiatives which we hope will contribute to a growing understanding of the impact of demographic ageing to our society.



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IDEAS to  
CHANGE LIVES

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## EXECUTIVE SUMMARY

More of us are taking on caring responsibilities for our parents and we are worrying more about how we will be cared for ourselves when we are older. But few are convinced that politics has the answers – only a quarter think the government has the right policies on social care, which was viewed in a recent poll as the second most important area of public spending, behind only the NHS and ahead of schools and infrastructure (Kellner 2013).

Most care for older people is not provided by the state or private agencies but by family members, at an estimated value of £55 billion annually. However, as the babyboomer generation ages, a growing ‘family care gap’ will develop as the number of older people in need of care outstrips the number of adult children able to provide it. This is expected to occur for the first time in 2017.

Overstretched services will struggle to provide extra care, with two-thirds of all health resources already devoted to older people and social care services facing a funding crisis. Adult children and partners will take on even greater caring responsibilities and more people, particularly women who outnumber men as carers by nearly two to one, are likely to have to give up work to do so.<sup>1</sup>

The Coalition government is responding by integrating health and social care services to make better use of existing resources, although current plans are not radical enough (Bickerstaffe 2013) and additional funding is likely to be needed (King’s Fund 2014). But even if these huge challenges were overcome, we would still need to rethink how we look after each other in later life, because traditional social care services are struggling to meet the social and emotional needs which matter as much to people as their physical and health needs.

Central to this is the opportunity to offer care and support as well as to receive it. But too often older people are stripped of their human role as caregivers and are isolated – not only through the major loss of loving relationships but also through the loss of small, everyday interactions with colleagues, neighbours, passers-by and strangers.

While some might not view tackling social isolation or help with simple activities such as transport or shopping as the role of the state, we argue that the post-war care system has in fact always depended on the unpaid care provided largely by family members to meet these needs. As this is naturally curtailed as more people live on their own and fewer have family to rely on, we must find new ways of replacing it if we are to aspire to a decent quality of life in old age.

Evidence suggests investing in keeping older people healthy and socially active can delay the need for professional care and contain the rising costs of health and social care (NAO 2014, Bolton 2009). Yet we show that community-based schemes that are saving money by preventing avoidable use of A&E, hospitals and GP surgeries, as well as delaying entry into formal care, are too often relegated to ‘special project’ status and fail to become a part of mainstream spending on elderly care.

With a narrow focus on physical and health needs, the current system too often neglects what it is to lead a decent life in later years. The starting point for any system of care should be to ask what it takes to lead a good life. This broader starting point would take us beyond solutions that centre on services, to place a greater value on mutual support and building on existing resources within families, neighbourhoods, community networks.

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<sup>1</sup> Even 10 hours of care a week affects people’s ability to stay in work and care.

Our central message in this report is that we need to transform our understanding of what ‘social care’ is in order to help people live decent lives, to put in place the right building blocks to prepare for an ageing population and to reduce future demand for care.

### The way forward: more power to people and institutions

Already at a local level many initiatives in the UK are working with communities to strengthen relationships and resources that already exist. For example, in Leeds, a system of ‘Neighbourhood Networks’ is keeping older people socially and physically active and reducing pressure on local NHS and social care services. Despite a growing 65-plus population, the number of older people receiving homecare and taking up places in residential care homes is falling.<sup>2</sup> If every authority were to contain rising demand for care in this way this would result in a savings of at least £0.36 billion per year.

However, in contrast to countries such as Germany, the Netherlands and Japan, the UK is lagging behind in cultivating these types of networks on a national scale. We argue that Germany is an exemplar for the UK. Germany’s *Mehrgenerationenhauser* (multigenerational houses) are funded by the federal government and are a key part of Germany’s ageing population plan. These community spaces provide support in daily activities for older people, crucially alongside other age groups. This national scheme is popular with families, employers and local public services as well as older people, because each benefits from the mutual support they unlock, which is simple in itself, but which cumulatively creates abundant value.

In the years ahead, these approaches will not be a ‘nice to have’ but a necessity, as families will need an extra helping hand to cope with caring responsibilities and pressure grows to contain the rising public costs of health and social care.

Our plan should be to **‘build’** and **‘adapt’**: to **build** new community institutions capable of sustaining us through the changes ahead and to **adapt** the social structures already in place, such as family caring, public services, workplaces and neighbourhoods.

This will require a different role for the state, one that is more about establishing partnerships with families and communities than traditional service delivery. The Coalition government has set out the right intentions for this in the Care Bill that has recently made its way through parliament. However, it is unlikely that the new duties set out the Care Bill for local authorities to consider ‘wellbeing’ will overcome the tension in a means-tested system between the needs of the wider population and the few entitled to state-funded care.

An alternative way forward would be to give more power to people and institutions to improve their own wellbeing, to support each other and to prevent care needs from arising, thereby benefiting from the ‘multiplier effect’ this would have through volunteer networks, as in Germany and Leeds. Investing in strengthening community networks across the country now would be a relatively small but sound investment in the future.

This is not an argument for the state to withdraw so that community-led solutions will flourish. There is no evidence to suggest that will be the case, as the Coalition government’s experiment with the ‘big society’ has shown. It requires neither a huge increase in time given to volunteering nor a nostalgic return to a ‘golden age’ of neighbourliness. Government should focus on making it easier for people both to *offer*

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<sup>2</sup> In Leeds, the number of people receiving home care has decreased from over 4,200 in 2010/11 to under 3,700 in 2012/13, while the number of residential placements funded by the council has also decreased steadily, from 172,810 bed weeks in 2002/03 to 135,522 in 2012/13.

and ask for help (for example, through ‘asset-based’ approaches, which build informal links). The Dutch experience has shown that this will do more to lead to growth in mutual support than tackling any perceived shortage of supply through efforts to increase volunteering.

## Recommendations

To ease Britain’s case of ‘generation strain’, the post-war model of social care needs to change. What the social care system is currently providing is often neither what people want nor what will prepare us for an ageing population. We put forward proposals that will reform the current social care system in three key ways:

- establishing a different starting point for social care services by asking: ‘what do people need to live a good life’?
- acknowledging family and mutual support as the frontline of care rather than services
- encouraging new providers by creating opportunities for community groups and social enterprises to play a part in the delivery of care in ways that challenge the dominance of the state and market.

The four key proposals below should form part of a five-year funding settlement across health and social care, instead of the current three-year cycle of spending reviews. This would overcome one of the main barriers to ‘mainstreaming’ preventative activities by providing greater flexibility to reprioritise spending and resources as well as establishing the long-term mind set needed for health and social care integration. There should also be a single outcomes framework across health and social care covering older people and those with long-term conditions.

### **1. New neighbourhood networks to help older people to stay active and healthy, help busy families balance work and care and reduce pressures on the NHS and social care.**

- In future, unevenness between local authorities in the quality of community support for older people and their families will only become more apparent as more people use the services.
- We recommend that upper-tier authorities with the least developed community-based provision, which indicative analysis suggests are likely to be in the North East, North West and South West of England<sup>3</sup>, are the focus of the greatest efforts to identify and strengthen community networks.
- We recommend that a minimum five-year programme of leadership and peer support is run by the Local Government Association (LGA) and Adult Directors of Adult Social Care Services (ADASS) to oversee this, based on the successful ‘London Challenge’ model in education.
- Funding of an estimated £2 million per local authority<sup>4</sup> should be made available from local public health budgets to fund the development of ‘neighbourhood networks’ with the aim of funding more of this from mainstream provision over the five-year period

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3 Indicative analysis of spending for older people suggests that the 38 local authorities with the greatest reliance on expensive residential and nursing care and the least developed community care are likely to be in the North East, North West and South West of England. However further analysis would need to be done to verify these findings. This is as measured by the proportion of total gross expenditure by councils with adult social service responsibility that is spent on residential or nursing care (data source: HSCIC 2013b).

4 This is calculated based on spending on similar initiatives, though the exact amount will vary depending on size of population and nature of the scheme developed.

- In developing neighbourhood networks, the UK should follow the example of the German *Mehrgenerationenhauser* (multigenerational houses) national programme and house services for different age groups such as childcare and eldercare under one roof, removing artificial boundaries between young and old.

**2. Care coordinators providing a single local point of contact, to replace the ‘case management’ currently provided by adult social services in every area by 2020, for all but the most complex cases of care.**

- Instead of ‘case management’ from social workers which, older people, their families and carers should be given a local care coordinator based in the community to help them make the most of local networks and services.
- Based on the Local Area Coordination scheme developed in Western Australia, which is providing better care outcomes at lower cost, local care coordinators based in accessible community locations should support the navigation of both the health and social care systems for older people.
- All but the most complex cases of care should be handled by care coordinators, with care management decommissioned by adult social care services by 2020.

**3. Option of a ‘shared budget’ to enable those using community care to arrange this collectively.**

- Giving older people, their families and carers the money to pay for services directly is a powerful way of putting people in charge of their own care. However older people, their families and carers are frequently discouraged by the responsibilities that come with this.
- Older people, their families and carers with a personal budget should have the option to pool their ‘direct payment’ with other local people to create a local ‘shared budget’ to meet their care needs collectively.
- More third-party organisations, such as community groups, faith organisations, mutual support groups and micro-enterprises should be invited to take on responsibility for developing packages of care and support for individuals in this way if they meet certain core criteria.<sup>5</sup>
- This option should be promoted by care coordinators and could be carried out by community organisations including neighbourhood networks.

**4. Stronger employment rights for those caring for people who need more than 20 hours of care a week, to make it easier for family members to combine work and care.**

- Workers caring for those with high physical and mental support needs should be given enhanced employment protection rights to allow them to combine work with care, rather than taking up a welfare payment.
- This could be through a right to adjusted hours or an adjusted role, with protection of their employment contract, for those with an underlying entitlement to carer’s allowance. It could also be through various options that have been put forward for family caring leave.
- Further assessment should be done of the costs and benefits of these approaches.

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5 To take part, community organisations have to meet criteria including community engagement and ownership; having an inclusive approach; a commitment to drawing on local community resources and volunteer development.

# 1. A GROWING PROBLEM: OLDER PEOPLE AND THEIR FAMILIES BEING LEFT TO COPE ALONE

A growing family care gap means that the number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017. By 2032, 1.1 million older people in England will need care from their families – an increase of 60 per cent – but the number of people able to care for older parents will have increased by only 20 per cent, creating a shortfall in our collective capacity to care for older generations (Pickard 2013).

This ‘generation strain’, as we have termed it, could become either a source of increasing anxiety or an opportunity to make progress, in terms of both raising the value we place on care as a society and transforming the way we care for each other.

The arrangements we have in place to support each other later in life are already faltering. State-funded care is increasingly being rationed, families and carers are providing ever more intensive levels of care, and a growing number of those who can neither afford paid care nor rely on family or friends are being left to cope alone.

A series of public bodies have issued warnings of increasing pressures on the system and the consequences for society if they are not faced up to. A House of Lords select committee last year found that:

**‘Social care and its funding are already in crisis, and this will become worse as demand markedly increases.’**

House of Lords Select Committee on Public Service and Demographic Change 2013

In an inquiry into the future of care and support, the Equality and Human Rights Commission identified systemic problems in the care system and urged that:

**‘Without fundamentally re-designing care and support for the future, there is a grave danger that we will undermine individual opportunity, the strength of family life and our future national prosperity.’**

EHRC 2011

The National Audit Office has recently highlighted the dangers of the government ‘not knowing’ whether the health and care systems are ‘approaching the limits of their capacity’ to absorb the growing pressures (NAO 2014).

Both the immediate and longer-term challenges require us to renegotiate the fragile balance between the four ‘pillars’ of a caring society: family, community, market and state. This cannot be done by government alone and will need a far wider public conversation.

Care for older people has traditionally been fairly low on people’s list of political concerns, not least because many only vaguely understand what ‘social care’ actually is. But as more people of different ages, including those in their 30s and 40s, take on caring responsibilities for parents and elderly relatives, and as more of us begin to worry about what will happen to us when we are older, there are signs that public opinion is changing.

- A YouGov poll for Progress last year found that support for the elderly was viewed as the second most important area of public spending, after the NHS and ahead of schools and infrastructure (Kellner 2013).
- An NHS survey last year found that just 25 per cent of people think the government has the right policies on social care, while fewer think people are treated with compassion when using social care services than NHS services (NHS 2014).

- An earlier Ipsos MORI poll found that ‘care for the elderly’ was the least popular choice when people were asked about areas of public spending that should be cut to help restore the public finances (Ipsos MORI 2009).

The issue will take on increasing political saliency over the next 15 years as the elderly population doubles in size, the ‘grey vote’ becomes more powerful and a babyboomer generation that has been at the vanguard of social change enters retirement. At the same time, there will be fewer and fewer adult children able to support these older generations. Unless the UK follows other countries around the world in preparing for this shortage of care, hundreds of thousands of babyboomers could be left to cope on their own, with overstretched services unable to make up the shortfall.

The problem goes beyond simple supply and demand. A greater number of older people are living alone, families are living further apart, and fewer older people have children to rely on. For many, a lack of social contact can mean that they feel a sense of separation from a society that feels very different to the one that existed even 20 or 30 years ago, as social mores shift and technology changes the way we live. Older people are frequently the recipients of care but they are too often stripped of their human role as caregivers – not only through the major loss of loving relationships but also through the loss of small, incidental interactions with colleagues, neighbours, passers-by and strangers.

### Facing up to generation strain in the next parliament

The first real tests could come sooner than expected. By 2017, half way through the next parliament, demand for unpaid care will begin to exceed supply, and the ‘care gap’ will grow sharply from then onwards. In turn, pressures on A&E departments and hospitals are likely to increase, as fewer older people receive the care they need and more are likely to slip into crisis. Already, the number of people over the age of 80 arriving at A&E has risen by 65 per cent over the last five years (HSCIC 2014).

As more adult children provide ‘intense care’ (over 20 hours per week) we can expect more people to have to give up their jobs to care. Even 10 hours of care a week affects people’s ability to stay in work, leaving women in particular with hard choices to make about how to balance family and work.

Public dissatisfaction with the care system is likely to rise even further, with over 40 per cent of local authority directors of adult social services already anticipating a rise in the number of legal challenges over the next two years (ADASS 2013). Since 2010 there has been a 13 per cent increase in reporting of cases of neglect and abuse. Although this increase may reflect increased awareness of abuse, says the National Audit Office has reported, it may also reflect overstretched resources and pressure within the system (NAO 2014).

If we don’t find ways of closing family care gap, we face the bleak prospect of ever-greater numbers of older people facing later years of neglect and isolation. On current projections, it is expected that nearly 2 million older people will be experiencing chronic loneliness by 2033 (Lawton 2014).

### The way forward: ‘build and adapt’

There is nothing inevitable about growing isolation and a shortage of care. Other countries, such as Germany, the Netherlands and Japan, are facing a similar challenge and are finding new ways to organise society in order to adapt to the generational shift. These solutions combine the best of society and the state by making better use of the

abundant resources already present in communities and by creating institutions to bring generations together with the aim of building a stronger common life.

In this report we ask why previous attempts to recognise the importance of individuals and their families in providing care have not been more effective or more widely felt, and how best to prepare for the full impact of our ageing society in the 2020s. We paint a picture of family life and caring in the UK today, seen through the eyes of Richard, Fiona and Jenny, and use their experiences to illustrate how this might change in the future.

Our central message is that we need to **build and adapt**: to **build** new community institutions capable of sustaining us through the changes ahead and to **adapt** the social structures which already exist, including family, public services, workplaces and neighbourhoods.

## 2. LOOK AHEAD: THE WAY WE LOOK AFTER EACH OTHER LATER IN LIFE IS CHANGING

Given current population projections, demographic change will produce more people needing care and more carers providing it unpaid. The number of people in the UK aged 65 and over is projected to increase from 10.3 million in 2010 to almost 17 million by 2035 (ONS 2011b).

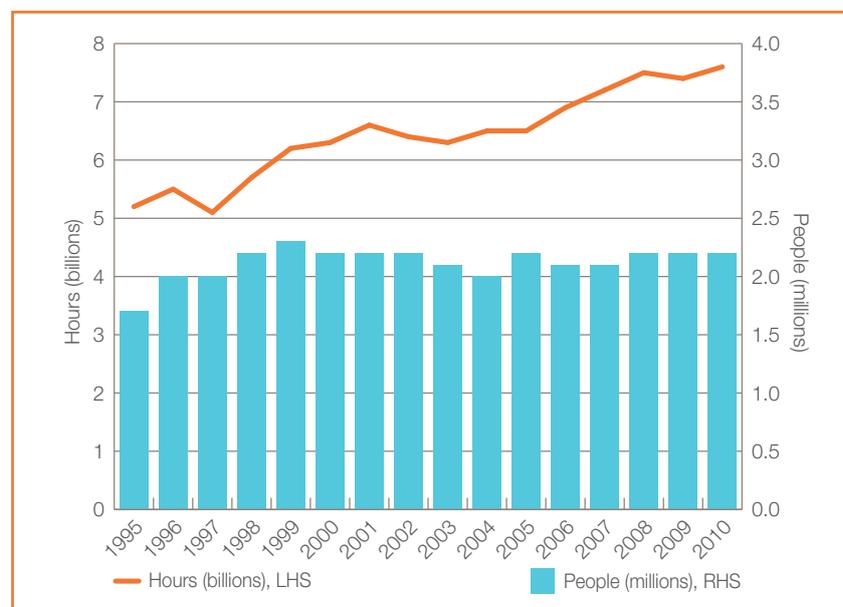
Currently, the 65-plus population accounts for 17 per cent of the total population in the UK. This proportion is also expected to rise over the coming years, to 23 per cent of the total population by 2035 (ONS 2012a). The fastest increase will be in the 'oldest old' group – those aged 85 years and over – who, at just under 1.5 million people, now represent over 13 per cent of the population over 65 (ONS 2013c). It is projected that this group will be almost 2.5 times larger in 2035, reaching 3.5 million (ONS 2012a).

### Adult children caring for parents will care for longer

In Britain, just as elsewhere in Europe, unpaid or informal care from families or friends is a vital part of the long-term care system, without which there would be an unsustainable burden upon formal services (Kraus et al 2011). Among those receiving care, the most important source of informal care at present is care by adult children.

Caring has increasingly become a full-time occupation. While the total number of informal carers has remained more or less constant over the past two decades, the total number of hours of informal care provided has increased substantially, by 2.4 billion hours between 1995 and 2010. This indicates that more and more informal carers are taking on more hours of care.

**Figure 2.1**  
Total number of adults caring (right) and hours of care provided (left), 1995–2010



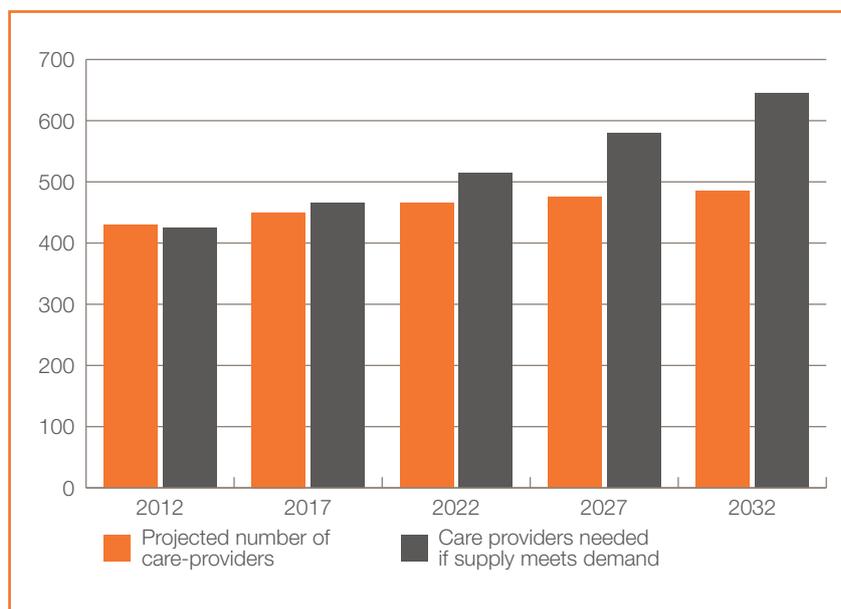
Source: ONS 2013a

### Adult children will not be able to provide care for all those who need it

However, the supply of unpaid care provided to older people with support needs by their adult children is unlikely to keep pace with future demand. In England alone, although the number of children providing care to their parents for more than 20 hours a week is projected to increase by 20 per cent to 485,000 by 2032, there is likely to be a shortfall of 160,000 caregivers, because demand will increase by 60 per cent over the same period.

Driven primarily by a sharp increase in the number of people aged 65 and over with disabilities (Pickard et al 2012), demand for unpaid care will begin to exceed supply by 2017 and the unpaid family 'care gap' will grow rapidly from then onwards (Pickard 2013). As a result, by 2030 we estimate that 230,000 older people who need intense care of more than 20 hours a week could be left to cope alone.<sup>6</sup>

**Figure 2.2**  
The family care gap: Caregivers and caregivers required, projections to 2032 ('000s)



Source: Pickard 2013

These estimates are based, with some justification, on people's propensities to care for their parents remaining constant. However, other commentators have suggested that factors such as the decline in older people living with their children and the continuing rise in labour market participation by women through the middle of their lives will affect people's ability and willingness to care, meaning that the potential care gap could be greater still (Colombo et al 2011, Haberkern et al 2011).

If the supply of informal care does not meet rising needs for care then this is likely to mean an increase in demand for formal care and an associated increase in long-term care expenditure, at a time when net spending on older people's social care is falling (Audit Commission 2012).

### Carers of working age will increasingly struggle to balance care with employment

Caring for a parent or relative comes with a specific set of demands, being less predictable and often involving a long, indefinite commitment that makes it increasingly difficult to combine with work.

Research has shown that providing care for 20 or more hours a week has a significant, negative effect on employment, although more recent work has suggested that even 10 hours may have an effect (King and Pickard 2013). Caregiving is associated with a significant reduction in employment and hours of work, especially for individuals

<sup>6</sup> IPPR analysis based on Pickard 2013.

providing a high intensity of care. Studies have confirmed that, in addition to lower labour force participation, informal caring leads to absenteeism, irregular attendance (coming late and having to leave work) and lack of concentration (Gautun and Hagen 2007, Gabriele et al 2011).

As a result, there are currently 315,000 working-age carers who have left work and remain out of employment (Pickard 2012). Of this group, 60 per cent are women; women make up the majority of informal carers (Pickard 2013) and care for longer hours and for longer durations than men (Carmichael et al 2008). This comes at a significant annual cost to the wider economy, with lost working hours estimated to be worth approximately £5.3 billion.. (House of Lords Select Committee on Public Service and Demographic Change 2013: annex 15).

In addition, caring can impact strongly on the health and wellbeing of informal carers. Of the 1.3 million people who provide more than 50 hours of care a week, just 56 per cent reported good health (ONS 2011 a).. In the Personal Social Services Survey of Adult Carers (HSCIC 2013a), a large-scale survey that canvassed the opinions of over 57,000 people providing care to family or friends, results suggested that stress and isolation were major problems.

- Just 29 per cent reported that they had as much control over their daily lives as they wanted, with 12 per cent saying they had no control whatsoever.
- 16 per cent said they had no encouragement or support in their role as carer. A further 40 per cent reported they had some encouragement but not enough.
- 14 per cent said they have little social contact and felt socially isolated.

Caring is significantly linked to increased levels of anxiety, depression and social dysfunction. These effects are most pronounced at key turning points in the caring trajectory and in more-demanding care situations. Carers who provide at least 20 hours care per week are often at greatest risk of poor health and adverse health changes because of their caring responsibilities. In particular, caring for a spouse or partner is associated with additional health problems beyond those that might be attributable to other determining health factors (Hirst 2004)..

Caring also has a considerable impact on carers' incomes. A Carers UK survey of 3,000 carers found that 44 per cent of those surveyed had been in debt as a result of caring (Carers UK 2013). The effects are twofold, with an impact on income from reduced hours worked as well as an impact in terms of extra spending to meet the additional and long-term demands of care.

### **There will be growing unmet need for care among older people**

It is already the case that many older people in the UK simply do not receive the assistance that they need from the social care system. Reliable estimates of unmet need are hard to come by, at least partly because of problems associated with data collection, given that those who have unmet needs are often by definition unknown to local authorities and may not themselves recognise that they have such needs. It is safe to assume a significant level of unmet need among older people, although variation in any exact numbers is huge because measurement of such need is extremely difficult. For example, among those who had difficulty or needed assistance with bathing/showering, between 15 and 61 per cent reported not receiving any support at all, depending on the dataset used (Vlachantoni et al 2011).

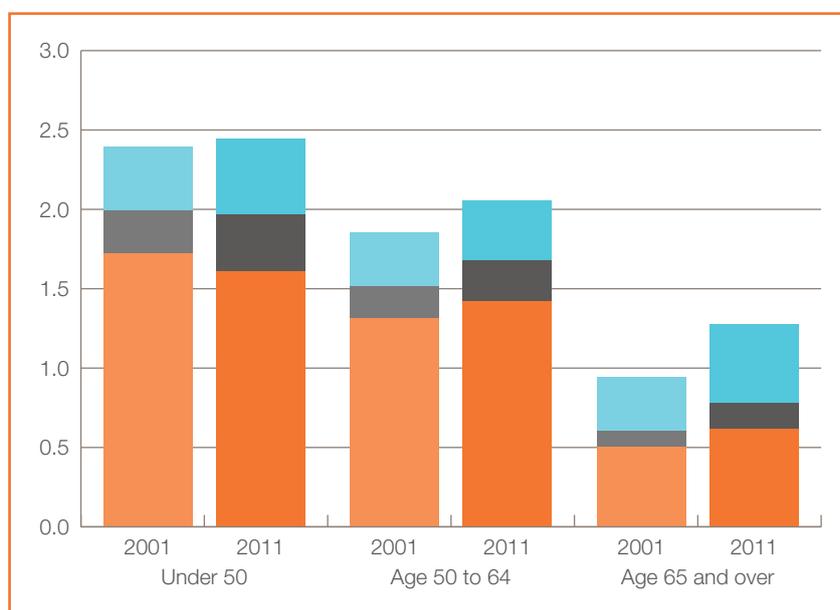
In addition, long-term projections for England suggest that in 2032 more than 1.2 million people with support needs aged 65-plus (of which 860,000 will be 75 or over) will not be receiving any informal care. This represents a rise of 71 per cent (80 per cent for over-75s) from 2007 levels (Pickard et al 2012).

Dramatic rises in the cost of care means that those ineligible for state funding, in the absence of informal sources, may struggle to afford formal care services. Since 2010, for example, the average annual cost for an older person who pays for a typical package of care has increased to £7,900 a year, an increase of almost £740 (Labour Party 2013). These costs are being borne by a growing proportion of people, as councils tighten eligibility criteria in order to make cost savings. Indeed, the number of people aged 65 and over receiving publicly funded care (in their own home and in care homes) has fallen from 1.2 million in 2004/05 to 898,000 in 2012/13, despite the growing elderly population (Lawton 2014).

### More older people themselves will be carers

Increasingly, older people themselves take on a caring role, often for a partner or spouse. While younger generations will remain the main source of informal care, the biggest increases in carer numbers are among those aged 65 and over. In particular, older people are now far more likely to be providing intense care of 50 hours a week or more.

**Figure 2.3**  
Number of carers by age and weekly hours of care provided, 2001 and 2011 ('000s)



Sources: ONS 2001, 2011

The reason for this is at least partly demographic: as more and more men live longer, the number of older couples able to support each other increases. The proportion of women aged 75 and over who are widowed is projected to fall from 60 per cent in 2008 to 39 per cent in 2033; during the same period, the proportion of men aged 75 and over who are widowed is expected to fall from 25 per cent to 18 per cent (ONS 2010). Over the next 30 years, the number of cohabiting older people with support needs is projected to rise faster than the equivalent number of single people (Pickard 2012).

However, relying on older people to provide care for others will have inevitable repercussions in terms of the support needs of carers themselves. Older carers may well have their own care needs and disabilities that could hinder their ability to take on a greater caring role, and caring may negatively affect their own wellbeing (Pickard et al 2012). The Princess Royal Trust for Carers (2011) found that two-thirds of carers over the age of 60 have long-term health problems or a disability themselves, and surveys of older carers suggest that they often feel ‘invisible and undervalued’ (Age UK 2010).

### More older people will be at risk of experiencing isolation and loneliness

Long-term social trends mean that ever-greater numbers of people, particularly the very oldest in society, experience some degree of social isolation in later life (Masi et al 2011).

- Nearly half (49 per cent) of all people aged 75 and over live alone. This figure has increased from 40 per cent in 1973 but is more or less the same as it was in 1983 – since then it has stayed between 47 per cent and 51 per cent (ONS 2012b).
- New generations of older people are less likely to have children. The number of people aged 65–74 without children to care for them in old age will almost double before the end of the next decade. By 2030, more than a million people in this age group will not have children, compared to 580,000 in 2012.<sup>7</sup>
- Today, children are far more likely to live away from their parents, sometimes as a result of labour market forces that have constrained the location choices of some workers (Grundy and Shelton 2001 cited in RVS 2013). Those who live further away are less likely to maintain regular contact with ageing parents (RVS 2013).
- Communities have been ‘hollowed out’, with the private and public sector institutions that have traditionally served as social hubs – local pubs, post offices and libraries – facing funding cuts or closing down (Bazalgette et al 2012).

Without regular family support, or informal support networks from the community that may substitute for this, a significant number of people may find it hard to play a role in their local areas. Six per cent of older people (equivalent to nearly 600,000 across the UK) leave their house once a week or less (Age UK 2009) and an estimated 5 million say that the television is their main source of company (cited in Age UK Oxfordshire 2011).

It has recently been established that loneliness and social isolation can have a similar impact on risk of death as smoking or drinking, and more of an impact than many well-understood risk factors such as obesity or lack of exercise (Holt-Lunstad et al 2010).

Loneliness, a related but distinct concept, is a problem for millions of people across the country, with the oldest in society much more likely to be affected (Griffin 2010). By nature of their age, those who are considered ‘very old’ are more likely to be affected by illness and physical impairment, to have experienced bereavement, or to be widowed, all of which are considered to be factors when predicting risk of loneliness (ONS 2013b). Seventeen per cent of those over the age of 80 said they often felt lonely, and it is a problem at least some of the time for just under half of this group (Banks et al 2012). This is supported elsewhere by Pearl Dykstra (2009), in a review of surveys from various countries, who finds that 40–50 per cent of people aged over 80 say they are lonely, compared to a baseline population rate of 20–30 per cent.

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7 IPPR analysis based on Pickard et al 2012 and 2010-based population projections (ONS 2011b).

## More older people want to care and contribute but not everyone has the opportunity

Demographic and socioeconomic trends have a continuing effect on intergenerational family relations. As older generations live longer and healthier lives, they are now in a position to develop deeper relationships with children and grandchildren, and to play a much more active role with their families and local communities. Grandparents are increasingly relied upon to provide childcare, for example (Statham 2011), and older people are more likely than younger generations to volunteer (ONS 2013b).

Traditionally, this caring has been done through immediate family. However, the increase in older people without children and greater international and domestic migration, driven in part by changes in the labour market, mean that older people increasingly lack local family networks through which they can access, and provide, support.

A lack of investment in local areas and the paucity of measures designed to reconcile employment with care duties for children and parents, such as affordable, high-quality all-day childcare, mean that younger generations often lack the incentives to stay in the local area, or to attempt to balance work with care (Hoff 2008).

At the community level, the emergence of institutions designed to provide a shared space for people of all ages, such as the *Mehrgenerationenhauser* in Germany (see chapter 4 below) represents a growing trend across Europe for new institutions intended to encourage intergenerational interaction outside of immediate family.

Increased intergenerational contact has been shown to have benefits for the individual, particularly in terms of health benefits, and the wider community, in terms of stronger community cohesion and higher participation (Sanchez et al 2007). On the other hand, a lack of interaction risks provoking negative attitudes about ageing and older generations (Robertson 2012). Focus group interviews with younger and older generations suggest that both groups are positive about spending more time together, but that they feel they experienced little contact beyond their own age group (4children 2011).

### 3. RICHARD, FIONA AND JENNY: ISOLATION, FRUSTRATION AND EXCLUSION

While clearly we need to understand the social trends that will shape the way we look after each other in the future, it is just as important to understand the personal impact of these trends on individual lives. The stories in this chapter of Richard, Fiona and Jenny capture the experiences of families today. They also illustrate three problems that are likely to increase as the family care gap widens: social isolation later in life, families providing ever more intensive levels of care, and a greater number of older couples caring for each other.

#### Richard, 74 – a story of isolation

Richard is a retired engineer and is living in supported accommodation with care on site. He has a neurological disorder that severely restricts his mobility and relies on carers four times a day to help him with getting up, dressing and eating.

Richard moved into his current flat more than 10 years ago, prompted by the fact that he was finding it increasingly difficult to climb the stairs to his front door. During his first few years, he was able to move about using a single crutch, which meant that he could go to social events organised for residents in his block of flats.

As his condition worsened, however, he was forced to use a wheelchair. Richard is unable to propel himself and, without the money to buy a powered chair, he relies on support staff to wheel him around. He says that the number of staff has been dramatically reduced recently, from four or five people on duty during the day to just one. This creates a situation where staff are forced to address the most urgent needs first – ‘they are pushed beyond the limit’ – which means that he is often overlooked.

**‘I just have to wait my turn [...] if you say you’re in trouble they have to prioritise that call.’**

Although over 30 people live in the same block of flats, Richard says that he doesn’t know any of them.

The lack of quality care compounds this situation. Although Richard is keen to stress that some of his carers are excellent – ‘very caring, very understanding’ – others seem to lack the motivation and, crucially, the time, to engage properly with him – ‘they just do the basic and no more’. At times, this can result in shocking and undignified treatment: he was recently left in a wet bed for five and a half hours and told he’d have to wait until the morning for someone to come and help him.

Richard used to involve himself with national campaigning organisations such as the National Pensioners Convention and Age UK by writing to them. However, after a setback last year he can no longer write or hold a pen. He is upset that he cannot get physical therapy to help him with this, as it means that a previously fruitful avenue of contact with the wider world is now closed to him.

Getting out in the community and maintaining social links is very hard. Though in a wheelchair, he used to get out and about with the help of the local dial-a-ride service. As well as transport, the service offered help getting in and out of places, which allowed him to go to the shops, for example, or to attend local groups where he could socialise with friends.

Due to local authority cuts, however, the dial-a-ride service has been terminated. Richard is now virtually housebound or, as he described it, ‘entombed’ in his flat. Without access to suitable transport he can now barely get out of the flat at all.

**‘I used to go the Salvation Army here in Luton, for lunch. That’s stopped. I can’t go there any more. I used to enjoy their lunches on a Friday. I’m a retired British railways engineer and we had a retired members group of professional and technical engineers that was held in Dunstable and I can’t go there any more [...] It’s terrible. Awful.**

**‘On the first Monday of every month I used to go with Age UK, they organised with the local church there, they had a senior’s lunch once a month, that was excellent and I used to go there every month, religiously. It was somewhere to go, it was enjoyable to meet other people and be able to [socialise] ... but that’s gone by the board.’**

With all of his family living far away, Richard’s only way of getting out of the house is through his local church group.

**‘I’m very lucky, I go to a local church, which is five to six minutes walk away. Every Sunday morning, they’ll come and collect me, provided it’s not raining or too cold and then kindly bring me home. That is a marvellous work in the community [...] There’s about three of them, they all volunteer and they take it in turns to take me and then bring me home. And I’m very grateful to them for their kindness.’**

If it wasn’t for the volunteers who take him to church, however, Richard would have no social contact whatsoever. While his physical needs, such as feeding and bathing, are met by the staff on site, there is no one to ensure that he is able to make the most of and contribute to his local community. He stays in his flat, with the television as his sole link to the outside world.



Richard’s story exemplifies a problem experienced by people of all ages. One in 10 people (11 per cent) in Britain report that they often feel lonely (Griffin 2010). However, the oldest and most vulnerable in our society appear to be at greatest risk of feeling alone. A study of older Britons in 2012 found that more than a fifth felt lonely all the time, and a quarter became more lonely over five years (Victor and Bowling 2012). Half of those who took part in the survey said their loneliness was worse at weekends, and three-quarters suffered more at night. Surveys of social care users suggest that over a third (36 per cent) of those aged 65 and over say that they are not satisfied with the way they spend their time, with almost one in 10 (8.4 per cent) saying that they don’t do anything they value or enjoy with their time (HSCIC 2013a). And people who are in poor health are more likely to report feeling alone (ONS 2013b) and there is a strong association between reported feelings of loneliness and reported limitations in performing daily activities: as many as 45 per cent of older people with a longstanding illness that prevents them from doing normal household tasks report that they felt lonely at least sometimes.

As we have shown, most older people expect social care services to help them to stay connected to their local communities, and to maintain and develop social links with friends and families. However, as Richard’s story shows, services are not currently set up to pay attention to people’s social needs. This is demonstrably counterproductive, as social isolation and loneliness impact directly upon quality of life, health and wellbeing (Cattan et al 2005, Findlay 2003, Pitkala et al 2009). Indeed, as noted in chapter 2, the effects of social isolation on mortality are similar to those of smoking or excessive alcohol consumption (Holt-Lunstead et al 2010)

### Fiona, 52 – a story of frustration

Fiona had to give up her job in human resources to look after her 91-year-old father Ted after he contracted MRSA and developed a number of other complications on top of his vascular dementia dysphagia. His complex care needs meant that he required 24-hour-a-day care. Fiona had to start arranging complex care packages with no experience of providing care and little support.

Fiona was angry and frustrated at the quality of care provided. Consistency and familiarity were important for her father, particularly as he had dementia, but there was very high turn-over in care staff – at one point, she had 13 new carers in the space of five weeks. Week-ends were particularly bad, with different carers arriving and some not showing up at all.

Despite some examples of excellent care, what particularly frustrated Fiona was the fact that they did not speak to her dad, often seeming to ignore him as they went about their tasks. Ted was frequently left in soiled sheets and carers often did not understand the conditions he had.

She was unable to get any respite care because her father's condition regularly worsened when she attempted to do this. She rarely got more than a few hours sleep and had to heavily supervise carers during the day.

**'Sadly, governed by my experience whilst in hospital and at home, (community) care standards are not adequate and society is ill-equipped to deal with dementia. The service delivery and calibre of staff left a lot to be desired. On numerous occasions I would have to both cover and assist when staff did not attend and or were running late. More often than not I would receive no notification from the agency.'**



Many people's reported experiences of care are generally positive, although there is a considerable minority for whom their experience is much worse. In a largescale official survey of care users (HSCIC 2013a), 55 per cent people of people aged 65 and over who received adult social care and support services said their quality of life was 'good' or 'so good it couldn't be better'; by contrast, 10 per cent said it was 'bad'. However, these figures may mask the reality of people's experiences, as evidence suggests that older people may have low expectations or be reluctant to criticise services (CQC 2013, EHRC 2011, Bowling 2002). This is perhaps because they fear that care will be taken away if they criticise it, or perhaps because such criticism would imply that their own needs are actually greater than is currently being provided for, making them feel like they are a 'burden'. Certainly, other studies which have included the views of family and carers have been more critical of the care provided.

Carers UK suggests that almost half (46 per cent) of carers have raised concerns about poor-quality care services. In recent IPPR research, many family carers agreed that the current care system provided a poor quality service.

**'They treat them like they're animals. And there's no communication – they just strip them and wash them and don't even talk. There's no dignity.'**

Family carer, quoted in Muir and Parker 2014

According to these carers, funding limitations and poor service design has led to care being reduced to a functional and transactional role, leaving no time or inclination to get to know the person involved.

**‘You get a report saying, “We came round but you didn’t answer the door”. My uncle’s paralysed, so he can’t answer the door. That’s why he has a carer ... It’s so fundamental that before you visit there [should be] a note saying, “This person is incapacitated, so you need to contact this family member”. [Carers] should have their records with them and right in front of them.’**

Family member, quoted in Muir and Parker 2014

In addition, communication between services can be poor, or even non-existent, meaning that older people and their carers have to navigate a confusing and contradictory bureaucratic system. Most seriously, there were numerous accounts of care professionals failing to deliver basic, appropriate care, which in some cases endangered vulnerable adults. There are few avenues for people to complain in these circumstances, and family members often reported that they didn’t feel like they had much power over who cared for their relative (Muir and Parker 2014).

One in four care users report that they feel they do not have adequate control over their daily lives (HSCIC 2013a) and just half of carers say that health and care professionals involve and consult them about the treatment of the person they care for (Carers UK 2013). Ellins et al (2012) reported that many carers feel undervalued by care professionals and that their expertise and knowledge is ignored. As such, they do not feel like a partner in decision-making.

### **Jenny, 64 – a story of exclusion**

Jenny’s husband James, 74, was admitted to hospital with pneumonia. This triggered his existing mild memory loss to become severe dementia, virtually overnight, requiring constant care. Following a consultation, hospital staff made a decision to place him in residential care without consulting Jenny and without taking into account the care Jenny provided to James.

**‘They knew nothing about me, nothing about my family circumstances, nothing about my family support. They knew nothing of that and nor did they ask. They just made an assumption based on what they saw of James that I wouldn’t be able to cope.’**

Jenny decided to fight this decision and she put together her own care plan with no prior expertise or help. She was virtually ignored by staff when she presented this, but eventually she got her husband home where he wanted to be. A hospital social worker found a place in a daycentre for James, but that was the only help given before he left the hospital.

However, as Jenny and James were ‘self-funders’ (meaning they would not be eligible for state-funded care) Jenny was left to arrange the care package completely on her own. Jenny found it extremely hard to deal with the changes brought about by the sudden deterioration in James’ condition.

**‘I don’t think I thought very much, I don’t think I planned very much. I was just living in the moment of just getting him up, getting him dressed. It was complete chaos and total exhaustion. I was drawing on every ounce of my common sense, every offer of help from each of our amazing friends.’**

A care coordinator was appointed to help Jenny and James but she did not coordinate the care required – she offered sympathy but no direct action. So Jenny had no one to help her navigate between different agencies or to point her towards local voluntary support groups. She was unfamiliar with what services were available to support her and her husband. She felt that, for staff:

**‘[James] wasn’t a person, he was a number, he was a case. They didn’t want to know who James was, they only saw his illness.’**

This, she believes, led them to ignore his informal support network of friends and family:

**‘There was an arrogance about the staff, a sort of “we know best”, patronising attitude. I don’t underestimate the challenges that they were facing, but that’s not an excuse for not communicating with the family.’**

After a chaotic and clearly traumatising few months, Jenny recognised that she was beginning to lose the ability to cope, which led to the involvement of a social worker. Jenny eventually managed to find private day and night carers to help, and James now has a package of support designed around both of their needs. This includes visits to a daycentre, home support to allow Jenny time to go out to her local choir and to an exercise class and, until recently, night-sitters for three days a week, so she could get a full night’s sleep. James is now settled and happy living with Jenny at home. They lead a full life despite the limitations of James’ dementia – last year he conducted a local orchestra and choir.



Jenny’s case is far from unique. The current design of the care system seems to actively exclude cared-for individuals and their families from having a real say in how they would like their lives to be. Jenny, in taking on full-time care for her husband, developed an arguably unparalleled insight into his condition. In her interactions with professionals, however, she did not feel that her knowledge, her needs as a carer and her relationship with her husband were taken into account. Instead, she has had to fight to ensure that James stays at home, and that they can both access the kind of care and support that will enable them to live their lives to the full. This battle has been emotional and stressful, and has exacerbated an already fraught situation.

There is a growing consensus from academics and practitioners on the benefits of care that is ‘co-produced’ in partnership between an individual, their family and care workers. In particular, there is evidence to suggest that allowing people a greater say in their own care can deliver overall value-for-money, more positive results from inspection and feedback, and health, capability and social benefits for service users (Needham and Carr 2009).

To this end, a key focus for recent reforms of social care has been the devolution of funding for care through personal budgets and direct payments. The motivation behind these reforms was to create services ‘personalised according to the needs and preferences of users’ (HM Government 2007), by giving individuals and their families a budget – either nominal or, in the case of direct payments, real – to spend upon services that they consider most appropriate to their needs.

However, as Jenny’s story shows, there is a lack of advice and, importantly, support to help people to make informed decisions about their needs. Without a dedicated advocate with

oversight of the different professionals and services involved, carers like Jenny are left to navigate multiple and complicated networks, constantly battling with professionals who, with the best of intentions, tend to see the medical problem first, rather than the person involved.

### Conclusions: Understanding and fulfilling expectations of care

The experiences of Richard, Fiona and Jenny show that the current system too often works against the priorities of care users and their families: to stay at home while maintaining a social life, to have a good relationship with those who care for them, and to have a say in how that care is delivered.

This reflects the fact that the care system has evolved in a relatively unplanned way, driven largely by shifts in eligibility criteria and funding, rather than by a good understanding of the lives of older people, their families and carers. A proper appreciation therefore of how older people and their families actually experience later life and where care (formal or informal) fits into this is essential in thinking about how society and the care system should adapt for the future.

### Staying at home and being connected to the community

Regardless of support needs, older people want to have a meaningful life that includes engaging activity and relationships that allow for the opportunity to give and share, as well as to receive (Age UK 2013). In particular, people value having relationships and links with their local or chosen communities and ‘being able to contribute to family, social, community and communal life and being valued for what you do’ (Bowers et al 2009).

Many studies have identified independence and self-esteem as key components of quality of life (Bowers et al 2009, Williamson 2010), linked to the ability to participate in communities on an equal footing. Like everyone else, older people want to have a purpose, to feel useful and valued, as ‘an employee; volunteer; mentor; entrepreneur; employer; hobbyist or source of advice with a cup of tea’ (Khan 2013).

Care that enables people to maintain control of their daily lives is therefore highly valued (Bowers et al 2009). This entails a need for help with practical tasks at home, which allows older people to stay in their houses (Cattan and Giuntoli 2010, Henderson and Backwell 2008). Indeed, the majority of older people want to live in their own homes for as long as possible, with support from family or from care workers (Commission for Social Care Inspection 2004 cited in Wanless 2006).

**‘I worry about going into a care home if [we’re] not as well looked after. I stay in bed when I want to, if I don’t want to get up, nobody bothers me, and I do what I like in a way, but would I be able to do that if I wasn’t getting as well looked after in a care home? I think I would lose my freedom, you see, and I wouldn’t like that.’**

Joyce, 92, Leeds, via IPPR’s Voices of Britain blog<sup>8</sup>

Older people also want to feel connected to others and comfortable and secure in their home. Personal relationships are a key theme (Katz et al 2011). Whether with friends, family or carers, older people place great value on social interaction, including both new and old relationships. This is of particular importance because older people are more likely to have problems getting out, may be unable to drive or use public transport, and are more likely to have lost friends or spouses.

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8 <http://voicesofbritain.com/post/63636625318/joyce-92-leeds>

### **Better relationships and consistency of care**

As well as maintaining and developing informal social networks, people naturally want to have a positive and fulfilling relationship with those who provide them with support in their daily lives.

Having someone enter your house to perform personal and often intimate tasks which you were previously completely capable of doing yourself can be intimidating and embarrassing. Indeed, professionals and volunteers report that older people tend to understate the extent of their needs and, in order to avoid this embarrassment, are often reluctant to admit that they need more support (ibid).

To this end, consistency and continuity in care is vital. Older people value having a named individual they can call on who they know is aware of their circumstances and can give tailored advice. This is preferable to having a series of strangers enter their home (Age UK 2013).

Furthermore, people who use services expect that care workers have sufficient time and flexibility in their job description to engage on a personal level. Interviews with older service users have pointed to the disruption caused by changing care workers and the importance of building trust with the people who enter their homes (Clifton 2011).

For those family members who take on caring responsibilities, as well as looking after their relatives, their priority is to keep a check on the impact this has on their social, financial and physical wellbeing. Carers want to be able to continue to live their own lives, to have time for themselves and their family, to avoid isolation and loneliness, and to keep fit and healthy (Qureshi et al 1998). They therefore need to be able to access services that they can trust and rely upon, so that they feel comfortable taking a break from care.

### **Having a greater say in how care is provided**

Older people say they want to be treated with respect and as an individual, demonstrated through services that are flexible and adaptable to their particular wants and needs (Age UK 2013). Even those with high support needs want their voices to be heard and their specific needs addressed (Potter 2009 cited in Katz et al 2011).

Although flexibility is generally welcome, many people – and in particular the elderly – find themselves at a loss when confronted by excessive choice, particularly where information is lacking (Glendinning et al 2008). Ageing can bring with it a sense of disorientation created by fundamental changes in a person's life, from diminished physical capability, the onset of disease and disability or bereavement. Previous studies have noted that many people, especially the 'oldest old', are happy to delegate key decisions to family or other trusted advocates (Ellins et al 2012, Katz et al 2011). Some of those who do not have these supportive people on hand to help them work through different options can find it difficult to make important decisions.

Family carers say that they want to be respected for the time they give and for their knowledge and experience of the needs of the person being cared for (Qureshi et al 1998). They see themselves, in an ideal world, working in partnership with care services

Those with high support needs are more likely to have low expectations of care, perhaps because they are often living in residential care environments, where it is less common for them to be consulted on their options. Nonetheless, they are likely to value personal identity and self-esteem very highly, while their desire for choice and control often revolves

around more prosaic issues, such as meal choices, what time you get up and what time you go to bed (Bowers et al 2009).

Attitudes to care are also changing as generations age. Those of the babyboomer generation have different expectations of later life and care. This generation places great importance on being able to socialise and enjoy company outside the home, and recognises the health value of being able to sustain or develop work-based or civic roles and responsibilities (Moultrie 2012). As informed and technologically competent consumers, they are more likely to collate information, make considered choices and complain if quality of service is inadequate (Roberts 2012, Harkin and Huber 2004).

Expectations may also vary by ethnic group. A report for the Joseph Rowntree Foundation suggested that, while people from minority ethnic groups want the same access to individualised services as other older people, they may have particular needs, such as interpretation services, shared community events in daycentres, or tailored information (Clough et al 2007). An IPPR poll found that black or minority ethnic groups are less likely to want care provided by professionals, preferring to rely upon friends and family (IPPR 2009).

Another study found that black Caribbean older service users are more likely to express a preference for support with their financial affairs than other groups (Wood 2010). Another, based on interviews with people in Bradford, suggested that older people from certain groups, particularly Polish, may have different expectations of care, informed both by cultural norms and personal life histories that reflect a distrust towards people outside of the family performing care duties (Cattan and Giuntoli 2010).



There are many excellent examples of care and of older people being supported to live as full a life as possible. But the stories of Fiona and Jenny show how hard it can be for people who simply want to act on their love for their relative or partner and look after them in difficult and sometimes distressing circumstances. Richard's story shows how unnecessary and pointless is the isolation due to limited mobility or health conditions of so many otherwise active and inquiring people.

The priorities of older people and their families for quality of life and care as they age are modest: to live at home and stay connected, to have better relationships with those who care for them, and to have a greater say in how that care is provided. In some cases, these priorities would be met if greater value was placed on needs often not seen as 'social care' priorities – for example having regular social contact or being put in touch with other local people facing a similar situation. A common desire was for support that demonstrated more of a 'human touch'. In the next chapter we examine why these priorities have been so difficult to embody in our care system as it has evolved.

## 4. LEARNING LESSONS: THE FAILURE TO TRANSFORM OUR CARE SYSTEM FOR OLDER PEOPLE

So far in this paper we have argued that the way we care for each other is changing as the baby boomer generation ages. In the previous chapter we showed how Richard, Fiona and Jenny are currently affected by issues that could intensify as the care gap widens: social isolation later in life and families left alone to provide ever greater levels of care.

These issues are increasingly shaping people's priorities for care, and at present the system is not responding. This is despite the fact that, in most cases, people's priorities – more care at home and a better appreciation of the role of the family and community in achieving this – are the same ones that are crucial for containing the public costs of a rising demand for care services.

In this chapter we examine why these priorities have been so difficult to embody in the care system and what we can learn from this. We show how the changes that need to be made to improve the system now are also those that will help us to prepare for an ageing society and the reduced availability of family care.



As noted in the previous chapter, the UK's care system has evolved more in response to changes eligibility criteria and funding than to any clear understanding of the needs of older people, their families and carers.

Efforts have been made by governments over the years to change this, to create a more 'person-centred' care system, reflecting people's priorities more closely. But as we have seen, for too many people this isn't the case. In thinking about how to create a care system which can adapt to the changing needs of society in the future, then, we need to ask why previous attempts to create a more 'person-centred' system have not been more successful or had a wider reach.

First, it is important to recognise that the current system is underfunded and exploitation of the workforce is common. The Institute for Government, in a review of the social care market, concluded that 'funding is low relative to need and stated policy aims' (Gash et al 2013). Responsibilities between central and local in relation to current funding arrangements are often unclear. However, one director of care explains why this suits vested interests in government:

**'It suits both [tiers of government] to not have ring-fencing because then local can blame central and say they don't give them enough and central can say that they do give them enough but its local government's decision making which takes [the funding] away from social care.'**

ibid

Resolving the imbalance between spending on social care and the NHS and creating a more efficient use of resources is one of the main intentions behind greater integration of the health and social care systems (Bickerstaffe 2013). However as the King's Fund Commission on the future of health and social care integration has recently identified, this approach is unlikely to resolve the problem of underfunding entirely. Therefore, serious consideration needs to be given to other options for finding the additional investment needed (CFHSC 2014).

Additional funding is also one of the improvements needed to address the low pay and poor working terms and conditions of the care workforce. The exploitation of many workers – sometimes paid below minimum wage and often not paid at all for travel time, holidays or sick leave – is a key barrier to improving quality of care. Aside from the appalling impact of current practices on care workers themselves, unless the status of care workers is improved, efforts to reform the quality of the care will be fatally undermined.

Two of the most significant approaches to creating a more person-centred care system have focused on ‘prevention’ and ‘personalisation’. It is worthwhile examining these briefly in further detail.

#### 4.1 Prevention

Previous attempts to improve levels of preventative activities in the social care system have rarely proven successful. The National Audit Office (NAO) describes preventative activities as: ‘keeping adults well and independent, intervening early when needs emerge, and assessing and reviewing adults’ needs so that services are appropriate’ (NAO 2014). The NAO and others have argued that prevention can result in better outcomes and greater value for money.

As local authorities continue to face pressure to reduce spending even as demand for care grows, councils have been warned that measures taken to efficiency savings so far will no longer yield results and that more fundamental changes must be made (TLAP 2013). In this context, shifting services away from reactive spending towards early action and delaying entry into formal care (as is being achieved in initiatives explored in the next chapter) may be the only way of containing rising demand for care in future.

However, despite good intentions, these activities have failed to extend far beyond special project status. For example, the Department of Health’s three-year Partnerships for Older People Programme, while initially showing signs of success, has since been shown not to have delivered the health benefits or savings it was strongly suggested could be achieved, and so it has had limited wider impact outside of its initial pilot projects (Steventon et al 2011).

Many factors contribute to the difficulty of establishing a mainstream role for prevention. These include inertia in the system as a result of poor incentives for commissioners to innovate, risk aversion, overly bureaucratic processes, and poor intra-agency working for fear of professional loss of control. However, there are two wider structural explanations.

First, there has often been an assumption that prevention is an ‘add-on’ or ‘additional service’ which runs alongside mainstream services. It is therefore perceived to increase costs, rather than replacing other, more reactive interventions as intended (Moultrie 2012). The result is that preventative activities remain as limited experiments or pilot schemes, rather than becoming part of the core rationale for providing care. A lack of confidence in the economic evidence base and a fear of ‘double running costs’ means that spending on prevention remains stubbornly low, at around 4 per cent of total adult social care budgets (ADASS 2013).

Second, as social care is means-tested, councils are legally bound only to focus on those people they are statutorily required to support. The new duty on councils to consider wellbeing and offer preventative services as part of the Care Bill aims to achieve a more universal offer for social care. However, it is unlikely to succeed: while some areas prioritise prevention and support *all* older people to stay active and live

independently regardless of eligibility, other areas focus solely on high-needs groups. Given the considerable funding pressures councils face, it is likely that the funding priority will remain those who are statutorily entitled to support (those with substantial needs), while preventative activities for the general population are likely to continue to be cut. This conflict between policy intention and outcome is no longer sustainable in the face of rising demand for care and a growing family care gap.

## 4.2 Personalisation

The introduction of personal budgets has been the central policy goal in social care for almost a decade, and is therefore the most important attempt to create a more 'person-centred system'. Under New Labour, central government set targets for self-directed support and take-up of personal budgets for 2011. A target of 100 per cent of eligible people to be receiving personal budgets by 2013 then became the main aim of social care policy under the Coalition government.<sup>9</sup>

This agenda has been more successful for disabled adults using social care than for older people, who are the largest group of social care service users nationally. Evidence suggests at best marginally positive outcomes for older people on personal budgets compared to those using mainstream services and at worst no change in terms of levels of control experienced. Evidence also suggests older people using personal budgets can experience higher levels of anxiety when managing their care (Netten et al 2011).

Over 70 per cent of those aged 65-plus on state-funded social care take up the option of a personal budget. Most of these people are on 'managed personal budgets' (70 per cent) which are largely held and managed by councils (ADASS 2013). For this group, the experience of having a personal budget has often been just as transactional as traditional services. The things people value most – relationships and continuity – are often no more in evidence for those on personal budgets than for those who are not (Age UK 2013).

This has led some to criticise the personalisation agenda as simply rebranding the same narrow range of traditional services people have always received in nominal cash terms.

Older people who take up direct payments experience more positive outcomes than those on personal budgets alone. However, they are less likely to take these up than disabled adults. The proportion of older people who take up direct payments is around 30 per cent of those on personal budgets (although there is wide variation across local authorities) (ADASS 2013). In addition, the number of people on direct payments across adult social care is plateauing.

It therefore seems that significant take-up of personal budgets has been achieved by councils, but with little real difference made in the lives of a significant number or in the nature of social care provision. Early claims for the capacity of personal budgets of reduce costs are also looking increasingly unfounded, with findings suggesting that the cost for assessment and support planning for people with an individual budget is £18 a week, compared with £11 a week for traditional practice (Slasberg et al 2012). It is not clear exactly why this is the case and whether this cost difference remains when overall savings as a result of people receiving care that meets their priorities are taken into account.

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<sup>9</sup> This target has since been reduced to 70 per cent, but it is still the government's intention that all of those eligible for ongoing council-funded social care should receive a personal budget.

As we look towards the next parliament then, we need to rethink the future of the personal budgets agenda. Personal budgets can clearly be enormously advantageous: people who have been passive recipients of services that may not have provided what they needed or wanted can now be in charge of determining what support they need and who delivers which service at what time. However, it does appear that their value has been undermined by a ‘one size fits all’ approach to implementation.

Having control over money has also not proven to be the same thing as having control over care: for many people, personal budgets have been just as transactional and restrictive as traditional forms of service delivery. And on one of the most promising claims made for personal budgets – that they will drive transformational improvements in the quality of care – there is little evidence beyond small changes at the margins.

Part of the reason for this is that personal budgets were implemented with little thought as to how this agenda would influence local social care markets. People are often buying just what they bought before: there has been no two-way development of the market.<sup>10</sup>

A number of new approaches are trying to overcome some of the obstacles to people taking up direct payments, as the form of personal budgets which have the greatest potential to improve people’s lives and influence the quality of local care provision. These typically bring people together in small groups and offer service users the chance to decide collectively how to spend their budgets with their peers, aggregating relatively low-value personal budgets to boost their buying power.

One form has been developed to be managed by providers – the Individual Service Fund (In Control 2013). Another approach is council-led, such as in Lambeth borough, where the council brings together small groups of service users to pool their budgets and, where necessary, employs personal assistants on their behalf, to avoid creating employer responsibilities for personal budget-holders.

Evidence suggests that user-led organisations<sup>11</sup> can be particularly effective in bringing personal budget-holders together, provided they have the capacity to meet the needs of older people, their carers and families, particularly for those with dementia, and that they are run by trained staff (Routledge and Carr 2013). While some people will be happy for the council or providers to broker care and support, others will prefer a trusted, local organisation that is not also responsible for determining eligibility, rationing resources or providing services. Perhaps the best example of this is the CPCE (combining personalisation and community empowerment) model, which has been developed by the Stamford Forum and is being trialled in Leeds, Belfast, Bristol and Sandwell.

Surrey council meanwhile is trying to correct one of the flaws of the personal budget finance mechanism, the complex Resource Allocation System (RAS), which is the means by which a personal budget allocation is fixed. Currently this is only able to include service solutions, rather than social capital and community resources. Surrey council aims to reverse this, starting instead with people’s existing networks, in a bid to bridge the gaps between informal and formal support and to make direct payments more affordable.

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10 Interview with stakeholder

11 Organisations where the people whom it represents or provides a service to have 75 per cent of voting membership on the management committee or board, and where there is clear accountability to members and/or service users.

### 4.3 Conclusion

People's priorities for care later in life are modest: to have more care provided at home, while remaining socially active, and for the social care system to have a better appreciation of the role of the family and community in achieving this. We have also seen how these same priorities are crucial for containing the costs of rising demand for care.

However, it has proven difficult to orient the care system around these priorities. Continued underfunding and the poor status, pay and working conditions of the social care workforce undermine efforts to reform the system in line with these priorities. We have also set out the cultural and institutional factors that can be barriers to realising policy intentions.

We also point to two crucial structural explanations. The first is the failure to 'mainstream' preventative activities, relegating them to the status of special projects or pilots. New policy agendas, such as personalisation, are often simply 'grafted on' to the existing system, without reforming underlying bureaucratic processes and structures. The second is the combination of 'means-testing' in social care and ever-tightening eligibility criteria in a tight fiscal climate, which means that local authorities will continue to focus most on those people they are statutorily required to provide care for.

Better integration between health and social care systems is essential for beginning to resolve this, including a joint outcomes framework between health and social care services for older people (see Bickerstaffe 2013). Some would also argue for a lowering of eligibility thresholds or more prescriptiveness in how local authorities carry out the prevention agenda, in order to ensure that a wider section of the population is included.

However, an alternative way forward would be to give the community itself a greater role in carrying out preventative activities – including responsibility for helping to improve levels of wellbeing and reducing social isolation. We explore further the grounds for doing this and how it might be achieved in the next chapter.

## 5. BALANCING THE FOUR PILLARS OF CARE AND LESSONS FROM OTHER COUNTRIES

As we have seen, it has proven difficult to reorient the care system so that services and professionals better recognise the fundamental role families and communities play. In the future, however, as the seismic shift of the family care gap is felt, the only way to meet rising demand for care will be for the state to work in partnership with families and communities.

This will require a renegotiation of the fragile balance between the four ‘pillars’ of a caring society: **family, state, market** and **community**. Here we look at the different capacity each will have to respond to this challenge, and how the balance between them will need to change.

### 5.1 Families

We have seen that families are already providing the vast majority of care. The number of working-age children providing intense care (over 20 hours a week) is expected to increase by a half over the next 15 years, and women caring are still projected to outnumber men by nearly two to one (Pickard 2013). However, older people aren’t simply recipients of care: they are also providing it. Intense care provided by spouses and partners is expected to increase by 90 per cent over the next 15 years. It is therefore difficult to see how families will be able to provide higher levels of care in the medium to long term. In addition, the fact that levels of employment for women with children and those over 50 are lower in the UK than in many other OECD countries suggests that, if anything, the problem lies in a lack of affordable, flexible and good-quality formal care, rather than family members not providing enough to care.

### 5.2 The state

It is estimated that around 800,000 older people who need personal care are not receiving this (Forder and Fernandez 2011), either because eligibility criteria have been cut back (87 per cent of councils are now providing care only for those with ‘substantial’ or ‘critical’ needs) or because they are unable to afford paid care. In contrast to childcare, where entitlements have increased in recent years, spending on care for older people has been cut back by 12 per cent in real terms since 2010. Councils are reporting a ‘demography pressure’ (spending to keep pace with the increase in the local older population) of 3 per cent. And this is before the impact of the family care gap has even been felt.

With councils expecting to spend around half of their budgets on adult social care by the end of the decade and the NHS already facing a £30–£50 billion funding gap over the same period, the capacity of these services to absorb greater care costs will be close to zero. Even with a more integrated health and social care system making better use of resources, these services will still struggle to keep pace with demand, let alone meet the additional pressures created by the squeeze on informal care.

### 5.3 The market

Given that the coming generation of older people holds greater wealth (in terms of income and capital) than previous generations and possibly the generations that will follow, it could be argued that they should be expected to contribute more towards the costs of their care. Certainly, a large growth in self-funded care, particularly home care, has been projected (Moultrie 2012) and it is also the case that when it comes to personal care tasks, many people prefer to pay for care rather than call on family members for help (IPPR 2009).

Similarly, in future, technology might also be able to help bridge the care gap. Despite concerns that there may be unwillingness among older people to engage with technology, research has shown that older people can see the potential for smart home technology

to enhance their lives and support their independence, though it is important that designs are user-friendly (Lynch and Draper 2014). While this presents a huge market opportunity a greater understanding is needed about exactly how technology can help and the extent to which it might reduce the need for informal care (Pickard 2013).

However, there is likely to continue to be a significant gap between what the market charges and what many people can afford. Elderly and disabled people are already paying almost £740 a year more for home care services than in 2010. And there are other risks too. The collapse of Southern Cross and abuse of residents within services run by Castlebeck Ltd in 2011 (Moultrie 2012) are just two examples which raise concerns about relying on the market to deliver high-quality care services.

While there is as much of a lack of transparency around levels of profits being made in the care market as in any other market, it is revealing that nearly 50 per cent of adult social care directors think that providers are facing financial difficulties, and 45 per cent of councils did not increase fees to care homes as a result (ADASS 2013). Care providers are also warning that legislation in the Care Bill could end the 'cross-subsidy' in social care, which sees self-funders being charged more on average (£35,000 a year) than those funded by local authorities (£25,000 a year). Unless this is resolved, it has been estimated that this could remove £1 billion from the care market for care providers annually, leaving some on the verge of collapse (Kirwan 2014).

The government hopes to create the conditions for a larger market in financial products for social care. However, no other country has seen a sizeable market for social care insurance develop without this being government-led. In short, the market solution is only a promising one for those who can afford to pay the costs involved.

#### 5.4 The community

One of the fastest-growing sources of unpaid care in the future is projected to be care by 'others', such as friends and family members other than children, spouses or partners. This is largely due to the increase in numbers of childless single people living alone. Where these people do receive informal care now, they are supported solely by friends and wider family members such as siblings (Pickard 2013). However, despite a projected increase of almost 70 per cent in caring by this group (ibid), it is likely that paid care will be the preferred option rather than support from friends at the point care needs become more extensive or intimate (Allen 2008, Twigg 2000).

This leaves the wider community, which we refer to here as those other than family and friends who voluntarily contribute to the provision of care. It could also refer to contributions made in the form of money, such as individual or charitable donations, or the provision by employers of flexible working, and more broadly refers to the way we define our collective responsibility towards those beyond our immediate circle.

The question of capacity here is more difficult to analyse than for the other pillars, because it is not recorded in the same way as informal care provided by family and friends. However, we do know that there are an estimated 600,000 community groups with no formal registration in the UK and 170,000 registered charities, 20 per cent of which are classified as working in welfare, wellbeing and social care. These have a combined income of around £8.3 billion (Moultrie 2012). Only a very small amount of this is state funding: the National Audit Office recently found that local authority grants to voluntary organisations to provide low-level support in the community make up just 1.6 per cent of overall spending on adult social care (NAO 2014), or approximately £192 million (1.6 per cent of £12 billion).

It is important to recognise that older people are not simply the recipients of this care. ‘Younger’ older people have been identified as being a particularly valuable source of community capacity for the future. The Commission on the Voluntary Sector and Ageing found that, in 2010, the working hours given by older volunteers to UK charities was equivalent to £10 billion and that this is expected to grow to over £15 billion by 2020 (CoVA 2014). A more recent ICM poll found that 65 per cent of older people say they regularly help out elderly neighbours, and are the most likely of all adult age groups to do so. They also tend to be members of more community groups than any other age cohort (Brindle 2011).

For some people, neighbourhood-level community activity will have limited value, because of the limited connections they have to the place they live in and its relevance to their wider social networks. However, for older people, who are sometimes limited in their mobility or affected by a health condition and may not have family and friends living nearby, those living in close proximity are a particularly important resource. Along with the disabled and others with social, physical or mental health difficulties, older people tend to rely more than others in their neighbourhood.<sup>12</sup>

As more people in future will face the challenge of combining work and care, employers will have an increasingly important role to play in managing the family care gap. IPPR has previously argued for the UK to consider more options to help people stay in work during periods of intense care rather than leaving altogether (Ben-Galim and Silim 2013). This could appeal to those employers who would prefer to retain employees, and could in future limit the impact on the employment rate of more family members providing intense care. However, these options do require a change in the culture of the workplace and greater flexibility on the part of employers and employees alike.

In summary, this pillar of the care system is one where, with the right encouragement, capacity could be expected to increase in future years, particularly as more people retire with the expectation of a higher number of healthy years ahead of them. However, it is important to be clear about its limits. When care needs become more extensive or intimate, and where there are no close family members to help out, paid or formal care is likely to be the preferred option, rather than community networks, neighbours or friends.

## 5.5 Conclusions

The balance between these four pillars of care that we have relied on to this point will not serve us in the future. We urgently need to reassess the balance between family, state, market, and community, based on this assessment of their future capacity to play a role in closing the family care gap.

- **Families** will be taking on more responsibilities than ever before, so the task must be to ensure that they are better supported in their role as carers and that impacts on health and employment are minimised.
- In light of growing funding shortfalls, the capacity of the **state** to absorb greater care costs will be close to zero, unless there is a new settlement for health and social care funding. Even if extra investment is secured, however, the help with simple daily activities and regular social contact needed cannot be provided by professionals working in services run by the state or the market. The state can play a vital role in building up community institutions to enable civil society to play a greater role.

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<sup>12</sup> From an untranslated PhD thesis by Dutch academic Lilian Linders, *De betekenis van nabijheid: Een onderzoek naar informele zorg in een volksbuurt* (2010).

- The **market** solution will remain out of reach for many, unless there is a breakthrough in creating a market for social care insurance products or new more affordable models of care.
- The wider **community** has the potential to play a more prominent role, in part because of the greater number of retirees who, on present trends, will choose to volunteer in their local community – however, support is needed to build up this role.

Across the world, countries with ageing populations are preparing for similar challenges. Countries such as Germany, the Netherlands and Australia, as well as initiatives in the UK, offer vital lessons on how to rebalance the four pillars of care.

### 5.6 Lessons from overseas and the UK

As we have seen, neither the state nor the market is best placed to provide help with the simple daily activities or offer the regular social contact that is vital for maintaining quality of life, independence and dignity and to prevent people from developing more serious health conditions. Many other countries facing this challenge are restructuring their care systems to adapt to their changing populations in ways that build up the capacity of civil society to respond.

The case studies examined below vary widely, but all share the following objectives:

- making it easier for family members to combine work and care
- cultivating institutions that can support communities to look out for and care for each other
- finding creative and inexpensive ways of building relationships between different generations.

#### Germany

In Germany, a comprehensive national ageing population plan draws together a wide range of policy measures but also includes funded measures to build new community institutions to bring people together.

##### German ageing population plan

- increasing the retirement age to 67 by 2030
- offering subsidies for parents who stay home with their infant children
- giving parents the right to access childcare places
- increasing social security contributions from 20 per cent to 22 per cent of salaries by 2029
- targeting skilled immigrants, including medical workers, mathematicians, IT specialists, natural scientists and technicians, and helping them integrate into society
- offering funding for ‘multi-generational houses’ where elderly people are encouraged to interact with younger generations
- subsidising developers who make better homes for the elderly and forcing them to build user-friendly homes for the aged.

Source: German Federal Ministry of the Interior 2012

The *Mehrgenerationenhauser* (multi-generational houses) bring together under one roof groups that had previously operated in isolation, such as childcare services, youth groups, support for young mums, day care for the elderly and advice centres. This means that all age groups have a single, universal community centre, where they can both give and receive support, according to their strengths and needs.

Forming a key part of the German government's ageing strategy since 2006 (expanded in 2012), the centres offer inexpensive services and support in daily activities for older people such as shopping and cleaning, food and care services. There are now over 500 multi-generational houses across Germany and 15,000 volunteers are participating in the programme, which is held up as a successful model for social involvement. Each house is supported by the Germany federal government for £33,000 per year, at a total cost of approximately £16.5 million, with additional funds raised locally.

#### **Multigenerational houses (*Mehrgenerationenhauser*), Germany**

Adapted from Deutschland.de 2013

*Multigenerational houses are somewhat like a well-organised extended family, bringing together all age groups – from babies to 80-year-olds. Every morning, three-year-old Emily and her great-grandmother make the same journey. Emily plays during the day at the Salzgitter Childcare Centre, while her great-grandmother receives the care she needs under the same roof. Emily's great-grandmother suffers from dementia, and spends the day in the geriatric day care centre, just a few steps away across the hall. For the children and the old people, the door to the other part of the building remains open. Artificial boundaries between young and old are removed, allowing people to encounter each other in an unconstrained and entirely natural manner.*

*The 'open meeting points' provide a focus – these are bistros or cafes where everyone is welcome. In all other respects, each multi-generation house is unique, and each may choose to emphasise different aspects. There are mobile phone surgeries for the elderly, homework support for schoolchildren, 'international kitchen chats' for people from every conceivable ethnic group, art and theatre courses.*

*Nationwide, nearly all administrative districts and urban municipalities now have their own multigenerational house. This financial support is part of the German government's demography strategy. These 'public living rooms' have come to be regarded as an important example of new concepts in a modern welfare state, where conventional institutional help is combined with mobilized civic engagement. Yet they also offer a great deal more: 'People are rarely happy on their own,' explains Dr Eckart von Hirschhausen, who attends a multi-generation house in Berlin's Zehlendorf district, 'which is why multigenerational houses are the model for the future: learning from one another, feeling needed, sharing joy.'*

People of all ages are encouraged to focus on their strengths and contribute their capabilities to the community. The houses most successfully engage 55–65-year-olds – those in the transition between work and retirement and the 'young old' who are particularly involved in supporting older people in need of everyday support and social contact and with respite care, especially to relieve the pressures on those in full-time work.

A particular goal of the multigenerational houses is to offer an alternative for older people who feel lonely and for young, often single-parent families who need support but have no grandparents living nearby. Both the houses and a similar scheme, the *Grosselterndienst* (Grandparents Service), give older people the chance to become ‘adopted grandparents’ by linking them up with children raised in single-parent families.

### **Grandparents Service (*Grosselterndienst*), Berlin**

Adapted from France Bénévolat 2012

*The Women’s Association of Berlin (Frauenbund), supported by the Senate of Berlin, gives older people the opportunity to become grandparents by ‘adopting’ children raised in single-parent families. In most cases, ‘natural’ grandparents live too far away or have no contact with their children. Founded in 1989, the association has more than 480 grandparents today, mostly aged 60 years or over. Grandchildren adopted are between 0 and 10 years; some of them keep in touch with the volunteers who look after them even as adults.*

*The Frauenbund association is in charge of interviewing aspirant grandparents, understanding their motivations and finding the most suitable family. Once a month, the association organises breakfasts for grandparents who can exchange experiences. ‘Adopted grandparents’ therefore provide psychological and material support to single mothers and fathers, who often cannot afford babysitting for their children, while guaranteeing a familiar atmosphere. Grandparents also benefit from their volunteering, as they remain active but also because their own grandchildren often live too far away.*

These initiatives provide inexpensive ways of joining up various social challenges – social isolation among older people, time-poor parents and increasingly scattered families – and stimulate the provision of informal care in the community.

### **Netherlands**

In 2013, the Dutch king announced the birth of the ‘participatory society’ in the Netherlands, declaring the end of the welfare state. Reforms underway since 2007 have sought to devolve more power to local areas, facilitate mutual support and prevention, and encourage more collaboration across different services. The experiences of stimulating mutual support in the Netherlands provide useful lessons for the UK.

Dutch research has shown that although plenty of people are prepared to help a neighbour, they will not generally do so until they are asked. Dutch academic Lillian Linders labels this the ‘*support scruple*’ (see Linders 2010). People are even less likely to ask for support, however, because they have learnt that they should take responsibility for their own problems (the ‘*request scruple*’).

The conclusion is that policy should focus on making it easier for people both to offer and ask for help (for example, through ‘asset-based’ approaches, which build informal links) and that this would do more to lead to growth in informal care than tackling any perceived shortage of supply, such as efforts to increase volunteering.

The Dutch experience also suggests that what mutual support is given tends to be as a result of personal relationships between two neighbours born more out of physical

proximity than any collective sense of community solidarity. Many people actually want to keep some distance from their neighbours.

The lesson to take from this is that if facilitating mutual aid is to be an aim of policy, it needs to be about connecting people who live close to each other or who have a reciprocal need, rather efforts to increase ‘community cohesion’.

The *Buurtzorg* model developed in the Netherlands is an example of one of a number of innovative services attempting to deliver integrated ‘neighbourhood care’ by improving links across health disciplines and giving frontline staff more autonomy.

### **Buurtzorg, Netherlands**

Adapted from KPMG 2012

*Home care organisation Buurtzorg (meaning ‘neighbourhood care’) was created to focus on patient value by putting professionals in the lead. The programme empowers nurses to deliver all the care that patients need. And while this has meant higher costs per hour, the result has been fewer hours care needed in total. By changing the model of care, Buurtzorg has accomplished a 50 per cent reduction in hours of care, improved quality of care and raised work satisfaction for their employees. With lower overheads and more autonomy for staff, the Buurtzorg model increases the amount of time nurses spend with those they are caring for.*

*One of the keys to the programme’s success is that Buurtzorg’s home care nurses organise their work themselves. Rather than executing fixed tasks and leaving, they use their professional expertise to solve the patient’s problem by making the most of their clients’ existing capabilities, resources and environment to help the patient become more self-sufficient. Satisfaction scores for the service are 30 per cent above the national average. In 2011, Buurtzorg was chosen as the Dutch employer of the year.*

### **Australia**

In the state of Western Australia, a model known as ‘local area coordination’ is forming partnerships with individuals, families and local communities to promote self-sufficiency and local solutions to care needs while delivering value for money. It has long been an important part of social care for people with disabilities in Australia, and a growing number of local authorities nearer to home – including Derby, Cumbria, Middlesbrough and most authorities in Scotland – are now also employing coordinators to help people with support needs, including older people, to make the most of, and make a difference to, their local areas.

### **Local area coordination, Australia and UK**

Local area co-ordinators (LACs) are recruited from a range of backgrounds, have close links to local neighbourhoods and operate an ‘open door’ policy, providing information, support, advocacy and advice to all, regardless of their support needs or their entitlements to funding. Support may involve linking people up to existing community groups, drawing on volunteer support to enable them to get out of the house, or negotiating a role for individuals to take a more active part in their community.

Coordinators can also support and advise people to access and control resources or services where they are eligible.

LACs are able to achieve successful outcomes with relatively little input, arguably because of their community location, which allows for drop-in visits, local knowledge and an informal approach, without the need for complex assessment processes (Peter Fletcher Associates 2011).

In turn, this creates the potential for cost savings for the local authority. The principal costs of LAC are for staffing, and each coordinator costs approximately £40,000. In the UK, Thurrock council estimates that 5 LACs plus an LAC manager would cost approximately £380,000 annually (Sitch 2013). Evaluations of LAC in Australia, Scotland and England have shown that the scheme delivers value for money, with key savings coming from diverting people away from more expensive crisis services. The evaluation of LAC in Derby showed estimated diverted costs of £800,000 within the first 12 months, while operating at 40 per cent capacity in two locations. In Australia, the cost to authorities per service user was found to be 35 per cent lower than the national average (Government of Western Australia 2003).

At present, LAC in Scotland and parts of England is grant-funded and, as such, essentially acts as an add-on to existing case management services. In Western Australia, the LAC model will form a key part of reforms to services for disabled people, replacing case management (Disability Services Commission 2013).

## **Japan**

Japan, the country with the oldest population in the world, is also realising that conventional approaches to caring for the older population will not be enough, particularly in the face of a growing population with dementia. There is a growing realisation in Japan that society should not simply leave the care of people with dementia to specialist health and social care services (Robertson 2013). It is now considered crucial that citizens should have a proper understanding of dementia and should support people with dementia in the community in which they live.

For example, the Ministry of Health, Labour and Welfare, together with organisations concerned with dementia, has launched a 10-year nationwide public campaign called the Campaign to Understand Dementia and Build Community Networks. The campaign has a number of elements, one of which is called the Nationwide Caravan to Train One Million Dementia Supporters. The idea is that volunteer dementia supporters will receive training and support in the nature of dementia and how best to provide support for people with dementia and their families. Volunteering and civic engagement are therefore seen as central to this national strategy to respond to the growing number of people with dementia.

## **UK**

In the UK too, 'asset-based' approaches to community development – which identify strengths and build on these, rather than the 'deficit model' of social care that focuses on 'needs' – are increasingly being adopted by local authorities including Leeds, Surrey and Walsall, and expanded by national programmes such as Shared Lives.

In Leeds, the preventative approach adopted by its Neighbourhood Networks scheme is delaying entry of local older people into the formal care system. Neighbourhood Networks is run by older people and the local community, covering 37 areas across Leeds. These share annual funding totalling £2 million from the council through a five-year settlement.<sup>13</sup> The networks have been funded in part by tough decisions by the council to sell council-owned residential care homes. So far, four old people's homes and four daycentres that were previously run by the council have been closed.

The networks provide a community base, with a recognisable and respected local identity, for community development projects and help to bring people together, by providing much-needed social contact, even in areas with distinct social divides.

Despite a growing 65-plus population, the number of older people receiving homecare and taking up places in residential care homes is falling. The number of older people receiving homecare has decreased from over 4,200 in 2010/11 to under 3,700 in 2012/13, while the number of residential care placements funded by the council has also decreased steadily, from 172,810 bed weeks in 2002/03 to 135,522 in 2012/13. If every authority were to contain the costs of rising demand for care this would result in a savings of at least £0.36 billion per year.

#### **Neighbourhood Networks, Leeds**

Since 2005, each local area across the city-region has had its own dedicated Neighbourhood Network. Through the networks and their many volunteers, local older people and their families get help with the everyday tasks of care, such as free or cheap transport, social activities, shopping, practical help at home, cleaning, gardening and breaks for carers. As well as helping older people, the networks help families and carers to juggle the demands of family, work and caring, delay entry into formal care, and reduce reliance on the NHS.

Each network is responsible for a particular geographical area, determined in consultation with the community, and provides services to reduce social isolation, provide opportunities for volunteering, act as a 'gateway' to advice, information and services, and promote health and wellbeing, and thus improve the quality of life for the individual.

Many of the networks had already been around for almost 20 years when the council took the decision to establish them as Neighbourhood Networks. These included existing local community institutions, such as charities, community groups, live-at-home schemes and faith-based institutions. They were offered sustainable five-year core funding and each organisation is run by a local management committee, which includes older people and members of the local community, with each member having an equal vote on proposals for what the network provides and how it is run.

<sup>13</sup> They are encouraged to fundraise from other sources, and many also receive money from the Big Lottery Fund and private donations. All the networks have been successful, to varying degrees, in raising funding from a range of sources other than Adult Social Care.

Three Neighbourhood Networks have also piloted the Asset-Based Community Development approach through the Senior Network Support (SeNS) project.<sup>14</sup>

The SeNS project is designed to combat social isolation, by developing new and existing group-based activities, such as baking groups and walking clubs. A ‘community connector’ – a local person who is passionate about their local area and a good networker – is employed to map existing social networks, identify local needs, and find and recruit local people with a desire to share their skills.

In one of the networks, for example, the community connector helped to put a local man with experience of making walking sticks in touch with other men in the local area, who had previously mentioned the lack of social activities explicitly designed for them, to create a club for those interested in learning how to make walking sticks from materials found in the local park. The connector was able to link people up, provide small amounts of cash for materials, provide a space for the club to come together, and arrange for the club to meet with the local park authorities to get permission to take sticks.

The Leeds Neighbourhood Networks are also piloting a service called Local Links. Inspired and set up by Ritchard Brazil of the Stamford Forum project, it works on the principle that if people come together to fund their care needs then they can more flexibly arrange vital services such as transport or help with day-to-day tasks such as shopping and cleaning, in ways which both go beyond the generic set of options they would otherwise receive, and they are likely to save money at the same time.

The network employs local support planners with detailed local knowledge, rather than council social workers, to help with this. The older person’s budget is held on behalf of the individual by the local network. If the overall package of care delivers savings on what traditional council services would have cost, half of the savings are returned to the council and half are retained by the Neighbourhood Network. Much of the support is highly tailored to the individual (learning new hobbies, meeting up with people to talk about shared interests) and delivered by volunteers – having a large, skilled and varied volunteer workforce is vital.

At first, all services offered are additional to an existing care package. With the help of a community broker, an individual develops a complete support plan, based upon what they want from their lives, informed by resources in the community and drawing upon voluntary capacity. A proportion of the financial savings achieved through this approach will be reinvested into the Neighbourhood Networks through a ‘social dividend’. This empowers the local community to extend the range of services provided to local people and, in time, to embed spending on social care into local communities.

*Elaine, 70, suffers mobility problems and has recently been bereaved. She previously just received home care from a professional agency. Through Local Links however her care package now includes a range of voluntary support, including social activities, regular visits and help with her shopping. As a result she has reduced her home care support and, in consultation with her GP, has stopped taking antidepressants.*

Source: Lockwood S and Carrier J 2013

<sup>14</sup> This is jointly commissioned by Leeds Adult Social Services and Library Services, with funding from the European Regional Development Fund.

The concept is also being trialled in Leeds Sandwell and Belfast. The model requires the local organisation to set up a separate community interest company in order to access start-up funds and protect the organisation from financial risk. To ensure it aggregates enough money to create a community dividend, it is assumed that each service would work for a population of around 25,000. It is hoped that this model will shift the balance of power towards service users, and incentivise care providers to focus on what people actually want.



These examples from overseas and UK illustrate the options that are available for rebalancing the roles and responsibilities of the four ‘pillars’ of social care. We can see that in contrast to countries such as Germany, the Netherlands and Japan, the UK is lagging behind in cultivating these types of networks on a national scale. This will require a different role for the state, one that is more about establishing partnerships with families and communities than traditional service delivery. The final chapter makes specific recommendations for tackling the family care gap in the UK.

## 6. FACING UP TO GENERATION STRAIN: OUR PLAN TO BUILD AND ADAPT

The UK's post-war settlement on health and social care is struggling to provide convincing solutions to the challenges posed by an ageing population. As we have seen, other countries facing this challenge are restructuring their care systems to place more emphasis on what people can do for each other to compensate for the disconnectedness of modern life and avoid over-reliance on the state.

The UK needs to respond in a similar way. This doesn't mean the state has no role – it means it has a different role. The aim of the welfare state should be to prevent need from arising in the first place and to offer a safety net after all other options have been exhausted, rather than forming the frontline of care.

In a future where we can no longer take the availability of family care for granted, we will need to revise our understanding of our collective responsibility for looking after each other in later life – as relatives, friends and neighbours. Some older people need professional care just to get by, but the vast majority need the kind of everyday help and human contact that neither the state nor the market can provide.

This is not an argument for the state to withdraw so that community-led solutions will flourish. There is no evidence to suggest that will be the case, as the Coalition government's experiment with the 'big society' has shown. Instead, an 'enabling' state should invest in strengthening community institutions so that they are prepared to offer the help older people and their families will need in the future. Far from crowding out informal care, as some on the political right would claim, these moves will stimulate it.

To ease this case of generation strain, Britain needs to **build** new community institutions capable of sustaining us through the changes ahead and to **adapt** the social structures already in place, such as family caring, public services, workplaces and neighbourhoods.

Attempts in the past to reduce reliance on formal care services through community based, preventative services have been well intentioned but have ultimately had limited impact. These activities have often effectively been 'add-ons' that have run alongside the interventions they were intended to replace.

Chief among the reasons for this is the unstable funding climate for local authorities. With short-term funding cycles, commissioners do not always know if they can maintain funding for new services for as long as is needed to demonstrate the benefits and achieve potential savings, so there is less incentive to make investments.

A longer-term, five-year funding settlement for local government would give adult social care departments greater certainty and so allow them to plan strategically, reprioritise spending and reorganise resources to reduce future demand. Equally, across health and social care, if instead of the current three-year cycle of spending reviews, funding commitments were given for five years (alongside a forecast for the following five years), this would both provide greater flexibility and establish the long-term mind set that will be critical to the integration of health and social care services (Bickerstaffe 2013).

In the absence of new investment, longer-term funding settlements are one way to encourage investment in interventions that are likely to save money further down the line. This approach should be taken to make a reality of the duty on local authorities set out in the new Care Bill to encourage 'wellbeing' and 'prevention' and for more community-based initiatives to be supported as part of mainstream provision, rather than as 'stop-start' pilots.

**We recommend a longer-term, five-year funding settlement for local government that would give adult social care services greater certainty and allow them to plan strategically, reprioritise spending and reorganise resources to reduce future demand.** Alongside this there should be a single outcomes framework across health and social care covering older people and those with long-term conditions.

The proposals we outline below will reform the current social care system in three key ways:

- establishing a different starting point for social care services by asking: ‘what do people need to live a good life’?
- acknowledging family and mutual support as the frontline of care rather than services
- encouraging new providers by creating opportunities for community groups and social enterprises to play a part in the delivery of care in ways that challenge the dominance of the state and market.

### 6.1 Recommendation: Neighbourhood networks for older people and their families in the areas that need them most

In some areas, older people, their families and carers can rely on community networks for everyday help and social contact. In other areas of the UK, older people are isolated, and their families and carers find it hard to ensure that their family members can access the practical support they need and have people nearby that they can rely on.

Richard, who we met in chapter 2, is in need of relatively low-level support, namely help to leave his flat and make the journey to social activities, which could make a significant difference to his life. If Richard lived in Leeds then he would have a dedicated Neighbourhood Network which he could turn to for help to arrange transport and link him up with local social activities, to give him the chance to contribute to local life. With his interest in local campaigning, Richard could also have joined the local management committee of the network, which is run by older people and their families and makes decisions about what services, activities and groups should be run locally. As it is, Richard has virtually no human contact with anyone other than the rushed carers who come four times a day or when he is occasionally accompanied to the local church by volunteers.



Neighbourhood networks do not provide the more regular, sustained and intensive support needed when care needs become more serious. But they offer a focal point in a local area to bring people together to help each other out. The actions are often simple in themselves, but cumulatively they create abundant value. In addition to older people themselves, they benefit families, friends, carers and employers – and ultimately the state.

For families and friends, they are a trusted local place to turn to if an older person needs support that they might struggle to provide themselves. For carers, group activities such as dementia cafes can offer the prospect of a short break from intense caring. For employees trying to balance their day jobs with taking care of relatives, they are able to coordinate informal support through the networks in the case of an emergency or crisis. For employers, this minimises working time lost as a result, and can help them to retain valuable employees.

The state benefits in a number of ways. Keeping people socially and physically active extends healthy ageing and increases the chance of delaying the onset of disease until

much closer to death (see Fries 2004). Higher spending on preventative, community-based care has been shown to result in lower spending on expensive and increasingly unpopular institutional care. In Leeds, in contrast to most local authorities and against the trend of population ageing, the number of people using home care is dropping and the average age of entry into residential homes is going up, which they attribute at least in part to the impact of Neighbourhood Networks. And, in Leeds, these benefits are secured with just under 1 per cent of the overall adult social care budget.<sup>15</sup>

In the years ahead, this kind of activity will not be a 'nice to have' but a necessity. Investing in strengthening community networks across the country now would be a relatively small but sound investment in the future. The policy goal should be for every community that would like one to be supported to build a network of this kind, and for those areas with the least developed community provision to be brought into line with the best.

The barriers to change are as much about institutional culture as finances. The differences in the patterns of spending among local authorities are often linked to the history of service development. For example, in the North West of England, resettlement of people from long-stay hospitals has relied on supported housing instead of on residential care, and so authorities spend more on this preferred and more affordable form of accommodation (Bolton 2009). Patterns like this can be difficult to shift.

In future, unevenness between local authorities in the quality of community support for older people and their families will only become more apparent as more people use and come into contact with services. A distinction has been made between 'Careland' and 'Communityland' to describe respectively those local authorities with the greatest and lowest reliance on expensive residential and nursing care (ibid). Those local authorities in 'Communityland' spend more on helping people to live at home and have fewer people living in residential and nursing care. They also have a lower overall spend per adult than other local authorities.

While the original analysis focused on spending for adults with learning disabilities, indicative analysis of spending for older people suggests that the 38 local authorities with the greatest reliance on expensive residential and nursing care and the least developed community care are likely to be in the North East, North West and South West of England.<sup>16</sup> However, further analysis would need to be done to verify these findings.

We recommend that upper-tier authorities with the least developed community-based provision (on this model) are the focus of the greatest efforts to identify and strengthen community networks. In these local authorities, health and wellbeing boards, which are already responsible for assessing the current and future health and social care needs of the local population, should lead local authorities and clinical commissioning groups in a process of creating a new dialogue with communities, at parish council or town council level.

The aim should be to understand the particular areas' strengths and aspirations in relation to older people and the lives they, their families and carers want to lead, and to draw up collaborative partnerships with them.

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15 Similar schemes are run in Surrey and Walsall, as well as variants such as time-banking and mutual support schemes, including Participle's Circle project: see <http://www.participle.net/>.

16 As measured by the proportion of total gross expenditure by councils with adult social service responsibility that is spent on residential or nursing care (data source: HSCIC 2013b).

Questions for interested community groups might include:

- What roles might they want to play in relation to reducing social isolation, improving health and wellbeing, and providing opportunities for volunteering?
- Which responsibilities are they interested in taking over?
- How would they be fully inclusive of their local community ?

Although initiated by local government, this is a 'bottom-up' process. The profile and interests of each area will differ, so the exact vehicle for the community network will look different in every area. However, based on common elements of successful community development initiatives, these networks should:

- be run by local people for local people
- have a volunteer base, or be able to demonstrate a commitment to cultivating one
- have a locality-focused setting, at either ward or multiward level, and include all of the local population, not simply certain sections.

Organisations would be drawn from among the local community sector, faith-based organisations or social enterprises, due to their established relationships in the local community and ability to build trust. These could include community groups, faith groups, mutual support groups, tenant management organisations (TMOs) or other similar groups. They should be identified and strengthened to take on core responsibilities for increasing social contact, health and wellbeing, and facilitating volunteering in the local population. In the few communities where no such organisation already exists, a community development worker should be employed to develop networks over time.

Depending on the size of the local authority and local population, the cost of strengthening local organisations as described above will be approximately £2 million per local authority per year, based on expenditure as part of the Leeds scheme. Community groups should raise a small proportion of the funds and then, together with local authorities, should seek matched-funding from the adult social care budget. If funding cannot be made available from this source, it should come from the local public health budget, which is managed by health and wellbeing boards and is intended to improve the health and wellbeing of the local population.

Until the organisation is fully fledged, it should be grant-funded and then contracted to meet outcomes in relation to the core activities agreed between the group and the council. In addition to more standard metrics, performance could be partly assessed through qualitative accounts by users, and networks should be encouraged to be creative in developing different ways of demonstrating progress. In order to provide the stable conditions and build enduring community institutions, this funding would need to be made available on a multiyear cycle, ideally of five years.

Developing community networks requires an approach to commissioning that is different from traditional commissioning of social care provision, being based more on partnership working, managing complex networks of providers and being able to adapt to changes in local priorities. We therefore recommend that at least a five-year programme of leadership and peer support is run by the Association of Directors of Adult Social Services (ADASS) to oversee this, based on the successful London Challenge model in education.<sup>17</sup>

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<sup>17</sup> See <http://www.ofsted.gov.uk/resources/london-challenge>

Local authorities should be evaluated on their success in setting up local networks and the extent to which they have shifted the balance of spending away from acute and towards preventative care.

**In a five-year programme based on the successful London Challenge, local authorities with the least developed community support for older people and their families should be the focus of efforts to bring this into line with the best authorities. Annual funding of an estimated £2 million per local authority should be made available from local public health budgets to fund the development of neighbourhood networks, with the aim of funding more of this from mainstream provision over the five-year period.**

Many local authorities are already supporting initiatives of this kind and the aim should be to strengthen these by putting them on a more stable footing financially. The greater flexibility to shift resources afforded by a longer-term funding settlement should help to achieve this. However, the aspiration should be for any community group that is owned and run by local people, focused on a local area and has a volunteer base (plus other local criteria determined by upper-tier authorities), to be supported to develop a neighbourhood network, as described above.

These institutions may require three to five years or longer to take on these responsibilities, but they will mature to form the basis of a new community frontline in care to meet both the opportunities and challenges of the UK's ageing population by the 2020s.

**Any community group that is owned and run by local people, focused on a local area and has a volunteer base (plus other local criteria determined by upper-tier authorities), should be supported to develop a neighbourhood network as a new community frontline of care.**

A particularly modern aspect of social isolation is the lack of contact enjoyed by people from different generations. As people live for longer, many families are enjoying the benefits of having several generations living under one roof. However, there are also a greater number of older people living alone and living apart from their families, who may live in different parts of the country or abroad, often due to moves to find work. This can deprive people of the simple joys of life that come with mixing with people of different ages.

A lack of contact between generations can also provoke negative attitudes about ageing and older generations, a particular risk when the age structure of the population will be changing so markedly and public spending on healthcare and pensions, which primarily benefit the elderly, could continue to be disproportionately higher than spending on child-care, education and training, which are used more by younger generations (Palier 2014).

In Germany, as well as a number of other European countries, there is a growing trend of new institutions designed to encourage intergenerational contact outside of the immediate family. As described in chapter 5, government-sponsored *Mehrgenerationenhauser* (multigenerational houses) provide a shared space at the community level for people of all age groups – from babies to 80-year-olds – to come together, like a 'well-organised extended family'.

The *Mehrgenerationenhauser* programme and 'Grandparents service' (also described in chapter 5) embody the principle of reciprocity, bringing together different age groups in a way which their immediate personal circumstances don't allow and from which they mutually benefit.

This approach should be incorporated into the expansion of neighbourhood networks, and the principle of housing care services for different age groups under one roof could also be applied more widely.

**The UK should follow the example of the German Mehrgenerationenhauser national programme and house services for different age groups such as childcare and care for older people under one roof. This will remove artificial boundaries between young and old and allow generations to come together in a natural way. It could also reduce overheads by encouraging shared use of community spaces, such as Sure Start Centres or community halls.**

Social isolation is not just a consequence of societal change but is also often aggravated by the way we design our environment, whether in relation to transport, technology or housing. The planning of housing development in a way which adapts to our ageing society is still very much in its infancy. One approach which is increasingly popular in Germany and the Netherlands is 'co-housing' which enables local communities to create and manage housing provision themselves.

Co-housing typically involves clustering individual homes around a 'common house', or shared space and amenities. These can be intentionally 'same-age', generally for people aged 50 or above, or 'intergenerational', where older people and families live side by side. In either case, members live together consciously as a community.

People's options for housing later in life are limited: the pattern tends to be that they receive home care until their needs become more intensive, and then they may move to sheltered accommodation, extra care housing if this is available locally, or a place in a care home. Co-housing is a relatively inexpensive way for older people to maintain their independence without sacrificing the richness of life brought about by living alongside others.

From a policy perspective, co-housing is a way of compensating for the anonymity of modern neighbourhoods at a time when single households are on the increase and many older people live alone. It also reduces demand for health and social care services by offering an additional option for the informal care and housing needs of people approaching old age, and by keeping older people active, healthy and less socially isolated (Brenton 2013). Instead of encouraging a culture of dependency as formal care sometimes can, co-housing is built on the principles of self-help and mutual support.

Despite the lack of any examples in the UK, there is evidence to suggest that co-housing appeals to the baby boomer generation, for whom the institutional models of care developed in previous centuries no longer feel appropriate (ibid). In order for co-housing to become a viable choice for people later in life in the UK, planning policy needs to be adapted.

As an option for rethinking how we live in the future, the development of co-housing communities should be considered as part of the design of new towns (see Hull and Cooke 2012) and might also be encouraged through 'housing innovation zones' (see IPPR North and NEFC 2012).

## 6.2 Recommendation: Local care coordinators to replace local authority case management over time

Jenny, who we met in chapter 2, is caring on a full-time basis for her husband, James, who has severe dementia. Jenny had to battle health and social care professionals who decided, without consulting her, that her husband needed to go into residential care because of his support needs. As his wife, Jenny wanted to care for her husband at home.

Because Jenny and her husband were not eligible for state-funded care, Jenny had to sort out a seven-day-a-week care package for her husband almost entirely on her own and with no prior experience. She had to do this at the same time as coping with the trauma and grief caused by the sudden deterioration in her husband's condition.

If Jenny had been able to benefit from one of the small number of 'local area coordination' schemes in the UK she would have been given advice and support, even though she and her husband were not eligible for state-funded care. A local care coordinator would have sat down with Jenny and put together a 'life plan' with her and her husband based on what they were able to do and what support they'd need for James to live at home. Jenny would have been put in touch with local groups to help her with her role as a carer.



Many people's experience of assessments, carried out by social workers employed by the council on behalf of adult social services or the NHS, is that they are fleeting, bureaucratic and don't get to the heart of people's personal circumstances. They are often used only to decide whether or not people are eligible for professional care, and rarely put people in touch with the local groups that can make a huge difference to the lives of people like Jenny, who as new carers can benefit from the experiences of other local carers and the peer support they can offer in trying circumstances.

Local area coordination schemes, as described further in chapter 5, operate an 'open door' policy, providing information, support, advocacy and advice to all, regardless of people's support needs or their entitlements to funding. Most importantly, rather than an 'assessment' from a social worker, they put together a life plan together with the person concerned, which builds on the existing relationships in their life and identifies local solutions to problems. In Australia, coordinators are based in 'shop-front' premises designed to be accessible to everyone living in the areas they serve, and this is the critical factor in their success. Coordinators themselves can come from a variety of backgrounds, such as community education, psychology, therapy, social work, health and youth work, but local knowledge and a flexible and proactive approach to building relationships and solving problems are essential.

The recent Care Bill intends to make local authorities responsible for the wellbeing of their local population – not simply those eligible for state-funded care – but it does not reform the current assessment process. There is strong public appetite for care that allows for longer-term relationships to be built, demonstrates a 'human touch', and fits more closely with people's priorities. Following the example of Australia, the UK should aim to decommission 'case management' for all but the most complex cases of care, transferring it out of traditional local authority institutions and into the community, by 2020. Rather than adding another layer of bureaucracy and complexity, the aim must be to eventually replace case management for all but those with the highest support needs.

This process should start with the expansion, on a phased timetable across England and Wales, of the local area coordination model in the eight towns and cities where it is currently being piloted.

**Instead of ‘case management’ from social workers, older people, their families and carers should be given a local care coordinator based in the community to help them make the most of local networks and services. All but the most complex cases of care should be handled by care coordinators, with the aim of transferring care management out of adult social care services and into the community by 2020. Care coordinators could be based in neighbourhood networks and other community locations.**

### 6.3 Recommendation: Option of a ‘shared budget’ for those eligible for social care

Fiona, who we also met in chapter 3, was distressed by the poor quality of care her 89-year-old father received, with as many as 13 new carers in five weeks at one point. She could not take any breaks from caring because she was concerned to leave him with the carers; despite just being in her early 50s, she had to give up work to look after him full-time.

Fiona eventually found out that she could take control of her father’s care by taking up a personal budget to coordinate the care herself. She eventually began to receive direct payments, which allowed her to purchase care directly from the agencies, but this did not lead to any real improvement in the *quality* of care provided. And she and her father were just as isolated as before.

If Fiona had been put in touch with one of a small but growing number of organisations that bring local people together to use their direct payments collectively, such as a neighbourhood network, she might have been able to pool her payments with others, while burdensome employment responsibilities would be managed on their behalf by the organisation. She could also have benefited from meeting others in a similar position.



Giving older people, their families and carers the money to pay for services directly is a powerful way of putting people in charge of their own care. However, too many of the people who could benefit from this option are put off by the potential hassle and stress involved, and by their dissatisfaction with the quality of care they currently receive.

In order to encourage more people to move off managed personal budgets and onto direct payments (which achieve more positive outcomes), more third-party organisations, particularly community-led organisations, should be supported to take over the responsibilities that put people off taking up a direct payment, typically employment, management and administration.

These groups could also offer people the chance to act collectively through a shared budget to meet care needs, which existing schemes suggest could also reduce the costs of direct payments by drawing on more informal supports in the community.

Only a small number of families, carers and older people will want to come together with other people in this way,<sup>18</sup> but shifting the balance of power towards a small number of service users could be enough to catalyse wider positive changes in local social care markets. As well as combining the value and therefore purchasing power of personal budgets for users, this is also one of the few ways to encourage the development of more diverse providers such as cooperatives, mutual and social enterprises, in the absence of a major injection of capital.

While some people will be happy for the council or service providers to act as third parties to broker care and support, others will prefer a trusted, local organisation that is not also responsible for determining eligibility, rationing resources or providing services. As noted in chapter 5, evidence suggests that user-led organisations can be particularly effective in bringing personal budget-holders together.

Current examples of this include community organisations in Leeds, Belfast, Sandwell and Bristol that are piloting this approach, which was developed by the Stamford Forum.<sup>19</sup> To take part, community organisations have to meet criteria including community engagement and ownership, an inclusive approach, a commitment to drawing on local community resources, and volunteer development. In future, a wide range of organisations, such as religious and faith groups, TMOs and mutual support groups, as well as expanded Neighbourhood Networks, could act as third parties if they meet these or similar criteria, established by their local authorities.

However, there has to be a sufficiently strong incentive for each of the different actors involved. Crucially, communities should be able to reinvest locally the savings that are achieved from a more community-based and preventative approach to care. The incentives for the different actors involved might break down in this way:

- **Personal budget-holder:** greater purchasing power, choice and flexibility over care from pooling budgets together with other people.
- **User-led organisation and local community:** being able to reinvest cost savings locally.
- **Local council:** improvements in their Adult Social Care Outcomes Framework annual results through a more person-centred focus, with less prescriptive care and support planning. However, it could also increase contract administration (if services used are not block purchased) and increase training needs for staff.

Rather than creating more arbitrary central targets, expansion should be achieved through a focus on building up local institutions. As part of their new ‘market-shaping role’, as legislated in the Care Bill, local authorities should promote this opportunity at the local level and it should be incorporated into their Adult Social Care Outcomes Framework. Legal status would give the user-led organisations formal recognition from statutory organisations and allow them to attract forms of finance such as third-sector loans.

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18 The increasingly high thresholds set for eligibility for state-funded care mean that many older people with personal budgets may have health, mobility difficulties or dementia, which will progressively limit their ability to engage with more complicated processes. This means that only a small number of older people will be able to come together to use their budgets in this way. However, others will have family members and carers who manage their budgets on their behalf.

19 These groups are open to all older people locally and do not distinguish between people based on whether they are receiving social care (either state-funded or self-funded) as older people, their families and carers do not identify themselves according to how their care is funded

In the future, technology developments, such as the Hertfordshire ‘virtual marketplace’, may facilitate this even better than current arrangements can (see Laja 2011). This would also create a link between personal budgets policy and local market development, the absence of which has been a major flaw in its implementation so far.

For start-up and staff costs (estimated at approximately £150,000 per 25,000 population, based on existing pilots) organisations should seek contributions from local public health and Better Care Fund budgets.

**Older people, their families and carers with a personal budget should have the option of pooling their budget with other local people to create a local ‘shared budget’ to meet their care needs collectively. This option should be promoted by care coordinators and could be carried out by community organisations, including neighbourhood networks.**

#### **6.4 Recommendation: Stronger employment rights for carers to balance work, family and care**

As more adult children provide intense care of 20 hours a week or more, more people are likely to have to give up work, as even 10 hours of care a week affects people’s ability to stay in work and care. This will leave women in particular with hard choices to make about how to balance family and work, as women carers are still projected to outnumber men by nearly two to one.

Some people will choose to give up work to care, as they will prefer to provide this themselves rather than paying for formal care. However, many people will prefer to be able to combine work with care, for example in a part-time capacity, or to take a period of leave.

Last year £593 million was spent on carer’s allowance (DWP 2013), the main welfare benefit specifically for carers. Many of the 400,000 people<sup>20</sup> on carer’s allowance would prefer to be able to work flexibly rather than receiving a welfare payment and give up work. However, carers can find it particularly hard to access flexible working (Carers UK 2013). Many have to use annual leave or do overtime to make up for taking time off to care.

Workers taking on new care needs should be given enhanced protection to allow them to combine work with care, rather than taking up a welfare payment. This could be through a right to adjusted hours or an adjusted role, with protection of their employment contract, for those with an underlying entitlement to carer’s allowance. With the annual cost to the wider economy of lost working hours from caring estimated at approximately £5.3 billion (House of Lords Committee on Public Service and Demographic Change 2013: annex 15), more people being able to combine work with care would also improve the tax base.

Similarly, greater flexibility would be given by introducing a ‘care leave’ policy. In Germany, a new *Familienpflegezeit* (family caring time) for employees was introduced in January 2012. This allows six months’ unpaid long-term care leave, followed by up to two years of reduced working hours, to a minimum of 15 hours a week. Employees are eligible either through a collective agreement or individual contract and are paid a lower income (although the reduction in income is less than the reduction in hours). When they return to full-time work, employees continue to receive reduced earnings to pay back the difference (Ben-Galim and Silim 2013).

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20 An additional 500,000, mostly those over pension age, have an ‘underlying entitlement’ to carer’s allowance, meaning that they do not receive the allowance, because they already receive income replacement benefits, but might be eligible for a carer premium/addition payable with means-tested benefits.

Unless options such as these are given serious consideration, families and carers will come under increasingly intolerable strain, employers will continue to lose valuable staff, and the benefits bill will go up while the tax base narrows. Further assessment should be done of the costs and benefits of these different options to determine the best approach.

**Workers caring for those with high physical and mental support needs should be given enhanced employment protection rights to allow them to combine work with care, rather than taking up a welfare payment. This could be through a right to adjusted hours or an adjusted role, with protection of their employment contract, for those with an underlying entitlement to carer's allowance, or through various options that have been put forward for family caring leave. Further assessment should be done of the costs and benefits of these approaches.**

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