

Real lives

Listening to the voices of
people who use social care

September 2016



Preface from the Richmond Group of Charities

The Richmond Group of Charities is a collaboration of 12 of the largest health and care charities in the UK. We come together as a collective voice to better influence health and social care policy and practice, with the aim of improving care and support for the 15 million people living with long-term conditions whom we represent.



Our goal is to ensure that everyone with a health condition has access to the right care and support to help them live as well as possible, for as long as possible. By bringing together our insight, policy and practice we work with the health and care system to encourage and facilitate the kind of transformational change that delivers better outcomes, more person-centred care and more effective use of our resources.

Millions of individuals of all ages interact with the social care system in their daily lives, whether as users of services provided by the state, as funders of services that they use, or as providers of unpaid care for their loved ones. The functioning of the system has a tangible impact on these individuals' health and wellbeing.

As leading health and care charities, we believe it is vital that the debate about social care funding is informed not only by the data, and the perspectives of the professionals working within the system, but also by the day-to-day experiences of those using the social care system.

That is why, working in collaboration with the British Red Cross and the Royal Voluntary Service, we commissioned The King's Fund and the Nuffield Trust to undertake a series of interviews with individuals with experience of using social care services.

The intention of this work was to complement, and add value to, a wider piece of research being undertaken by The King's Fund and the Nuffield Trust to examine the future sustainability of the social care system, by examining the provision of social care for older adults (people aged 65 and over).

We hope that the stories told here will serve as an important reminder that behind every statistic and every policy are real impacts on people's real lives. It is all too clear that work to place the social care system on a more stable financial footing is now more urgent than ever.

About this report

This report was written by The King's Fund and the Nuffield Trust, and commissioned by the Richmond Group of Charities in partnership with the British Red Cross and the Royal Voluntary Service.

The report is based on seven interviews, capturing the experiences of people aged 65 and over with recent experience of the social care system. Participants were identified and recruited by the partner charities according to agreed criteria, and interviews were conducted by researchers from The King's Fund and the Nuffield Trust. Where requested, participants' real names have been changed to protect their identity.

The interviews covered individuals' and carers' personal circumstances, experience of services and their opinion of whether, and how, the services they receive had changed over time. Individuals' stories are presented in this report as vignettes that try to capture the mood and content of the interviews, as far as was possible, in interviewees' own words.

These vignettes are presented alongside insights from The King's Fund and the Nuffield Trust's wider piece of work, Humphries R, Thorlby R, Holder H, Hall P, Charles A (2016) *Social Care for Older People: Home Truths* The King's Fund: London. That report is based on 65 interviews with local authorities, Clinical Commissioning Groups, NHS and social care providers, the voluntary and community sector, and local Healthwatch, as well as extensive national data analysis. The full report is available at www.kingsfund.org.uk/publications/social-care-older-people. Throughout this present report, the wider piece of research will be referred to as the *Home Truths* study.

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In partnership with:



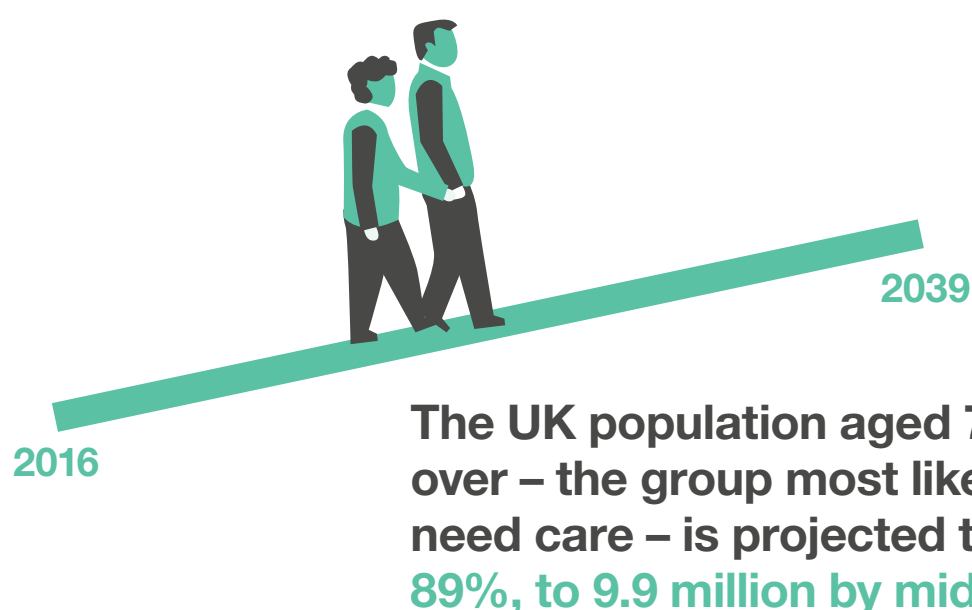
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Introduction

The social care system provides vital support to millions of adults and children. It is a complex system with care offered in a range of settings, funded with contributions both from the public purse and from private individuals, and by many different providers including private companies, voluntary sector organisations, families, between friends and from within local communities.

However, the social care system in England is becoming unsustainable. Six consecutive years of budget reductions to publicly-funded care, increasing demand, increasingly acute levels of need to be met, workforce pressures, provider failure and market exit are all converging to create the perfect storm. As summarised by the National Audit Office, *'national and local government do not know whether the care and health systems can continue to absorb these cumulative pressures, and how long they can carry on doing so'*.¹

This report focuses on the experiences of one group of people who use the care and support system – those aged 65 and over. As the proportion of older people in our society grows, an increasing number will rely on the support (paid and unpaid) of others to live independently. The UK population aged 75 and over – the group most likely to need care – is projected to rise by 89 per cent, to 9.9 million by mid-2039.² But the system is in trouble. The publicly-funded safety net is shrinking and this impacts all those who use social care, whether or not they are publicly-funded. It also has wider knock-on effects, as the viability of caring arrangements is also directly linked to use of other public services such as housing, and importantly, the NHS. Inadequate social care provision can lead to increased use of primary care or hospital services, at a time when NHS budgets are also under pressure (even though NHS funding has been protected compared to local authorities).





At the same time that local authorities are dealing with funding and demographic pressures, they are also dealing with implementation of the Care Act 2014, which has brought significant changes to the system

This report complements the other work that The King's Fund and the Nuffield Trust have carried out to explore these issues in relation to older adults, namely the study *Social Care for Older People: Home Truths*.³ In the present report, the experiences of older people who use care are drawn upon to understand and exemplify the human cost of changes happening within the system. While the cumulative effect of pressure on the social care system is felt strongly by the organisations involved in commissioning and delivering services, it also affects the lives of people who use services, their families and communities. This research reveals the story of seven individuals with experience of using care and support services. Through their stories we illustrate some key features of the social care system, both positive and negative, and its relationship with other public services.

We are currently in a critical period for the social care system. At the same time that local authorities are dealing with funding and demographic pressures, they are also dealing with implementation of the Care Act 2014, which has brought significant changes to the system.⁴ The Act passed into law on 15 May 2014, and local authorities became subject to its duties in April 2015. The Act was the most significant reform of social care in more than 60 years, consolidating a complicated legal framework dating from the beginning of the welfare state, and building in significant new rights and responsibilities for people who need care

and support and their carers. It was introduced through a relatively cooperative political process, and broadly reflects the aspirations of the sector. But there are real and growing doubts about the feasibility of its ambition within the existing financial settlement.

Funding cuts have also had a serious impact on private and voluntary sector providers of social care. Low levels of pay and the demands of the role mean that there are increasing difficulties in recruiting and retaining staff, particularly qualified nurses.⁵ This raises concerns about how the quality of care can be sustained, at a time when all care settings are dealing with individuals with more acute needs.

The Chancellor's announcement, in the 2015 Spending Review and Autumn Statement, of a new national living wage has been welcomed, but will add at least £2bn to workforce costs by 2020.⁶ This will also put additional pressure on local authority budgets. This has triggered fresh concerns about the financial viability of many care providers after several years in which fees from local authorities have been frozen. Some of the largest providers of home care have already withdrawn from the market.

The net effect of these pressures is now clear: social care in its current form is not sustainable and requires both immediate investment and long-term reform to prevent crisis and meet the aspirations of the Care Act 2014.

Themes and stories

Millions of older people receive social care support. The quality and sufficiency of these services has been described as a key barometer of a good society.⁷ However, evidence from national, local and user-level data paints an unequivocal picture of a sector that is struggling to keep pace with demand and to continue to protect those most in need.

The *Social Care for Older People: Home Truths* study undertaken by The King's Fund and the Nuffield Trust has brought out a number of key themes which have been powerfully exemplified in the lives of the individuals we interviewed. These themes are: access to high-quality care, the connection between national policies and what can be achieved locally, the sustainability of the provider market, support for unpaid carers and the ongoing challenge of integrating health and social care.

Below we introduce these themes and tell the stories of the individuals we met who have lived experience. More detailed discussion of these themes can be found in the *Home Truths* report, available at www.kingsfund.org.uk/publications/social-care-older-people.

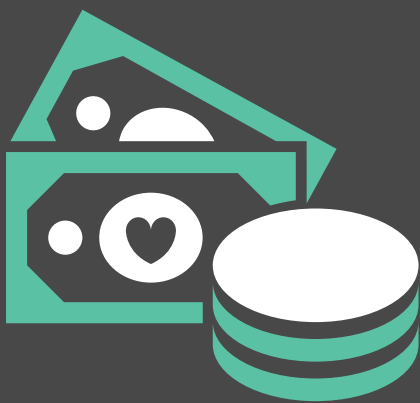
Theme 1

Access to high-quality care

Since the Government's decision to reduce overall public spending in 2010, gross spending on social care for older people by local authorities has fallen by nine per cent in real terms, with income from user charges and transfers from the NHS preventing an even greater decline (2009/10 to 2014/15).⁸

The result is that around a quarter of a million fewer older adults received publicly-funded care in 2014/15 in comparison to 2009/10, with wide variations across the country in terms of the proportion of the older population who receive support and the types of support on offer.⁹

Estimates suggest that the numbers of people going unsupported are significant and growing.¹⁰ The introduction of the social care precept means that local authorities will be able to raise up to two per cent in council tax specifically for social care services. In 2016/17 this will be worth around £381 million.



Gross spend on social care for older people by local authorities has fallen by 9%

The four local authorities involved in the The King's Fund and the Nuffield Trust's *Home Truths* research felt that they had managed to protect services for the most vulnerable people by targeting their scarce resources at those most in need.¹¹

However, while local authority interviewees felt that there was not, as one defined it, '*an unmet eligible need*', there seemed to be no consistent exploration of this issue. Local authorities explained that they relied on soft data from Healthwatch groups or the voluntary sector, or assumed that people would be picked up in other parts of the sector such as in general practice or A&E. Other local stakeholders were less optimistic. One social care provider said that '*every now and then*' they were called to do an assessment and found someone in an '*appalling*' condition. All four Healthwatch interviewees across the case study sites reported that there was an absence of hard data about what was happening to people and that, despite their efforts to reach out to social care users, it remained difficult to get feedback. This concurs with the Association of Directors of Adult Social Services (ADASS) budget survey of local authority Directors of Adult Social Services which reports that only 34 per cent of councils have arrangements in place to monitor unmet need.¹²

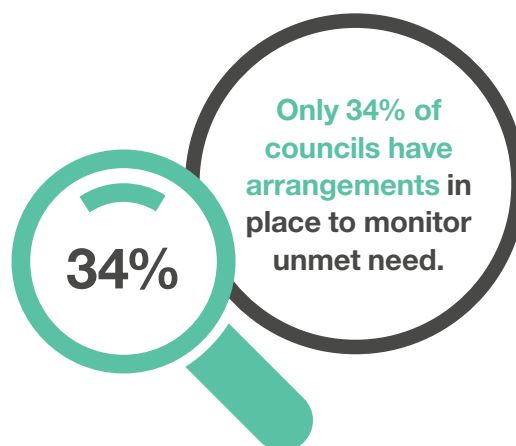
Participants in the *Home Truths* study also reported concerns about those who were already in receipt of care. Some social care providers suggested that reductions in their budgets were beginning to have an impact on the quality of care they were able to offer. Examples were given of providers making savings by not investing in new furniture, or requiring staff to buy their own gloves or aprons. Others were sceptical that high-quality care could be provided on the fees paid by local authorities, and were particularly concerned that budgets were not sufficient to recruit and train a suitable workforce.

National data gives a sense of users' experience. For example, complaints to the Local Government Ombudsman about social care have increased by 18 per cent since 2013¹³ and Care Quality Commission (CQC) inspections rated around one-third of care home providers as requiring improvement or inadequate.¹⁴ However, user surveys of those receiving publicly-funded care still report consistently high levels of satisfaction.¹⁵

As will be described later in this report, Susan's husband Bruce was mistreated during a short stay in a local care home and this resulted in a complaint to the CQC. Ann, Fred*, Robert* and Joyce all talk about their reliance on their family, local community or voluntary sector services to provide them with the additional support they need. Pat describes the quality of her care workers as '*changeable*' and Alison talks about her experiences as '*a bit touch and go*'. For carers, the situation was also variable and nearly all described inadequacies in support for their wellbeing.

The Care Act 2014 places explicit duties on local authorities to consider unmet need and access to the market for all users. The King's Fund and the Nuffield Trust *Home Truths* study with local stakeholders suggests that this is yet to be realised. While the reductions in numbers receiving care may be in some small part due to the promotion of independence and the encouragement of people to find support from within families, communities and the voluntary and community sector, the scale of the increase in numbers of older people with multiple health conditions and more acute levels of need still suggests that there should be more people receiving care, not less.

The impact of reduced budgets also appears to risk some providers' ability to provide high quality care. A retracting public sector offer means that monitoring access to high-quality care is of vital importance, as is the provision of support for carers and the role of organisations who can identify and signpost carers to this support, where it exists.



* These participants' names and some elements of their stories have been changed to protect their identities.



Susan and Bruce live in West London. Susan worked for many years for Ealing Council and is now on the board of Trustees at Dementia Concern. In 2001, Susan's husband Bruce had a stroke. Two years later he was diagnosed with Parkinson's disease. In 2011, he was diagnosed with dementia with Lewy bodies and told he'd have six years to live.

The struggle to find quality care: Susan's story

Susan's story shows the significant strains placed on carers, how devastating it can be when statutory services fail to provide adequate respite care and how the impact of reductions in spending have made it difficult to access and retain good care in the home.

Bruce's dementia diagnosis was 'devastating' for Susan and Bruce. Initially, they were put in contact with a few local charities that run activities for people living with dementia and their families. For a number of years, contact with the voluntary sector meant Susan didn't seek support from statutory services. But when her mother died and Susan needed to go away to deal with the estate, Susan and Bruce had to seek support from the council.

Experiences of poor care

While Susan travelled to the coast to sell her mother's home, the local authority found a place in a local care home and Bruce was admitted for a week. Susan was relieved as she felt reassured that Bruce would be safe while she was away. But the reality of his stay made her determined to keep him at home at all costs.

"My friend and her husband went with me to pick him up, and he was unrecognisable. He hadn't been shaved, he couldn't walk, and his eyes were crusted, because he suffers with blepharitis. All his clothes were missing, it was awful, absolutely awful, and I couldn't believe it. I cried, cried, for weeks afterwards. He'd been abused really, neglected. I vowed that I'd never put him in again."

Susan took the matter up with the CQC and the local authority. After some time, the matter was dealt with. Bruce was then assessed as eligible for a home-based package, but unfortunately the experience of home care was also poor.

"They didn't know what they were doing. It seemed like they'd never cared before. They turned up at five o'clock in the afternoon to put my husband to bed. Or they turned up at ten once I'd already helped him to bed. Absolutely awful. I hated them."

Fighting for better

After a great deal of chasing, Susan eventually managed to get the council to agree to use an agency recommended by other carers whom she had met through the local voluntary sector. The new agency made all the difference.

"They came in and they were brilliant. The assessor did an assessment of Bruce. Very professional. I fought to get them. We've gone from strength to strength since then."

Susan's fight to get the best home care was aided by the efforts of one particular social worker who advocated for her and Bruce. Her positive attitude helped Susan to trust her, and she has been helpful when Susan needed advice. The social worker acted as her single point of contact and went, in Susan's words, 'beyond the call of duty'.



They didn't know what they were doing. It seemed like they'd never cared before.



“

The first day he came home
I had to help out because
he really did need two.



EFFORTS TO REDUCE DELAYED TRANSFERS OF CARE BY BETTER INTEGRATING HEALTH AND CARE SYSTEMS ARE DISCUSSED UNDER THEME 6 – PAGE 42.

Set back in hospital – discharge

Unfortunately when Bruce's care needs escalated following an admission to hospital for problems with a trapped nerve in his spine, there were problems arranging a new package, and Bruce's discharge was delayed. A lack of communication between the local authority, the existing agency and new agencies who could deliver the double-handed (two care workers) visits Bruce now needed meant he was stuck in hospital beyond the point at which his medical issues had been stabilised. Susan explained:

“Nobody was speaking to anyone else, social workers weren't speaking to the care agency, and neither of them were speaking to me. They blamed each other.”

At Susan's request, an occupational therapist reassessed Bruce and said he could probably cope with a single care worker visiting him, so he was able to be discharged into the care of the existing care agency.

However in reality Bruce's support continues to require two pairs of hands, and Susan has had to step in to provide the care for which Bruce was initially deemed eligible. She feels that if she had not done so he would have remained stuck in hospital.

“The first day he came home I had to help out because he really did need two people. But if I didn't do that, I'd have never got him out of there.”

Carers' support

At this point Susan really needed support to enable her to keep caring for Bruce. She said:

“I was losing my hair, I had to go to the hospital. I was just binge eating, put on too much weight.”

She put this down to the stresses of caring for Bruce. She was pleased to find out that the council would soon offer a more comprehensive assessment for carers, under the Care Act 2014. Although she had to wait from April when the changes were implemented until November 2015 to get her assessment, she was

eventually awarded seven hours a week respite as a carer. She has been able to get away from the home more and go on holiday with her son.

This support has been invaluable to Susan. She speaks highly of a number of the professionals she's been in touch with at the council and in the voluntary sector. But she is also very critical of the imbalance of power carers face when confronted with complicated systems of eligibility and assessment. For Susan, the worst part of dealing with the council is being made to *‘feel small’* when confronted with the complex and fragmented care system.

“You go in there, and you've got no idea about anything, about care. It's like going in on the first day at school. You try to find out as much beforehand on the internet, but, some of these people are horrible, you know, they really just don't care.”



Nobody was speaking to anyone else, social workers weren't speaking to the care agency, and neither of them were speaking to me.

Impact of cuts

Susan thinks part of the reason some people at the local authority don't seem to care is because they are stretched by budget reductions.

“The staff are so cut, they're just running round ragged.”

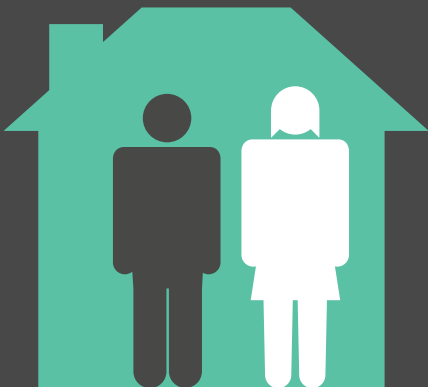
Susan's story reflects the determination of those who work to get the best deal for their loved ones. She has been failed by the care system, but the diligence and care of some professionals has ultimately made all the difference for her. While the Care Act 2014 has had an impact on her life, she had to wait too long for it to take effect, and every improvement has come at a cost for Susan's own wellbeing.

Theme 2

Personalisation, asset-based approaches and care in the community

The Care Act 2014 carried out a consolidation of a patchwork of legislation and best practice that had developed over the years. Two key elements of practice enshrined in the Act were the promotion of a preventative and asset-based approach to statutory assessment, and the concept of ‘personalisation’, which was inspired by the Disabled People’s Movement for Independent Living.

All four local authorities involved in The King’s Fund and the Nuffield Trust’s *Home Truths* research framed their approach to reducing budgets in the language or rhetoric used in this latest legislation. They described a process of redefining publicly-funded social care to move from a paternalistic, *‘gift-giving culture’* to one that was based on *‘a new vision’*, an *‘asset-based approach’* or on *‘promoting independence’*. Building local support networks, increasing family support and encouraging the use of personal budgets were all seen as ways of achieving this, and were also seen as potential solutions to the lack of capacity in social care.



A process of redefining publicly-funded social care to move from a paternalistic, *‘gift-giving culture’* to one that was based on *‘a new vision’*, an *‘asset-based approach’* or on *‘promoting independence’*

However, while these approaches were now seen as *'accepted wisdom'* among local authorities, some expressed concern that the public had yet to be brought along with them, and that these approaches required a societal culture shift that would be difficult to achieve. Clearly there are risks to implementing such approaches – which have long been called for by service users in the disability movement and beyond – in the context of cuts: rather than being seen as empowering, they could be seen as (and indeed may even become) a way of shifting responsibility away from local authorities.

The Care Act's framing of social care provision as a means of enabling individuals' autonomy, has reinforced the long-standing policy shift towards providing care in people's own homes wherever possible. However, the increasingly acute needs of those using services, cuts to district nursing, demand pressures on general practice and reductions in community-based social care all point to a potential disconnect between the policy aspiration and what was deliverable on the ground. As one social care provider suggested *'There's people with very, very, very heavy need... some of them suffer terribly from loneliness.'*¹⁶

With regard to prevention, for example, recent research suggests that despite advances made by local authorities in response to the Care Act 2014, there is still wide variation in how local authorities understand the term *'prevention'* and few have yet translated plans into enhanced provision.¹⁷

In conversation with our interviewees, it was clear that while the adoption of these narratives could have a significant positive impact on people's wellbeing, this will only be realised if initiatives are implemented in full and in the spirit intended and not just within the letter of the legislation.

It is clear that, for Alison and Sue, personal budgets have been liberating, but have also placed large demands on them. Fred's case demonstrates why the mechanism of a personal budget is of limited value without access to a diverse market: despite being awarded a direct payment, he remained unable to find appropriate respite care. And in Ann's case, the council's inflexibility has meant she has paid out of her own pocket to get the care she needs.

Both Ann and Fred describe the crucial role that local support networks and voluntary sector services have played in making it possible for their loved ones to live at home – so in this sense their stories exemplify an approach that policy makers want to encourage. But both have found the support available from the statutory system has not been well-tailored to complement this. Joyce's story also reinforces the significance of these community networks but raises the question: how realistic is it for policy makers to seek to replicate local networks that, in Joyce's case, are the product of living in the same area her whole life and being a carer for 35 years?

For Robert, far from offering him a more personalised experience, the crude application of a *'reablement'* approach¹⁸ has been disempowering, making him feel small. Clearly reablement approaches are not intended to be about stubbornly insisting that *'you can do it'*, but instead should foster collaborative effort to rebuild confidence and maximise quality of life. Unfortunately the reality of Robert's experience has fallen short of the policy intent.

In general, it therefore seems that despite widespread adoption of the policy narratives promoted in the Care Act 2014 in response to budget reductions, some local authorities are still being far too inflexible and there is still a tendency to attempt to *'impose'* traditional care packages on families who would benefit from a more individual approach.



Ann and Cyril live together in Oxfordshire. They have been married for 54 years. Ann provides care for Cyril who is living with dementia. They live next door to their daughter and her family. They have close ties to their community and to their church. Ann is a former district councillor who cares for her mother and previously cared for her aunt as well. Despite being offered a package of support from the local authority, Ann and Cyril have been frustrated by the lack of flexibility in the care system. They have found it difficult to make the social care system complement the support that is already available to them from friends and family.

Not personalised enough: Ann's story

Ann and Cyril's story highlights the difficulty people face in trying to access support on their own terms when they don't want to access a traditional (care home or home care) package.

After Ann and Cyril retired, Cyril began having memory problems and was eventually given a dementia diagnosis through a local memory clinic. The diagnosis was a start, but Ann felt there was little follow-up support, and instead they had to make arrangements via their GP. Following diagnosis Cyril was assessed by the local authority social care department, which found he was eligible for a personal budget of £79 per week. Ann and Cyril talked about how best to find support. They considered taking a direct payment, but ultimately decided that employing their own support staff seemed like too much of an administrative burden:

"They didn't explain I would have to employ people, pay a stamp for them and start a pension for them. That all came out afterwards, and I said, 'I can't do that. I'm just not physically fit enough and I don't want to do it'."

MEMORY CLINICS ARE AN NHS PROVISION OFFERING MULTIDISCIPLINARY DIAGNOSIS AND POST-DIAGNOSTIC SUPPORT FOR PEOPLE EXPERIENCING MEMORY PROBLEMS AND THEIR FAMILIES.

Only five weeks later she was told that she would have to pay back all but £2.50 of the payment allocated anyway.

Ann felt that the assessment of Cyril's needs did not take account of the support he already had, but instead just looked at his problems. She spoke of how she'd have liked to use the money to which Cyril was entitled to provide informal recognition of the support of friends and neighbours, perhaps through giving small gifts, rather than by making formal employment arrangements, which would only add further stress to the family situation.

"The other lady would come in, she'd have a coffee with Cyril, then she'd either stay or have a sandwich with him here, or she'd take him out somewhere. But she's a friend, we take her to church, he doesn't look on her as a carer."

They wanted to do the same with their grandson who was already providing significant support to them both.

"My grandson will sleep overnight. He's 19, he doesn't want paying, but I want to show appreciation for his time. He's given up going out with his friends."

The relationships that make up Cyril's care aren't traditional roles of 'carer' and 'cared for'. They are family relationships and friendships. But Ann found the council unwilling to support her in a way which would help her in maintaining these relationships.

"We are lucky, we own our own property. We have a lovely daughter next door...she's a teacher, she then feeds my husband. When he falls over, we can rely on one of the boys to help out. They love him dearly and they are fantastic with him. We are so lucky. But they can't always be there."

As a result Ann and Cyril have not taken up the package offered to them and instead Ann and her family have relied on arranging and paying for care themselves. Ann says she doesn't mind contributing, but if the local council were more flexible, her situation could be a lot more stable and secure.

A particular worry for Ann is what will happen if her health gets worse, and a recent admission to hospital for an operation has compounded her fears about this situation.



IT IS DIFFICULT TO TELL IF DECREASES IN SOCIAL CARE SPENDING ARE TO BLAME FOR ANN'S SITUATION, BUT HER STORY REFLECTS A NATIONAL PICTURE. FIGURES ON DELAYED DISCHARGES ARE COLLECTED, AND IN OFFICIAL FIGURES THEY CAN BE ATTRIBUTED TO THE NHS, SOCIAL CARE OR 'BOTH'. THE NUMBER OF DAYS IN WHICH DISCHARGES HAVE BEEN DELAYED DUE TO SOCIAL CARE REASONS HAS RISEN SHARPLY OVER THE LAST 12 MONTHS.¹⁹ THIS IS DISCUSSED MORE UNDER THEME 6 – PAGE 42.

Difficulty arranging care from hospital

When Ann was admitted to hospital for an ankle injury she needed to arrange care for Cyril until she could be discharged. But she found the council were inflexible in their offer.

“When I was in hospital, I wrote to the local authority and said, ‘look, can I have £300 to give to the lady who’s coming in during the day to look after Cyril, and can I have £100 for my grandson?’ They said ‘no’; I said, ‘okay then, you send somebody in. It’ll cost you £165 a night, for someone to sit in my sitting room and do nothing.’ They moan about lack of money but I mean...it’d be making the most of the support we have, making sure they can keep helping us.”

Ann managed to make arrangements, but then found her own discharge was delayed because no care was available to support her to get home, instead the hospital suggested she should go into a care home – but this would have left Cyril without support. Ann was frustrated and feels that the recent reductions in social care spending really have had an impact on her, and her husband’s, care.

“I didn’t want to be in the hospital, I wanted to be home, but they said I couldn’t. I thought I was entitled to care, but they said there was a shortage. You just feel like a package. They’ve done the operation, they now want to get you out. I felt like there was no point in doing the operation if you can’t get the aftercare right.”



I thought I was entitled to care, but they said there was a shortage.

Ups and Downs

Eventually Ann was discharged and, with the help of her family, was able to resume some of her caring responsibilities. However she remains on crutches and is coping with just a little bit of help from a cleaner. The whole process has taken its toll.

THE STRAIN FELT BY THOSE CARING FOR PEOPLE LIVING WITH DEMENTIA IS WELL DOCUMENTED.²⁰

“I became very depressed. Very, very depressed, very weepy. And that’s not my nature. That’s not my nature. I just felt nobody cared.”

But Ann is determined to make her situation work. She and her family want to continue to live their lives on their own terms.

“I’m a fighter, I’m really trying to make the situation better.”

Ann is supported by a strong family caring for one another. However, the arrangements can feel precarious. More flexible support from the local authority could potentially shore up this arrangement for the longer term, by helping Ann to continue in her caring role and securing the other elements of Cyril’s ‘natural’ support in the wider family and community. In policy terms this would be called asset-based care planning. Ann would just call it common sense.

“

I'm a fighter, I'm really trying to make the situation better.





Joyce is in her seventies and has been her younger brother's carer for the last 35 years. Her brother has learning difficulties and needs support with washing and cooking. In addition to the support provided by Joyce, her brother regularly attends day centres and respite care, which they pay for themselves. They live in the north east of England in a city with high levels of deprivation. They have lived in the same house for the past 50 years, which has allowed Joyce to build up strong local networks.

Continuity and stability – a community of care: Joyce's story

Living in the same area her whole life has meant that Joyce has built up a close network of fellow carers who support one another. She has also benefited from having continuity in her brother's social workers. Successive governments have emphasised the need for our social care system to work with and build upon individuals' own family and community networks to enable them to more effectively support themselves.

Joyce's story exemplifies the benefits of these networks, but also raises questions about how realistic the government's ambitions to spread these networks more widely really are, especially among those less able to build up local connections.

Joyce has been her brother's primary carer since 1981 when their mum died. For Joyce, becoming a carer wasn't a difficult decision:

"When my mum died they all said 'put him in care', and I thought it'd break my mother's heart... I did it for my own satisfaction because I didn't want to be on my own... We've lived together all our lives."

Building local support networks

Family responsibility is something that Joyce feels acutely.

"I don't call myself a carer...it's just my duty. It's how I was brought up." She's also satisfied making financial contributions to her brother's care when necessary *"I contribute to most things... Yeah, if you can afford it."*

Over the years, Joyce has coped with the demands of caring by building up a strong support network in her local community, having lived in the same area for her



THE SUPPORT GIVEN TO UNPAID CARERS IS DISCUSSED FURTHER UNDER THEME 5 – PAGE 36.

whole life. She describes other local carers as a *"group of friends... if we've got a problem we ring each other, try and help each other"*. She adds, *"I think friends help you more than anything"*. Many of these friends she met through volunteering at the centres and clubs her brother attends. He goes to a day centre from eight to three every day and goes into respite four days a month, *"it gives me that bit of a break."*



I don't call myself a carer...it's just my duty.



“

I don't know how I'd
have survived... I think
you need support.



THE IMPORTANCE OF CONTINUITY
IN SOCIAL CARE PROVISION IS
DISCUSSED UNDER THEME 3 –
PAGE 24.

She is full of praise for his social workers and how their continuity has meant that they have developed close relationships.

“His social worker is brilliant... I had one for about 20 years and she's become a friend. And then I've got [another social worker], we've had him about 20 years I should think... [My brother] can sit and talk to them like a friend.”

She also shared stories about the time she broke her arm and a local charity helped her during her recovery. After having the operation, the doctor was concerned about her discharge.

“He got in touch with the Red Cross, and they came and sat with me... she said ‘I'll go and get you something to eat’... they brought me home. She got a meal ready for me because I couldn't do anything. And then they came every day until I went into hospital. Then they came and took me in hospital and she sat with me until they came to see me.”



His social worker is brilliant... I had one for about 20 years and she's become a friend.

Participation and peer support

Volunteering, food shopping for neighbours, participating in local stakeholder meetings – Joyce is well connected to others in her community who are in a similar situation. She describes her actions as gathering knowledge that helps her support her brother and other carers.

“I've got a lot of support from the council because I go to a lot of meetings. I'm on a partnership board for learning disabilities... And I'm in a nurses' group, I go there once a month... I go to the carers' centre in Hull. [...] Because being on the partnership board for learning disabilities I find out things that they don't know you see, and I tell them.”

Her involvement in local council activities has given her a voice.

“When it originally started we used to be at the Guild Hall, and it was on such a big table, people at the end, you couldn't hear them. And you felt as if they're not carers, they're speaking down to you. But they have got better as the years have gone on... I mean if I've had any complaints I tell them. I never used to open my mouth. I thought well, nobody's going to stick up for me so you need to stick up for yourself.”

Successive governments have emphasised the need for our social care system to better support and enable communities to support one another, by building strong networks between individuals. Joyce's story exemplifies the real benefits of just such a network. However, speaking from her own experience, Joyce recognises the limitations of these approaches in so far as you cannot force people to seek out support or to build relationships.

Thinking back on her experiences, she reflected:

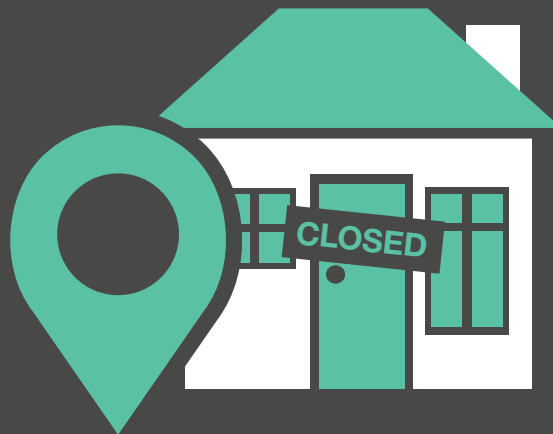
“I don't know how I'd have survived... I think you need support... [but] some don't want it, do they, and it's silly really. Because [neighbour], she's in a care home now, and she wouldn't let the nurses over her doorstep. I mean my house is a mess, but...”

Theme 3

The sustainability of the social care provider market

Until last year, a common way in which local authorities tackled reduced budgets was to freeze or reduce their fees to social care providers.²¹ Despite recent increases to fees, the levels of funding available leave care homes at less than a 'standstill' position²² and, in the last year, 77 areas have reported seeing at least one care home provider cease trading.²³

It is a similar picture in the home care market. For example, the minimum sustainable price for home care is estimated at £16.70 per hour, with one survey showing that last year just 14 per cent of local authorities paid the minimum price.²⁴ Two of the largest national home care providers have already left the publicly-funded market and two others have posted operating losses in the last year.²⁵ In the last 16 months, home care providers have handed back contracts in 59 local authority areas and at least one home care provider has ceased trading in 48 areas.²⁶



77 areas have reported seeing at least one care home provider cease trading

The funding pressures affecting publicly-funded care have had two important consequences. Firstly, providers have turned to self-funders to fill the widening gap created by the low rates available from local authorities, with one estimate suggesting that self-funder rates have increased by 40 per cent over the past five years.²⁷

In some areas, self-funders are cross-subsidising local authority residents and receiving generally the same care and accommodation.²⁸ As one provider who participated in The King's Fund and the Nuffield Trust's *Home Truths* study reported, "If... all I'd been able to admit was people on local authority we'd be bankrupt". Others reported trying to tap into other funding sources, such as clinical commissioning group (CCG) funding available to help solve the pressures facing acute trusts. However, this was also felt to amplify the capacity pressures already faced by local authorities.

Secondly, in areas with higher proportions of self-funders, providers are focusing on developing services aimed at this market. The result is an emerging two-tier market in which choice is increasingly restricted to those who can pay. As a social care provider commented, *"Most of our residents are publicly-funded... so you know, you can't expect all the bells and whistles. We have to operate very economically here."*²⁹

Choice is increasingly restricted to those who can pay.

The introduction of the National Living Wage – increasing the minimum wage of over-25s to £9.15 per hour by 2020 – will intensify pressures on providers. The total increase in payroll costs to frontline staff is estimated at £2.3bn by 2020, plus £1.7bn for above-inflation increases in the National Living Wage.³⁰ While the increase in salaries has been generally welcomed by providers, it does not solve the recruitment and retention problems facing the sector.

Under the Care Act 2014, local authorities have a requirement to ensure market oversight and that preparations are made in the event of a provider failure.³¹ Failing to do this could potentially have very serious consequences not just for local authorities, but for significant numbers of often vulnerable individuals. However effective oversight is a challenge given the sheer number of providers and, in some affluent areas in particular, their reducing dependence on local authority contracts.

It is clear from our interviews that it is not just full provider failures that impact individuals who use services, but also changes in ownership and management of care agencies and chains. The interviews show how the volatility of local and national markets for care – and the resulting processes of buy-outs, market shaping, market exit and brokerage – can have direct and significant impact on people's wellbeing. For example, Robert has had significant experience of changes in management and rapid staff turnover affecting his ability to communicate with the agencies supporting him, and Susan spoke of the poor quality of the council's go-to care provider and her struggle to get access to home care for just £15 per hour.



The introduction of the National Living Wage – increasing the minimum wage of over-25s to £9.15 per hour by 2020 – will intensify pressures on providers.



Robert is a retired engineer in his late 60s. In 2003, Robert had a serious neurological episode and his life changed forever. Since then he has been using social care services to support him to live independently in his own home.

Unstable care: Robert's story

Robert's experience of social care services has been frustrating and at times disempowering. He has been significantly affected by changes in the local home care market that have had a real impact on his experience of services.

Robert came into contact with social care services after his first 'episode': a neurological trauma that led to him spending almost 30 weeks in hospital. He stayed for a few days in his local hospital, before being moved to a hospital in the city with a specialist neurological unit. Robert was struggling with his speech, with eating and with his mobility, but it took some time to reach a diagnosis. He spent 25 weeks in the specialist unit, waiting for a clear diagnosis and for the council to arrange care. He was eventually moved to an intermediate care facility (which has since closed) and then to his new, more accessible flat. He had to retire from work.



I had to rely entirely on the voluntary sector, yes, they were helpful, but they go ahead and do things without talking to you.

Support and frustration from care, health and housing

Robert relied on advice and help from a local voluntary sector organisation to help him secure his new housing. Although grateful for their help, Robert felt unable to do things on his own terms:

"I had to rely entirely on the voluntary sector, yes, they were helpful, but they go ahead and do things without talking to you... I know they're doing it in the best will and your best interests, but it would be nice just to be asked..."

Robert was discharged in 2004, and the council commissioned a small home care package to be delivered by a local agency, to support him to live independently. But, again, he felt like he wasn't being listened to. He was allocated one visit a day, with an additional weekly visit to help him bathe. He described his experience of assessment and care planning as '*one plan fits all*'. However, over the years he was able to develop a wider support network including, in particular, his GP and the local church:

"I'm very fortunate, across the way opposite here is a very good medical centre and my church. They've both offered me support and understood that I couldn't do certain things, my GP was a former specialist in neurology. They've helped me when I had to convince the council that my condition was serious."



ROBERT'S ACCOUNT FITS IN WITH THE ADOPTION OF A 'REABLEMENT' APPROACH IN SOCIAL CARE DEPARTMENTS OVER THE PAST FIVE YEARS. OLDER AND DISABLED PEOPLE WHO HAVE EXPERIENCED A DETERIORATION IN THEIR HEALTH OR AN INCREASE IN THEIR SUPPORT NEEDS, ARE GIVEN AN INTENSE UP-FRONT PACKAGE (OFTEN SIX WEEKS) OF SUPPORT DESIGNED TO MAXIMISE THEIR ABILITIES BEFORE THEY ARE GIVEN A LONGER-TERM PACKAGE.

THERE IS A GROWING EVIDENCE BASE THAT SUGGESTS REABLEMENT IS COST-EFFECTIVE AND WORKS FOR MANY PEOPLE. HOWEVER, THESE INTERVENTIONS SHOULD FOCUS ON BOOSTING CONFIDENCE AND INDEPENDENCE, NOT MAKING PEOPLE FEEL INADEQUATE. THIS ISSUE IS DISCUSSED IN MORE DETAIL UNDER THEME 2 – PAGE 14.

Feeling small

After suffering another neurological episode, Robert's care package was **'beefed up'** to four visits a day, as Robert had suffered further deterioration in his mobility: he struggled with a number of daily living tasks including getting out of bed in the morning, washing and preparing meals.

Although professionals did arrange access to further support, Robert described how care staff insisted that he should do more for himself, and made him feel **'small'** because he couldn't carry out everyday tasks himself.

"I find them [council staff] extremely difficult, they won't accept that I can't do certain things. Now, I'd love to be able to make you a cup of coffee, but if you want one, I'm afraid I'll have to ask you, there... it's all out there."



I felt very badly handicapped by having different care workers nearly every day.

Impact of a shifting home care market

Over the years, Robert's care has been provided by a number of different home care agencies. After being discharged in 2008, he was allocated a care agency who he describes as having a **'serious shortfall in professionalism'**. Despite there being some care workers who showed respect, kindness and patience during visits, most were rushed and focused on the tasks, not on Robert as an individual.

Robert has experienced a **'revolving door'** of different care workers:

"It was difficult trying to get to know a lot of people as well in a very short space of time. I'm still active up here [points at head], but I'm at their mercy. I have to use a special fork and I drink with a straw and it's got a lid lip on so I can open it, but I, yeah, I felt very badly handicapped by having different care workers nearly every day."

And it has not only been the individual care workers who have changed frequently, but also the management of the agencies:

"They changed their names four times while I was with them. The management changed every six months and that made it difficult for you to communicate with the managers if things went wrong. The field care supervisors were, well, they just couldn't care less, that was their attitude, because their jobs, I think, were on the line anyway and then all of a sudden, without any warning, they decided they wouldn't deal with disabled people. So they sent us back to the council."

When the first agency eventually dropped Robert's case, the council brokerage team found a new agency. They were good. They were on time. The care workers showed Robert some of the compassion and respect he felt had been lacking. But they didn't last long:

"And then without any warning, I got a letter saying they're pulling out. They just said that they found that it was becoming increasingly difficult to meet the requirements and that they felt it was no longer part of their portfolio."

For Robert, therefore, the impacts of shifts in funding, and policy, at the local authority level are translating into real and often unintended consequences in his individual experience.



“

And then without any warning,
I got a letter saying they're
pulling out.

Theme 4

A care workforce fit for purpose

Downward pressure on providers has had a knock-on effect on their ability to recruit and retain good quality care staff. The care sector has a vacancy rate of 4.8 per cent, compared to a rate of 2.6 per cent across all sectors.³² This rises to nine per cent for qualified nurses.³³

In the four local authority sites participating in The King's Fund and the Nuffield Trust's *Home Truths* study, providers described intense competition with retail and service industries as well as the NHS, not helped by the low rates of funding made available to them. As one social care provider stated "*it is now proving almost impossible to find the staff who are willing to work for the low pay which is made available by councils.*" One estimate suggests that the social care sector could face a gap of over one million care workers by 2037.³⁴



The care sector has a vacancy rate of 4.8%, compared to a rate of 2.6% across all sectors

Most of our interviewees had encountered poor quality care workers – with some describing staff as under-trained, and others finding staff uncaring – and many had experienced high levels of staff turnover. Susan talked about her first agency’s lack of experience. Pat and Patricia had seen care workers come and go and Robert has had a really mixed experience with care staff. Alison’s daughter Sue explained that it was very difficult to know if the carers you were hiring had the right training.

But despite worries about the quality of the social care workforce, many of the interviewees were also keen to highlight particular professionals who had made a real difference to their situation. Robert talked with enthusiasm about the care he received from one particular care worker. Susan and Joyce both praised their social workers.



One estimate suggests that the social care sector could face a gap of over 1 million care workers by 2037



Alison was 47 when she was diagnosed with multiple sclerosis (MS) and has been using social care support for the past twelve years. She is now in her seventies. Alison lives at home but has a large package of care and uses an electric wheelchair. Alison's care is predominately paid for by the council through a direct payment that is managed by her daughters on Alison's behalf, but she also pays some top-ups.

No option but to take control: Alison's story

Accessing direct payments has dramatically improved the quality of Alison's care and has given her greater control over who provides her care and when. However, her daughter Sue describes the complications of managing one. As employers of care workers, at times they feel ill-prepared and unsupported to deal with the challenges that present themselves.



Gaining control

Alison has always received support for the cost of her care from her local authority. When Alison first started receiving care, she did not have personal budget and was dependent on agencies selected by the local authority. She quickly asked to change agencies after a 'scary' and 'dangerous' realisation that the same front door password was being used for all users in the street, meaning that any carer could go into any house at any time. This left Alison and her family feeling extremely insecure.

The introduction of direct payments gave Alison and her family the freedom and control they were looking for. Alison has a bank account that was set up especially for her direct payment receipt and payments to her carers. It is managed by Alison's daughters Sue and Jackie, working alongside a local accountancy firm, arranged by the council. As Sue explained:

"They [the carers] fill in a timesheet so I have to send the timesheet to him [the accountant], then he does the wages and then I pay them out of the bank account direct... So it's good because we have the same carers all the time so Mum knows who's coming to her every day; she's got a relationship with them; they know Mum."

Alison's setup is a good example of person-centred care in action: she can choose the carers she wants and when she would like them to come.



It's good because we have the same carers all the time so Mum knows who's coming to her every day.

Bureaucracy and risk

However, there have been downsides to the flexibility offered by the direct payment, as Sue, Alison's daughter, explains:

"We get all the admin to do. We're in such a big package and a big need for care, we then have to employ enough carers to cover the hours and then do a rota... I'll make sure that there's carers here to come in when Mum needs them and that they can all cover... we're not experienced employers... I'm not experienced in employment law. And there isn't a lot of backup for you."

Job interviews, staff meetings, rotas, annual leave, wage slips, pensions, submission of account information – Sue and her sister are providing the engine room to the care machine – and it is a big job.

"It would be very difficult for mum on her own... [Without us] I think she would have probably been in a home."

While Sue feels that *"you've just got to take that responsibility haven't you? You've got to do your bit"*, it clearly takes its toll – she says that the stress from her mum's situation has sometimes made her and her sister feel like they may not be able to carry on. In fact, she has recently gone part time in her job to give her more flexibility and time for her family responsibilities.

Sue also feels like she's taking risks in selecting the carers:

"A few of them, we've taken on through word-of-mouth or 'Someone's got a carer that's really good and she's looking for some...' That sort of thing. We've fallen lucky with our girls but it's a bit difficult to know whether these girls are going to be suitable for what they're doing..."

Alison sums up the care she has received as at times *'a bit touch and go'*; and in the past they've had *'unsuitable people'*.

Sue and her sister feel they receive little support in their role as carers *"I've rung the council in despair sometimes."*

Discharge troubles

While Alison's MS is relatively under control at the moment, meaning that her interactions with the NHS are minimal at present, she has faced problems as a result of poor joining up between health and social care around the discharge process.

On one recent occasion on which she was admitted to hospital, she felt that the social worker wanted to place her in a care home regardless of her desire to return home. And on another occasion, her discharge was delayed due, as far as Alison could see, to a lack of understanding of how personal budgets worked.



THE CHALLENGES FACED BY INDIVIDUALS DUE TO LACK OF INTEGRATION BETWEEN HEALTH AND CARE SYSTEMS, AND THE PROBLEMS ASSOCIATED WITH DELAYED DISCHARGES ARE DISCUSSED UNDER THEME 6 – PAGE 42.

Maintaining independence

Despite these problems, both Alison and Sue are positive about parts of Alison's care. The council has given her grants to adapt the kitchen and fit a new front door so that they are wheelchair accessible. And due to restrictions in her movement, the council recently fitted hoists to help her move around and now she has funding for two carers for each call.

Despite all of the stress, home care organised through a personal budget is still their preferred option.

"If I was in the care home, I suppose I'd have more company but I wouldn't have the independence I get now. And I can get through that door and go anywhere and they can't, can they?"



ALISON'S DIFFICULTIES AROUND THE QUALITY OF CARE EXEMPLIFY THE ISSUES DISCUSSED UNDER THEME 1 – PAGE 8.



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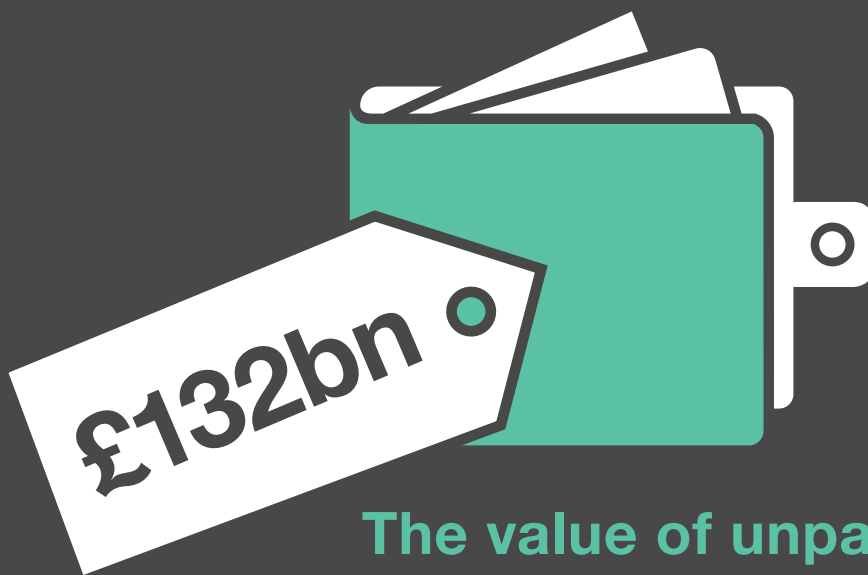
We're in such a big package and a big need for care, we then have to employ enough carers to cover the hours and then do a rota... we're not experienced employers.

Theme 5

Do unpaid carers get enough support?

According to the Family Resources Survey 2013/14, 5.1 million individuals provide unpaid care.³⁵ This includes 3.7 million adults of working age, 1.3 million older adults and 100,000 children. The value of unpaid care is estimated at £132 billion, almost equivalent to national care spending.³⁶

The Care Act 2014 offers new rights for carers but one year on, research by the Carers Trust indicated that it had made *'little or no difference'*.³⁷ Other research suggests that around one in six carers has seen a reduction in the care and support services they receive due to cost or availability.³⁸ Of those, 13 per cent said that no replacement service was offered. The latest national survey of adult carers reports lower levels of satisfaction compared to older people who receive social care, and that satisfaction levels could be declining, though the impact of differing expectations may be significant here.³⁹

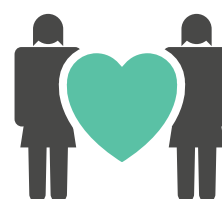


The value of unpaid care
is estimated at £132 billion

Two of the four local authorities participating in The King's Fund and the Nuffield Trust's *Home Truths* research expressed concern that their support for carers may have reduced. One authority described it as '*a more negative picture*' for carers than users and the other conceded that they had sometimes '*dropped the ball*' in relation to carer assessments.

Our interviews bring out the pivotal role of unpaid care delivered by families, friends and communities, but they also show the risks and strains associated with this form of care. Patricia's commitment to supporting Pat to stay at home, while staying in full time employment, has had implications for her own health. Susan's determination to get Bruce the best care has also taken its toll. The support Cyril receives from his wife, her family and from the community in their village is invaluable, but feels precarious. Fred needs good quality, personalised respite care, but has struggled to access it. Sue's administration of her Mum's personal budget alongside her other caring responsibilities has led her to reduce her working hours. Joyce's 35 year journey caring for her brother has been sustained thanks to the support of friends in her local community, and from the local voluntary sector.

Without the support of unpaid carers in each of these cases, the individuals who need care and support would not be able to live as well, and would cost the state more. And while many carers were keen to explain why they felt it was right that they should provide care, and that they were happy to do so, it is also clear that in many cases if they had not been willing to provide unpaid care, there would be no statutory provision available in its place. It is also clear that many carers continue to feel unsupported in their roles and, while the implementation of the Care Act 2014 has provided some carers, like Susan, with more support, others spoke about how their caring responsibilities were negatively affecting their wellbeing.



Without the support of unpaid carers in each of these cases, **the individuals who need care and support** would not be able to live as well, and would cost the state more.



Fred cares for his wife, Ruth, who is living with dementia and arthritis. Fred and Ruth met at university. They married and moved near a government facility where Fred worked his entire career. Fred retired in his mid-fifties, followed shortly by Ruth, but it soon became clear that something wasn't right with Ruth. She was beginning to forget things. Eventually she was diagnosed with mild cognitive impairment. Ruth also struggles with pain as a result of arthritis. Over time Fred has become her full-time carer.

Struggling to care: Fred's story

Fred's story highlights the problems carers face in accessing appropriate services to support them in their role. While the local authority has deemed Fred entitled to support, he has struggled to find respite care that is high quality, affordable and suited to his wife's needs. Instead, he has relied on help from the local community. More recently he has been connected with a local Shared Lives scheme, which he hopes will finally offer him a chance for real respite.

Fred describes himself as 'not a natural' carer, but explains that he moved into the role gradually as his wife's memory problems progressed.

"We started noticing that she was having some memory problems. It starts off as a sort of a bit of joke, you know, 'you never listen to me do you?' Then it starts to become an irritation, and then it starts to become a problem."

Fred and Ruth sought help at a local memory clinic, where Ruth was diagnosed with a mild cognitive impairment (MCI). The news was devastating, putting an end to plans for a retirement road trip through France. Instead, over the years, Ruth's short-term memory has become progressively worse, even while she has retained her long-term memories.

"She doesn't have much short-term memory, you know. She could be here having coffee with us, but when you go, by the time we've put these mugs in the dishwasher she will have no memory of the conversation whatsoever. But, if you want instruction in the finer points in Latin grammar, you can still have it. No problem."

A market for respite?

Over the years, Fred has had to commit more and more of his time to Ruth's care and has now become her full-time carer. Although they were given very thorough and decent medical attention, Fred feels they have not received the same from the social care system.

As self-funders (people who are not eligible for financial support with care costs), they feel that while there is a great deal of information available, there is very little formal respite support. Instead they have relied on support from within the local community.

"We live in a village, the village community is great. The village WI is fantastic, we have great friends, that girl next door rang up this morning and said, 'does Ruth want to come to the screening of the opera tonight?' All of those things are just great."

But this community support is not able to meet Fred's need for a proper stress and guilt-free break from caring, and he has struggled to get these needs recognised and met.

"It [respite care] would help me because I would be able to continue with it [caring duties]. If I can find some sort of relief which would let me into retain some sort of life of my own, then the future would not look quite so bleak for me."



“

Very, very, few care homes will provide respite care, because care homes are run like hotels, what you want is full occupancy.



UNDER THE CARE ACT 2014, LOCAL AUTHORITIES ARE REQUIRED TO 'PROMOTE THE EFFICIENT AND EFFECTIVE OPERATION OF THE MARKET FOR ADULT CARE AND SUPPORT AS A WHOLE.' THE OPERATION OF THE MARKET IS DISCUSSED UNDER THEME 3 – PAGE 24.

Looking for something different

Fred feels that the typical offer of support from local authorities (home care or care homes) won't work for his wife. Home care is both prohibitively expensive and complicated to organise. Care homes are also expensive and Fred has encountered problems in arranging short stays:

“Very, very, few care homes will provide respite care, because care homes are run like hotels, what you want is full occupancy.”

He also feels that residential care would be too institutional and intense for his wife. His involvement with local carers' groups has drawn him into discussions with the local authority regarding their wider plans for the social care system – but through this work he has encountered dissonance at the heart of the system:

“There are some very good people who are redesigning the model of respite care and they have got a really good model. But I go to another meeting where they're talking about we need to save £60 million. On the one hand, good people are doing good things, on the other hand they're never going to achieve anything.”



A lot of the carer support groups which are very helpful and valuable are actually provided by the voluntary groups.

Shared Lives?

But Fred hasn't given up on accessing good respite care. He has recently begun accessing a Shared Lives scheme, which he describes with great enthusiasm:

“We have made contact with a super lady who is based in the village across, she runs Shared Lives. She has the right drivers and motivations. We're busy building that up at the moment, Ruth goes over there on Fridays. I'm hoping to build that up to a point where I get the odd weekend off and then perhaps I might get the odd week off.”

SHARED LIVES, AND SIMILAR COMMUNITY-BASED CARE SOLUTIONS, ARE A VITAL DEVELOPMENT FOR PEOPLE WHO WANT SMALLER-SCALE, LESS TRANSACTIONAL FORMS OF CARE. IT IS CURRENTLY USED BY OVER 12,000 PEOPLE IN THE UK AND IS GROWING BY THE DAY.

The impact of the voluntary sector

Despite some bad experiences, Fred does not speak negatively about all the support he has received, and he is grateful for the support of voluntary sector organisations.

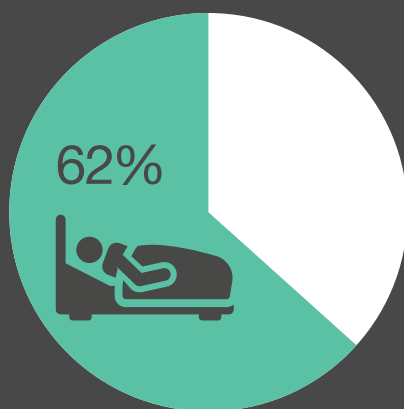
“A lot of the support I get comes from the voluntary sector, a lot of the carer support groups which are very helpful and valuable are actually provided by the voluntary groups like Age UK and Alzheimer's Society.”

Theme 6

Integration of health and social care

Older people in need of care and support are affected not only by changes in the social care system, but also by wider shifts in public services, and particularly the NHS. An NHS budget that has not risen in line with demand, workforce pressures in general practice, reductions in community services (particularly in numbers of district and community nurses) and a lack of capacity in intermediate care services all have implications for those with long-term conditions and disabilities.

Keeping people well and out of hospital has been an important part of national and local strategies to reduce NHS spend. A particular focus has been on people aged 65 and over, who are the biggest users of hospital care and accounted for 62 per cent of total number of bed days in 2014/15.⁴⁰



People aged 65 and over accounted for 62% of total number of hospital bed days in 2014/15

In the four case study sites involved in The King's Fund and the Nuffield Trust's *Home Truths* research, many interviewees felt that improved joint working between the health and social care sectors was an important step towards creating a culture in which the pressures caused by increased demand, reduced budgets and inefficient processes were seen as a shared problem with shared solutions.

Although there were some examples of progress towards these goals, other interviewees reported a lack of understanding, and some frustration between the sectors. In one local authority, a CCG commissioner accused the local authority of 'cost shunting' for trying to get more people onto Continuing Health Care, whereas the local authority felt that they were 'obviously' supporting people who should be eligible. Programmes such as the Better Care Fund were viewed by the majority as a step in the right direction. However, many were uncertain as to whether these programmes could really deliver the kinds of culture change and efficiency savings that are needed.⁴¹

Another focus of integration work has been to try to reduce the number of days that people who are medically fit wait in hospital before discharge. These experiences, known as delayed transfers of care, or delayed discharges, have risen sharply in the last 12 months.⁴² Sixty per cent of the delays were recorded as being attributable to the NHS; however, it is not known how far cuts to social care have had an impact on these figures and on other pressures on the NHS. What the data over time does indicate is that the number of people waiting for care packages at home has increased by 163 per cent over the past five years. The National Audit Office suggest that escalating delays are symptomatic of insufficient money, workforce and service capacity, and poor coordination and information sharing between different parts of the system.⁴³

In a number of the interviews with individuals who use social care services, people described frustration at being caught in the middle between the health and care systems, where entitlements are unaligned and communication is difficult. Ann, Alison, Susan and Robert all described being stuck in hospital while they waited for care to be arranged. Ann was told that there was not enough local home care capacity for her

to be discharged to care at home. Susan likened her experience of trying to arrange her husband's discharge to the first day of school where you have no idea how anything works. In two situations, Robert and Pat were able to use their pre-existing relationship with their GP to help them navigate the complexities of the dividing line between health and social care.

The interviews in this report with people who use services also demonstrate how individuals can be caught in the middle when reduced budgets inadvertently incentivise local authorities and NHS organisations to focus on maximising income and minimising expenditure, rather than on the needs of those who use services. This is particularly true with regard to the current complexities of NHS Continuing Care funding – with which Pat and Patricia continue to grapple.

This key interface is highlighted in the Barker Commission, which was set up to discuss the need for a new settlement for health and social care. It found that:

'The fault lines between health and social care affect people of all ages, with serious issues of integration within health care as well as between health and social care. But they are perhaps illustrated most acutely, as in the accounts we include here, in the battles over what is known as NHS Continuing Healthcare – where an individual's combined health and social care needs are so complex and intertwined, and at such a high level, that the health service continues to provide all care for free, in place of means and needs-tested support. Whether or not people qualify for that has big financial implications, both for families and individuals, and for the health and social care systems as this determines who should pay for what. The assessment also has a big emotional impact'.⁴⁴



Pat was born in India and had lived in Singapore before moving to Malaysia and finally the UK. Pat built a life and became an accomplished researcher and academic. In 2005, she suffered a stroke. She was in hospital for nine months. When she was discharged, she had serious problems with her speech and her mobility; and these profoundly affected her ability to carry out basic tasks of daily living.

Disintegration: Pat and Patricia's story

After suffering a stroke, Pat chose to live at home with the support of her partner Patricia. They are supported by a number of professionals across health and care. But health and social care aren't working effectively together and can't agree on who is financially responsible for Pat's care.

Supported to stay at home

After Pat's stroke, it was clear that she would need significant ongoing care and support. Professionals in the hospital offered her a choice between going into a care home or returning to her own home with a significant package of support.

Pat was clear that she wanted to stay at home, despite her children's preference for her to enter residential care. So at this point her partner Patricia had to *'step up'* to make sure this could happen, not only by providing care for Pat, but also by supporting her to get what she was entitled to through both the local authority and the NHS. It wasn't easy.

"At first, when Pat came out of hospital after nine months of hospitalisation, there were two choices: Pat going to a residential care accommodation or coming home. Her family were all for the idea that Pat should go to a home. But she said she'd prefer to stay at home."

Stuck between health and social care

The process of getting Pat set up at home was difficult and involved many different professionals: social workers, community nurses, occupational therapists and others. Patricia moved in. Pat and Patricia were supported with 40 hours of care in the home and significant adaptations.

Pat needed 24-hour care and ended up having to leverage some of the value of her home to get it. However, it became clear that Pat's needs were so acute that she may be eligible for NHS Continuing Healthcare (CHC) funding (where the NHS pays to meet the whole of someone's needs). After a great deal of persistence, and a helpful intervention from the GP, Pat and Patricia finally heard that Pat had been assessed and was entitled to CHC funding. It was a huge relief to them both.

"So, we went to the GP and the GP, being a pragmatic guy as GPs are, said, 'What would you like to happen?' He said, 'Would you like me to send you a geriatric consultant to look at Pat's needs?' I said, 'Absolutely' and that is what led to the CHC decision."

Not only were Pat and Patricia freed from the burden of having to pay for care and support, but they also hoped it would mean an end to being *'passed around the system'* or *'fobbed off'*. Unfortunately, their relief was short-lived.

Pat's condition was recently reassessed by community nurses, who have said that they feel that Pat has made progress and would now no longer be eligible for full NHS support. As a result Pat and Patricia are preparing for a full reassessment of their needs, and are once again feeling the stress of uncertainty over funding and facing the *'all or nothing'* nature of the assessment.



I think the responsibility that I accepted when Pat left hospital, it was one of the most daunting times in my life. Not even the loss of my parents had been so overwhelming for me.

Emotional impact

The strain of caring has had a big emotional impact on Patricia. She has received support from her GP for her mental health and her time as a carer has obviously affected her. The decision to stand by Pat's decision to live in her own home was momentous:

"I think the responsibility that I accepted when Pat left hospital, it was one of the most daunting times in my life. Not even the loss of my parents had been so overwhelming for me, and the responsibility was because the family wanted something else and Pat wanted another thing. I supported her."

Volunteering, community and family support

Pat and Patricia talked about the need to reconnect generations and the real difference that a volunteer had made to Pat's life just by '*hanging out and watching Richard Attenborough programmes*'. Ultimately, Pat and Patricia felt that state (local government, NHS and central government) resources are best spent encouraging and supporting families and communities to care for one another, rather than providing more services.

"Policymakers and the state will not give you love and that's what people need, I think, and they need to provide support that is relevant to the families..."

Despite their frustrations, Pat and Patricia talk positively about the difference some professionals have made to their lives.

"In our case we had fantastic professionals who have given advice, who have trained us, because we had several physiotherapists and different people who come."

Pat and Patricia refuse to fit into the stereotype of '*vulnerable*' older people.

"For me, the thing that I would like you to take away is Pat's determination. Pat has a very full day, Pat never says 'I give up', and her determination to conquer her stroke is what drives me."



“

**Policymakers and the state
will not give you love and
that's what people need.**

Conclusion

The social care system is under incredible strain. A bird's eye view suggests that with less money going into the publicly-funded system, there are negative impacts being felt by publicly-funded users and by self-funders alike. Without more funding, some local authorities will start struggling to meet their basic statutory responsibilities.

Some social care providers are already having difficulties staying in business; trying to deal with rises in demand and increasingly acute needs alongside increased workforce costs and challenges in recruiting and retaining staff. Providers' investment in the self-payer market and low rates paid by local authorities suggest that the range of choices available to users will polarise depending on where they live and their financial resources. The impact is also being felt by the NHS, which is experiencing delays in discharging patients back into the community due to a lack of capacity, confounding existing pressures in general practice and community nursing.

The interviews with people with experience of using the social care system reflect each of these areas and are poignant reminders of the real-life consequences of decisions made by national policy makers, local government, the NHS and providers of social care. There were many positive examples that illustrate the potential of social care services and professionals to promote individuals' wellbeing. However, interviewees also gave examples of poor-quality care, unmet need and extremely stressful situations that had a real negative impact.

This report looked at six key areas which were identified as needing further attention by policy makers in The King's Fund and the Nuffield Trust's *Social Care for Older People: Home Truths* study and which were seen to have significant impacts in the lives of the individuals to whom we spoke.

Access to high-quality care

The number of people receiving publicly-funded care is declining despite increases in demand. Unmet need is not routinely monitored by all local authorities even though this is now a statutory duty. And there is concern around providers' ability to continue to provide high-quality care at the rates paid to them by local authorities.

Interviews with people with experience of using social care services provided examples of poor-quality care and situations in which individuals have needed to rely on family, friends or the voluntary sector to provide them with additional support.

Personalisation, asset-based approaches and care in the community

Movement towards an *'asset-based'* approach to care whereby individuals, families and communities are supported to undertake more responsibility for caring for one another was supported, in theory, by commissioners and providers. However, it is clear that many families and communities already offer significant support, and the extent to which additional support can be leveraged into the system has yet to be tested. If such approaches are implemented ineffectively, there is a risk that unmet need may rise.

Successive governments have encouraged personalisation and provision of care in the community to encourage independence. However, the increasingly acute needs of service users, pressures in the recruitment and retention of qualified staff, and capacity issues in primary care and community nursing, threaten local areas' ability to achieve these objectives.

The interviews in this report demonstrate how initiatives such as direct payments can be liberating, but they also place additional pressures on users and carers; that the effectiveness of direct payments is diminished without access to an adequate local market; and that services are not always as empowering as intended.

Sustainability of the social care provider market

Reduced fees paid to social care providers by local authorities have meant that some providers have left the market and many others are at risk of following. Many providers have relied on self-funders to cross-subsidise income and have increased fees to these users. Where they have had this option, providers have tended to focus on developing their offer to the self-funder market and, as a result, access to a variety of high-quality services seems increasingly dependent on where a user lives and their financial resources.

Our interviews illustrate how the volatility of the provider market can have negative impacts on people's wellbeing with, for example, long-standing relationships with care workers being broken, and a sense of disempowerment resulting from a feeling of being treated as a *'package'* rather than a valued individual.

A care workforce fit for purpose

Providers are struggling to recruit and retain good quality care staff and there are high vacancy rates, particularly for qualified nurses.

Our interviewees gave some extremely positive examples of care workers or social workers who had supported them. However, they also described some situations of poor quality care and difficulties in knowing whether their carers were suitably qualified.

Support for unpaid carers

Changes introduced by the Care Act 2014 to provide additional support to carers are yet to have an impact and a proportion of carers have seen a reduction in the care and support services they receive.

Interviews with people with experience of using social care services demonstrate the pivotal role of unpaid care delivered by families, friends and communities. Some carers suggested that their wellbeing had been affected by their caring responsibilities and access to respite care was described as particularly essential.

Integration of health and social care

The integration of health and social care services has been an important strategy for keeping people well and out of hospital; reducing delayed transfers of care; improving patient experiences; and reducing NHS spend. At the local level, there is a general consensus that integration of services, and in some instances, of commissioning too, will contribute to solving the funding issues facing the NHS and social care. However, there are variations across the country in how successful these collaborations are, and some doubt that they are moving at the scale and pace necessary to bring about the changes required.

The interviews in this report illustrate the consequences of being delayed in hospital and the lack of communication and understanding that can occur when individuals are moving between the health and social care sectors.

It is clear from these interviews and the The King's Fund and the Nuffield Trust's *Home Truths* study that, for the social care system to continue to support people who need it now and in the future, we need a renewed national debate about how we pay for and provide care, alongside an acknowledgement of the implications for individuals, families and wider society.

The Care Act 2014 was a step forward in terms of enshrining in law local authorities' duty to promote and support people's wellbeing, provide preventative care, monitor unmet need and contribute to an effective market for adult care and support as a whole. However, this research sits amongst a growing body of evidence which serves to highlight the uphill battle local authorities face in making this a reality.

Without change it seems inevitable that unpaid carers will be expected to do more, more individuals will be required to pay for their care, which will come as a surprise, and more people will go without the care and support they need.

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Real lives

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