CREATING A BRITAIN THAT WORKS AND CARES

February 2024

The Centre for Social Justice

Contents

Acknowledgements 1

Working Group 2

Executive Summary 3

Recommendations 5

Foreword 7

Introduction 9

Chapter One: Facts and figures in social care 13

Chapter Two: Fiscal Benefits 24

Chapter Three: Registration and Navigation 30

Chapter Four: Domiciliary Care 34

Chapter Five: Housing 41

Chapter Six: Specialist Housing Schemes 50

Chapter Seven: Community 54

Chapter Eight: Employment 62

Chapter Nine: Digital tools and technology 72

Chapter Ten: Changing the culture 77

Chapter Eleven: Conclusion 83

Appendix 1 85

Appendix 2 89

Appendix 3 90

Acknowledgements

We are grateful to the individuals and organisations who have generously given of their time and experience during our research over the past year.

They have shared a vision of family as the best support for the most vulnerable among us: children, parents, spouses, siblings are selflessly looking after those they love, ensuring that their day to day is as satisfying as can be.

Individual experiences have informed our report, as has the work of the specialist charities supporting unpaid carers. Our illustrious Working Group, which drew members from different disciplines and included many with care experience, has steered our research throughout. They have facilitated access to organisations that are creating viable, and in some cases scalable, solutions for family carers: from transportation and companionship to get-togethers and respite, these groups deliver what carers need. We hope that our report will drive wider acceptance of their tried and tested initiatives.

Working Group

Stephen Burke
CEO, Goyal Foundation and Hallmark Care Homes Foundation

Dr Carole Easton OBE
CEO, Centre for Ageing Better

Catherine Foot
Director of Phoenix Insights

David Goodhart
Author, The Road Home

Jonie Hawksley
Magistrate and carer with lived experience

Emily Holzhausen OBE
Director of Policy and Public Affairs, Carers UK

Paul McGarry
Head of the Ageing Hub, Greater Manchester Combined Authority

Wade Newmark
Chief Executive, BN Care

Chris Poole
Director of Business Development, Sanctuary Group

Susan Walton
Senior Advisor, Overseas Development Institute

Executive Summary

Government has made ending economic inactivity its priority. Focusing on the nearly 400,000 family carers who left employment to care for a disabled or older person would help achieve this mission.[1] It would also support a cohort whose contribution to society, in terms of reducing pressure on social services and the NHS, has been calculated at £162 bn per annum.[2]

Formal support for our older population and for adults with a disability is patchy, costly, and difficult to access: although more than half of LA budgets are spent on adult social care (**£26.9** bn in all) thresholds have become so high, due to budget constraints, that **818,000** people received adult social care support but twice as many asked for it. [3] Two-thirds of family carers find the support, when it is delivered, unsatisfactory.[4]

Families are having to step in where the state is failing.

There is no national register of family carers, so calculating how many individuals care for a vulnerable family member is problematic: the NHS PSS survey[5] reveals that only about 320,000 adult carers are known to councils, whereas the Census[6] indicates there are 5 million adult carers in total in England; Carers Week reports[7] instead 10.6 million. This uncertainty risks many in this cohort losing out on benefits, entitlements, and opportunities.

In too many cases, the family carer is forced to forego or reduce paid employment: exclusively for this report, the CSJ and Opinium carried out a national survey of 1,530 working age carers that found as many as **41 per cent** are considering leaving the labour market or reducing their hours over the coming year.

Disrupted employment has a negative impact on

- employees who are family carers, leading to cumulative disadvantage, notably in pension and retirement;[8]
- the UK economy, as unplanned absences by carers cost it around £3.5 billion a year;[9]
- employers, in terms of
  - reduced work productivity,
  - increased absenteeism,

1 DWP, "Family Resources Survey: financial year 2020 to 2021", Updated 12 May 2023.

2 Maria Petrillo, Matt Bennett, *Valuing carers 2021: England and Wales*, Centre for Care, 2023.

3 Association of Directors Adult Social Services, Survey: *Adult social care: People waiting for assessments, care or reviews*, 2022.

4 The King's Fund and Nuffield Trust, *Public satisfaction with the NHS and social care in 2022*, Results from the British Social Attitudes survey, March 2023.

5 NHS Digital, *Personal Social Services Survey of Adult Carers in England*, 23 June 2022.

6 ONS, *Unpaid care England and Wales: Census 2021*, 19 January 2023.

7 Carers Week, *I care: Carers Week report on unpaid carer identification*, 2023.

8 The carer who leaves paid employment will not be covered by auto-enrolment and will miss out on employers' pensions contribution. The independent review of the state pension age made specific mention of carers as a group of concern. Department for Work and Pensions, *State Pension age independent review: final report*, 23 March 2017.

9 Carers UK, *State of Caring 2023: the impact of caring on: finances*, October 2023.

- reduced employee engagement and morale,
- high staff turnover rates.[10]

The CSJ-Opinium survey found that three in five (**59 per cent**) full time workers and almost seven in ten (**69 per cent**) part-time workers would return to work or increase their hours at work with the "right support in place".

- **40 per cent of** respondents not in paid employment would go back to work if their employers were to grant them five days' paid leave.
- **40 per cent of** respondents not in paid employment would go back to work if the Carer's Allowance had a higher earnings limited
- **40 per cent of** respondents not in paid employment would go back to work if those they cared for would receive 10 hours free domiciliary care a week.
- **33 per cent of** respondents say home adaptations would support them back into work or enable them to work more.

"Creating a Britain that Works and Cares" makes the economic and fiscal case for better support of working-age carers. [11] The Treasury stands to lose £2.8 billion in 2024 in benefits payments to individuals who are not working due to unpaid caring, plus another £3.3 billion in taxes and national insurance contributions forgone on this cohort's lost earnings. [12]

The CSJ cost benefit analysis of the survey makes the case for three key policies to provide the support that working-age carers have identified as incentives for their return or their entry into paid employment: some free care at home; free adaptations to make the homes of those they care for safer and more accessible; and a more generous allowance for carers.

We also make recommendations about introducing a Family Carer's Register to allow national and local government, as well as community organisations, to identify and support family carers; establishing a One Stop Shop for Carers, based in GP surgeries and hospitals, that guides the family carer through the complex social care system; and asking the DWP to roll out a communications campaign to improve take-up of Attendance Allowance and Pension Credit.

"Creating a Britain that Works and Cares" sheds light on national and international examples of best practice. From Japanese toilets that at the press of a button will wash and dry someone vulnerable without offending their dignity or straining their carer's back; to the carers' networks that enlightened employers are introducing in the workplace; solutions abound. Family carers draw timely and effective support from place-based schemes led by grassroot organisations. They also benefit from inexpensive and user-friendly digital technology: this makes digital inclusion an urgent national priority. Well-planned schemes delivering integrated health, housing and social services also deliver effective support. Finally, **all** carers, whether employed in the formal social care sector or a family member, would benefit from a cultural shift that rewards caring as an essential and valuable activity: this report includes some simple mechanisms to validate their contribution.

Family carers play a crucial role. Without them, the most vulnerable risk suffering indignities including penury and frustrated needs while state services will be under greater pressure.

10 A Lafferty, D Phillips, G Fealy, G Paul, C Duffy, L Dowling-Hetherington, M Fahy, B Moloney & T Kroll, *Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role*, Community, Work and Family, 26:3, 292-311, 2023.

11 Ibid.

12 See Appendix I for our cost benefit analysis.

Recommendations

1. The DWP should explore moving the Carer's Allowance recipients with the lowest 20% of household income to the UC system, where they will receive the carer element in addition to the Personal Allowance, thereby protecting the most disadvantaged carers from penury.
2. The DWP should roll out a communications campaign to improve take-up of Attendance Allowance and Pension Credit.
3. The DWP should reduce the six-month waiting period for the Attendance Allowance to three months, bringing it into line with other disability benefits.
4. Introduce a Family Carer's Register to allow national and local government, as well as community organisations, to identify and support this cohort.
5. All Local Authorities should be required to publish a statutory Local Offer for Adult Social Services, similar to the one they are required to publish for children and young people with SEND.
6. Introduce a One Stop Shop for Carers that guides the family carer through the social care system. Major hospitals could fund this through the NHS Apprenticeship Levy. In GP surgeries, it would be run by social prescribing link workers. One Stop Shops would facilitate data sharing across an ICS, helping to progress the integration of health and social care.
7. Homes England should increase the proportion of their grant allocated for retirement housing.
8. The Government should revise the National Planning Policy Framework to explicitly require all local plans to include a specific policy and target for new wheelchair accessible homes (known as M4(3) in building regulations), and where no local target is set, to require 10 per cent of new homes to meet the standard.
9. Government should introduce a new planning use class that takes into account the very specific nature of retirement housing, removing constraints on building new retirements homes.
10. Local Authorities should invite older residents, those affected by a disability, and their carers, to participate in discussion groups to inform planning decisions.
11. Government should ensure its NPPF guidelines to local authorities specify the inclusion of the ten HAPPI principles to the design of new build developments.
12. Local Authorities' housing lists should prioritise family carers seeking to live close to those they care for.
13. DWP should administer a Home Adaptations Grant of £2,000 to 5 per cent of individuals looked after by working age unpaid carers each year (this equates to around 175,000 grants per year).
14. All hospital discharge teams should work closely with a Home Improvement Agency or with home improvement services in their area, including LA housing teams, housing providers and voluntary sector organisations to help patients return to a home which meets their needs.

15. The CSJ echoes the Centre for Ageing Better in calling for accessible and adaptable homes (known as M4 (2) in building regulations) Category 2 housing to become the new minimum standard for new-build homes.
16. Government should deliver 10 hours free domiciliary care a week to the 10 per cent adults with most needs. There are significant economic and fiscal benefits due to supporting unpaid carers to work more, which reduce the net cost of the policy, although they cannot offset it totally. This however needs to be considered alongside the improved wellbeing of care recipients and the easing of the mental and physical burden on unpaid carers.
17. Extend the Family Hub offer to include support for older people or individuals with a disability, to offer respite for their carers.
18. In their commissioning, Local Authorities should issue longer term (four year minimum) contracts and issue reporting requirements that are manageable for small voluntary organisations and grassroot groups.
19. The CSJ calls for a government-led public health campaign, carried out across both traditional and social media, messaging the five days of unpaid carer's leave and – once agreed upon -- the five days paid carer's leave.
20. Given the need of support for family carers, and the economic advantages of such legislation, the CSJ urges Government to introduce a statutory five days paid leave for employers with more than 10 employees.
21. Government should encourage employers to introduce a Carers' Network as a means of identifying and supporting their carer employees.
22. Businesses employing more than 50 staff must provide a mid-career MOT, while smaller businesses would be accessing this through JobCentres Plus.
23. Government should encourage more employers to sign onto the "Carer Confident" scheme by communicating it more widely, linking it explicitly to the campaign to end economic inactivity.
24. The DWP should encourage the 15 ICS testing the new WorkWell programme to include family carers in their initiative.
25. Reduce VAT on social tariffs to 5 per cent.
26. Encourage providers to improve their social tariff speeds to match average speeds.
27. Promote collaboration between families and health and social care professionals: the Department of Health and Social Care should introduce a protocol around speaking with family caregivers and registering their concerns and suggestions regarding the care for their relative.
28. Trusts and foundation trusts should use their budget for Training and Development to fund training schemes for family carers in non-medical interventions.
29. Trusts and foundation trusts should use their budget for Training and Development to fund training for domiciliary carers to gain access to hospital or community employment opportunities.
30. Amend the Equality Act 2010 to include being a carer in its list of protected characteristics.

Foreword

Every one of us is likely to become a carer – often sooner than we think. Women have a 50:50 chance of caring by the time they are 46 and men by the time they reach the age of 57.[13]

The consequences of our failing social care system for our physical and mental health are well-known,[14] as are the burdens it places on the NHS.[15] But another facet of the issue — the economic impact — attracts less attention.

By looking after older or disabled adults, including doing their shopping, accompanying them on GP visits, ministering medicine, feeding and bathing them, family carers contribute an estimated £162 billion per year worth of unpaid care.[16] This dwarfs the total taxpayer bill for care of £26.9 billion.[17]

Thanks to family carers' efforts, hospital discharge can be completed more quickly, the number of A&E calls and need for residential care is reduced, as is the pressure on council budgets.

This comes at a cost, however: many of these selfless and dutiful citizens risk poverty, debt and ill health.[18] A staggering one in three report having to cut back on food or heating because of the cost-of-living-crisis.[19] Many carers find they cannot hold down paid employment, and are forced to retire early.[20]

With economic inactivity at near record high, failure to help unpaid carers secure and sustain employment is already costing us dearly. We can ill afford for the number of economically inactive carers to grow further, [21] but this report publishes an exclusive CSJ survey carried out with Public First which shows that within the next 12 months 41 % of carers in paid employment are likely to either leave their job or reduce their hours.

Yet they long to stay in paid employment. All they seek is a little support, the survey found, in the form of a higher earnings threshold at which the Carers' Allowance is cut off; a more generous (£2,000) home adaptation grant; and 10 hours of free domiciliary care. The cost benefit analysis included in "Creating a Britain that Works and Cares" shows that these demands are eminently affordable.

The Greater Manchester Combined Authority has rolled out a successful programme, Working Well, that has delivered wrap around support to those who seek employment but are unable to take it up because of health conditions, disabilities and/or care responsibilities. The Government has recognised our initiative as a means to reduce economic inactivity and is now adopting our template with its own

13 Carers UK, *Will I care? The likelihood of being a carer in adult life*, November 2019.
14 Maria Petrillo, Matt Bennett, *Valuing Carers 2021 England and Wales*, Centre for Care, 2023.
15 Skills for Care, *The state of the adult social care sector and workforce in England*, 2022.
16 Blanche Le Bihan, Barbara Da Roit B, Alis Sopadzhiyan, *The turn to optional familialism through the market: long-term care, cash-for-care, and caregiving policies in Europe*, Soc Policy Adm., 3 June 2019.
17 Maria Petrillo, Matt Bennett, *Valuing Carers 2021: England and Wales*, Centre for Care, 2023.
18 Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
19 Carers UK, *State of Caring Survey 2023: the impact of caring on finances*, October 2023.
20 Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
21 Centre for Ageing Better, *Health warning for employers supporting older workers with health conditions,* April 2018.

Working Well programme. This report argues that while welcome, an effective strategy must support the nearly 400,000 individuals who have left employment due to caring responsibilities.[22]

We know that the benefits of paid employment stretch beyond ensuring financial security to include improved self-confidence, socialisation, a sense of purpose. "Creating a Britain that Works and Cares" also highlights the pivotal role of small charities and grassroot groups in supporting family carers. This too is at the heart of our place-based strategy in the GMCA: voluntary organisations can deliver assistance that is flexible and immediate. They are embedded in the community, and are familiar therefore with its particular challenges. Enabling these groups to carry out their laudable mission means creating a level playing field when it comes to local contracts – simplifying the procurement process, and time frames that accommodate smaller organisations' capability constraints.

With this report we seek to ensure those parents, spouses, siblings and children who look after those they love won't have to sacrifice their own welfare. To look after one another in sickness as in health, in old age as in youth, forms the basis of a social covenant without which relationships fray and mutual trust disappears. A society that values care is one that recognises the dignity and intrinsic worth of each individual, regardless of their age or abilities. Let us create a Britain that works and cares.

Andy Burnham
Mayor of the Greater Manchester Combined Authority

22 DWP, "Family Resources Survey: financial year 2020 to 2021", Updated 12 May 2023.

Introduction

A national strategy to support family carers could not be more timely: the number of formal carers are declining,[23] just as a growing proportion of our population is older and as many as one in five working age adults report being affected by a disability. Family breakdown, family dispersal and a surge in lone households are further shrinking the pool of carers just as they are needed more than ever. [24] And when the family recedes, the state must step in.

The Government's previous attempts to address this issue have met with failure, however. The Care Act 2014 [25]summarised the social care system as a 'general duty' on Local Authorities to 'promote individual wellbeing', including 'participation in work' where appropriate. But these admirable principles have not been upheld.

Instead, successive Governments have issued a series of doomed policy suggestions. The Dilnot Commission in 2011 had called for a fixed lifetime cap on social care charges and a more generous means test; in 2017 Theresa May sought to have older people pay for care in their own home unless their assets were below £100,000; and more recently, the Government said they would raise NI contributions by 1.25 per cent to fund health and social care. All proposals have been shelved or even reversed. The succession of controversies (May's proposal for example was branded the "dementia tax") and U-turns has alarmed politicians and social care risks slipping off their agenda as they prepare for a General Election.

This would be a mistake. Improving the support of family carers promises to deliver huge benefits. Enabling them to stay in paid employment boosts tax revenues and NI contributions while saving on benefits. It also ensures carers' financial security during their working life, allowing them to save into a workplace pension and receive employer contributions for that. Paid employment confers other benefits, too, as Mayor Andy Burnham has highlighted in his Foreword: it boosts self-confidence, reduces isolation, bestows a sense of purpose.

More support for carers is about more than drawing them back into employment. It is about giving parents, spouses, siblings and children the opportunity to look after those they love without having to sacrifice their own welfare; and it is about celebrating their role as carers. Family carers are seemingly forgotten by even the professionals who benefit most from this volunteering army: in his 267-page Annual Report on Health in an Ageing Society, Chris Whitty, the Chief Medical Officer mentions family carers only in three paragraphs – and omits to thank them. [26]

This report draws on semi-structured interviews carried out over March-December 2023 with health and social care professionals, councillors and LA staff, as well as frontline workers from the more than 650 charities that make up the CSJ Alliance. It follows the previous CSJ report, "Ageing Confidently: Supporting an Ageing Workforce", and makes the case for all parties' election manifestos to prioritise

23 ONS, *Unpaid care, England and Wales: Census 2021,* 19 January 2023.
24 Independent Age, *Ageing without children*, 2023.
25 Gov UK, Care Act 2014.
26 Chief Medical Officer's Annual Report 2023: *Health in an ageing society,* November 2023.

supporting this valuable cohort, and to this end delivers a host of practical suggestions for achievable, measurable progress.

Our research has uncovered examples of best practice, national and international, that show the answers to many of the challenges facing the social care system are already known. We highlight these initiatives and urge Government to recognise and, where possible, scale them.

While this report focuses on families who look after their more vulnerable members, it recognises that the social care system cannot adopt a "family only" approach. Many informal carers will continue to rely to some degree on formal care. Friends and neighbours also often step up to deliver informal care, and we applaud their admirable contribution, while highlighting how to better support their work, too. And despite our focus on working-age carers, we acknowledge the extraordinary role that as many as 800,000 young carers are filling every day.

Trying to navigate the maze of national, local and NHS requirements and entitlements can prove overwhelming for those who suddenly find they are the lifeline for someone they love. Even more troubling, many of the family carers who contributed to this report have described Local Authorities that place barriers before parents of adults with complex needs or children of older and vulnerable parents: delayed, or difficulty in obtaining, access to services is a recurring theme in the lives of too many families.

As a result many carers find they cannot hold down paid employment, and are forced to retire early.[27] The Centre for Social Justice with Opinium carried out a national survey of unpaid working-age (16-64 year old) carers in November 2023 that should alarm us all: Two in five (41 per cent) of unpaid carers currently in work are either likely to reduce their hours or give up work altogether in the next year. Three in five (61 per cent) say that their care duties currently prevent them from taking up paid work or as much paid work as they'd like to.

The government has made reducing economic inactivity a priority and are investing in mental and occupational health therapies alongside providing bespoke, keyworker support to those with health conditions and disabilities. This report argues that while welcome, an effective strategy must support the nearly 400,000 individuals who have left employment due to caring responsibilities.[28]

Our national survey found that family carers share a clear appetite to work (or work more): two thirds of those not currently in work (65 per cent) said they would take up paid employment if they could, while a similar proportion of those in part-time work (64 per cent) said they would like to increase their hours if they could.

Our respondents were clear also about what would induce them to increase their labour market participation. Three in five (59 per cent) full time workers and almost seven in ten (69 per cent) part-time workers told us that they would return to work or increase their hours at work with the "right support in place".

We have costed three key policies that, according to our survey respondents, would represent the "right support" to induce them into work or, if part time, into working more hours. These include reviewing the Carer's Allowance; receiving ten hours of free domiciliary care; and receiving £2,000 of home adaptations.

27 Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
28 Ibid.

Our cost benefit analysis shows the fiscal and GDP net benefits of carers receiving support to the point where they would be able to return to work, part time or fulltime: adding the loss of income tax and national insurance contributions to the extra spending on benefit, the cost to the public purse of family carers being out of work is £6.2bn.[29]

To ensure family carers receive the support they need, we shall look at:

Financial Benefits

The link between caring and poverty is well-evidenced. Given how much they save the state and the taxpayer, carers deserve financial support.

Local Government entitlements

A bed at home costs the council a lot less than a bed in a care home: it is in the councils' interest to deliver some free domiciliary care (as is already happening in Hammersmith and Fulham)[30] and speedy and more generous home adaptations.

Housing

Carers cannot leave their loved ones at home alone when the Centre for Ageing Better finds that only 7 per cent of the UK's housing stock "meets basic accessibility standards." Planning regulations need to change to encourage developers to build more age-appropriate and ability-appropriate housing. Councils and housing associations should prioritise individuals who will live near their loved one in order to provide care on their housing lists. Innovative housing schemes exist already—we highlight some of the best.

Navigation

The social care system is too complex. Introducing a One Stop Shop for Carers in every big hospital—where most care pathways start — and in GP surgeries through social prescribing link workers, will deliver a guide to family carers as they struggle through the thicket of benefits, entitlements, voluntary and community support. A new register of informal carers will identify and accredit those looking after their older or disabled relatives.

Community

Family carers feel isolated and marginalised.[31] Many small, grassroots charities do a brilliant job supporting carers but the process for securing local government contracts is labour intensive and hard to navigate. Local Authorities should ensure contracts cover a minimum of four years, to allow relationships and communities the time to flourish. We reveal the most successful local schemes.

29 CSJ calculations, Appendix 1

30 Interview with Counsellor Ben Coleman, September 2023.

31 Joseph Rowntree Foundation, *The caring penalty,* 18 July 2023.

Employers

One in seven holding down a job in the UK have unpaid care responsibilities. Retaining this cohort spares employers the expense of turn-over and recruitment. In addition, their caring experience hones significant skills and qualities that render these employees an asset in any workplace. It is therefore in an employer's interest to support them through improved carer's leave, mid-career MOTs, and carer representatives.

Recognition

The NHS should invite informal carers to train and pursue professional development within it, thereby raising their status.

This report starts by establishing the scale of the challenge in supporting family carers, then proceeds to reveal the results of our national survey. It sets out measures for improving support for all family carers, in particular those of working age, showcasing national and international best practice found through our research and interviews with front line workers, experts and Government. We have invited individuals with lived experience to contribute to our research.

Chapter One:

Facts and figures in social care

What is social care?

Social care supports adults with physical or learning disabilities, physical or mental illnesses. Depending on the individual's needs social care can include "personal care", when a trained care worker helps with dressing and washing, at home or in a residential care setting; or "domiciliary care", when a trained worker helps with shopping, cleaning, budgeting at home.[32]

The current adult social care system is in trouble.

People worry about the potential cost of securing adequate care for themselves or their relatives.

The Government worries about demand, which will continue to soar, given our ageing population, while the system must rely on an ever shrinking, poorly paid, low-status professional workforce.

Finally, the current system assumes that a family member will always be on hand to accompany the vulnerable or older to appointments, take notes, ensure they take their medicine, organise carers' visits – and yet this family carer needs neither recognition nor support from health and social care professionals.

Moreover, the surge in family breakdown and especially "silver splitters", who divorce in their 50s or later; childless as well as lone households; and families who are dispersed means that delivering care is becoming more and more challenging for family members, and more precarious.

Social care represents more than half of LA spending, costing £26.9 billion in 2021/2.[33] Without a national register of family carers, calculating the numbers caring for a vulnerable family member is a challenge: the NHS PSS survey [34]reveals that only about 320,000 adult carers are known to councils, whereas the Census[35] indicates 5 million adult carers in total in England; Carers UK reports a figure closer to 10 million.[36]

Social care is not free at the point of use, as health care is. It is either self-funded or provided through a local authority. It is means tested. Councils carry out two assessments – one for needs, one for assets. Individuals with over £23,250 in assets and savings must pay for their own care. Below that, a

32 National Audit Office, DHSC, *The Adult Social Care market in England*, 25 March 2021.
33 The King's Fund, *Social Care 360: Expenditure*, March 2023.
34 NHS Digital, *Personal Social Services Survey of Adult Carers in England 2021-22*, 23 June 2022.
35 ONS, *Unpaid care, England and Wales: Census 2021*, January 2023.
36 Carers Week, *I care: Carers Week report on unpaid carer identification* , June 2023.

sliding scale is applied; only those with less than £14k pay nothing. [37] Those who qualify for council help are given a care plan with care providers who may be employed by the council or by a charity. Councils are supposed to give those who qualify a list of local care providers.[38]

Even those eligible for LA care may have to pay care charges, which come out of benefits. Care charges vary from LA to LA.

The Health and Care Act 2022 gives the Care Quality Commission powers to audit local authorities' delivery of adult social care. As of September 2023 the Commission will start formal assessments, completing all by autumn 2025. [39]

Such scrutiny is welcome: the sector is affected by workforce shortages (vacancies grew by 52 per cent in 2021-2022[40]), high turnover, and low pay of staff. Moreover, provision is not standard across the country: Local Authorities can set different thresholds in assessing who receives domiciliary care, residential, nursery and community-based care (e.g. day centres) as well as the Disabled Facilities Grant for home improvements. Key workers in charities that are part of the CSJ Alliance of more than 650 charities, and family carers we have interviewed, report that several Local Authorities are failing in their statutory duty (under the Care Act 2014) [41]to provide support to vulnerable residents, whether disabled or older. The Local Government and Social Care Ombundsman has upheld 70 per cent of disabled facilities grants appeals and 67 per cent of assessment and care planning complaints in 2022/3, reflecting "a decade long trend of increasing levels of fault." [42]

In 2021/2 818,000 people received adult social care.[43] More than twice as many people had requested it, however, with 1.98 million in 2021/22 asking for support, 612,000 of these being of working age.[44]

The Local Government Association recently revealed that over half a million people were waiting for a care needs assessment, a care package, a direct payment or a review of an existing care plan. [45] Current budget constraints risk pushing more and more individuals with needs into this cruel limbo. With an ever more significant gap between supply and demand, relations between some councils and family carers have become confrontational. Charities working with informal carers have told the CSJ that a number feel frustrated by the councils' failure to respond to their complaints, and are forced to escalate to appeal to the Social Care Ombudsman. As one parent of an adult with disabilities told us, "we hold peer support meetings with parents in similar circumstances and people were tearing their hair out."

Many family carers would look after their spouse parent or adult child regardless of access to formal social care; but others feel that the shrinking offer from publicly funded care leaves them no choice but to look after family members themselves. A third (33 per cent) of adult social care services reported that they were having to ask individuals to take paid or unpaid leave from work as services could not meet their family member's care needs. [46]

37 The King's Fund, *Home care in England: Views from commissioners and providers*, December 2018.
38 Ibid.
39 The King's Fund, *Reform of adult social care: vanishing over the horizon*, 13 April 2023.
40 Skills for Care, *The State of the Adult Social Care Sector and Workforce in England*, 2022.
41 House of Lords Library, *Future of Adult Social Care*, section 2.3, 20 March 2023.
42 Local Government and Adult Social Care Ombundsman, *Review of Adult Social Care complaints 2022-23*, September 2023.
43 The King's Fund, *Social Care 360: Expenditure*, 2 March 2023.
44 Ibid.
45 House of Lords, Adult Social Care Committee, Monday 18 July 2022.
46 Casey, Rachel, *Unpaid care and poverty: unpaid carers' priorities for change through participatory co-design,* Joseph Rowntree Foundation, 6 June 2023.

Specialist housing schemes are an important part of the social care landscape. They include "Supported housing" which typically accommodates those with learning or other disabilities. Supported Housing residents live in group accommodation where residents share certain characteristics and receive care. "Extra care" refers to retirement housing schemes that offer onsite care and provide access to activities such as cinema, a gym, etc. Residential "care homes" are for those whose needs call for greater support but not necessarily nursing care.

Social care available in a formal setting is more expensive than care at home – a home carer costs on average £20 an hour while a care home costs on average £800 a week, and a nursing home, £1078 a week.[47] A recent survey found that 90 per cent of pensioners found care homes and nursing homes unaffordable.[48]

The Government's White Paper, published in December 2021 announced reforms to address 'catastrophic' care costs. [49] In the Autumn Statement of November 2022 however, the government announced that some of these reforms would be postponed until October 2025. [50] And in its "Next Steps" document of 4 April 2023, the government cut back or cancelled other measures from the White Paper, including its pledge of £500 million for workforce training, qualifications and wellbeing – now halved to £250 million; while the £300 million to transform housing options has been replaced by £102 million for smaller in-home adaptations.[51] This about-turn echoes the fate of the 2011 recommendations resulting from the Dilnot Commission – which government initially accepted but has stalled on implementing in the intervening years. [52]

Policy-makers are able to side-line social care issues because there is no single government department accountable for these. [53] The current system is made up of different entitlements, overseen by different departments: specialist housing comes under the Department of Levelling Up Housing and Communities; the Attendance Allowance and the Carer's Allowance come out of the DWP budget; the NHS pays for "continuing health care" and nursing care for those with long-term complex needs. The result is a fractured strategy, addressing issues piecemeal, and lacking a clear vision of integrated support for some of the most admirable individuals in our country.

47 Age UK, *Paying for Permanent Residential Care,* April 2023.

48 Sure Safe Survey, *The Impact of the UK cost of living crisis on care-based decisions*, June 2022.

49 DHSC, *People at the Heart of Care: adult social care reform white paper,* 1 December 2021.

50 HM Treasury, *Autumn Statement 2022*, 17 November 2022.

51 DHSC, Next steps to put people at the heart of care, 4 April 2023; The King's Fund, *Reform of adult social care: vanishing over the horizon*, 13 April 2023.

52 Commission on Funding of Care and Support, 21 February 2013.

53 Charlotte Paddison, Nadia Crellin, *Falling short: How far have we come in improving support for unpaid carers in England?*, Nuffield Trust, October 2022.

Who cares?

Case Study: Gemma

"I am her niece, not her carer! I know that sounds harsh but when my aunt — aged 93 — came out of hospital for what should have been easy recovery after a minor fall, I was suddenly told that as next of kin I had to help her manage the care package that the hospital was putting in place. I have two children still at home, I work in a nursery, and I live half an hour's drive away. It's not easy. While in hospital my aunt had got an ulcer on her leg and a bed sore – all of it could have been prevented if the discharge team had been on top of her case. The hospital took several days to get the package ready – and when the first care team showed up, they were two burly men. Who thinks that a woman of that age would be comfortable with two strange men washing her or putting her on the toilet? She told them not to come near her, so they just did some washing up and wrote some notes and left me with her.

"That meant I had to get my husband over so that together we could lift my aunt to get her to the toilet. We didn't have a hospital bed so moving her around for eating and washing hurt my back. The district nurse came two days later and she was brilliant but the community matron was on sick leave. The hospital, ambulance service, social care and other services just don't talk to each other, leaving me in the middle. The GP surgery was a nightmare. Only when the district nurse insisted on authorisation for end-of-life care did we get a home visit. It's sad: until you are dying no-one is going to help you."

Interview with CSJ, 16 November 2023

Case Study: Po Ki

"I had to quit my job to look after our son. My son is 27 years old and severely disabled. I was born and raised in Hong Kong where I would have expected my family to help us out. In Asian society it is taken for granted that your family takes care of you – my brother, as the first born, lived with our parents until they passed.

"It is my responsibility and my privilege to look after my son but I think it is too much to ask of us parents to also take on the authorities for support.

"Core care is patchy which means my husband and I are complementary to, rather than replace altogether, the state. We have to quality control, whether the carers have carried out the task they were supposed to do, whether they are on top of the dosage and timing of medication, and is our son suitably stimulated. This will be equally true of someone who is older as it is of our son.

"I am on a couple of peer to peer WhatsApp groups of parents with children who are vulnerable adults and the constant refrain is the lack of support from the council. One of our members was a single mother who had had to give up her work to look after her 13 year old autistic son. She had no family support, and found the social workers assigned to her of little help. During lockdown, her son grew worse – all his routines had been broken and any activity in the outside world had become impossible; every time we spoke she told us he was suffering. No one looked in on them -- and one day she smothered him with a pillow. It was a tragedy – but totally preventable."

Interview with CSJ, 14 April 2023

Case Study: Samir

Mum developed vasculitis of the kidneys and lungs in 2015, and the impact of these triggered dementia. In 2019 she had a stroke – and we had to call in a care agency. They were terrible, and as my 90 year old father was too frail himself to look after mum, I moved back in with my parents. We are Indian so I suppose this is expected of me; and I am single so the pressure is even greater. But I am self-employed as a landscape gardener, and this has played havoc with my work commitments. Whenever Mum has an outpatient appointment, I have to arrange hospital transport for mum -- and dad, otherwise he sits anxious at home. But as he is not the best person to speak with the consultant, I have to give up my work and show up at the appointment. It means I cancel a job. Then there is the waiting in the hospital, and then the waiting to pick up the medicine form the pharmacy. We get home and there will be a visit from a carer but that can be a real lottery: sometimes they have been wonderful and they stay long enough for mum to feel comfortable with them. But sometimes they are hopeless, aren't careful with her, we even had one who made her fall and couldn't pick her up so I had to rush back from a job halfway across town. I am lucky in that I am single so caring for mum is ruining my professional, not my personal, life. But I can't imagine anyone putting up with a man who is constantly rushing off to hospitals, GP surgeries or pharmacies with his 90 year old parents.

Interview with CSJ, 8 November 2023

Government Spend

- Net LA expenditure on social care is £21.6 billion.
- £3.4 billion Carer's Allowance for working age adults
- £15.772 billion paid in Personal Independent Payment (PIP)
- £6.1 bn spent on Disability Living Allowance
- £2.8 bn on home (domiciliary) care
- Local authorities spent a further £1.9 billion on social work-related activities such as assessment and safeguarding + £2.0 billion on commissioning and service delivery.
- Learning disability support for working-age adults is £5.7 billion
- Physical support for older people is £5.3 billion

Formal Carers

The great majority (97.3 per cent) of older people live in private households and more than 75 per cent of adults with disabilities live with their parents [54]. Most care, then, is done at home. But many family carers will rely on some form of formal care, whether they pay for it themselves or the Local Authority does. The quality and accessibility of this formal care varies widely between Local Authorities. The sector as a whole has been losing workers for decades, with turnover rates as high as 29 per cent: 400,000 people left their jobs last year[55]. This is perhaps not surprising when 4 out of 5 jobs in the economy pay more than jobs in social care. [56]

Nearly a quarter (23 per cent) of the workforce is from black, Asian and minority ethnic backgrounds[57].

Care providers have limited opportunities for professional development or continued training.

Some of the care-experienced users of our CSJ Alliance charities have reported that formal care training needs to focus more on patient and family-centred care. There is no national register of carers, which allows poor quality carers to move from job to job.

LAs have been encouraging the shift from institution-based settings to home and community care, as a way to significantly reduce the high costs of institutional care: the average cost of placement in an LA-run residential care home is £760; care at home costs the Local Authority £18.88 per hour on average.[58]

Informal, or Family, Carers

Family carers are relatives, friends, spouses, or neighbours who support, in an unpaid capacity, an individual with physical or mental needs. Carers are not a homogenous group: they have different relationships with the recipient of their care; the care they deliver may be intense and long-lived or light-touch and for a brief period; they may be living with or apart from the individual they care for. While some carers will be adept at basic care-giving, others will be completely unfamiliar with the skills necessary.

The ageing of our population, and the increased life-span for individuals with disabilities or age-related infirmity, are developments to be celebrated – but they have put huge pressure on the social care sector. As a result, family members have had to step up to take on more care duties. This too often comes at a significant personal cost.

There is no national register of family carers, so calculating how many individuals care for a vulnerable family member is a challenge: the NHS PSS survey [59]reveals that only about 320,000 adult carers are known to councils, whereas the Census[60] indicates there are 5 million adult carers in total in England; Carers UK reports instead a figure closer to 10 million. [61] This uncertainty risks many in this cohort losing out on benefits, entitlements, and opportunities. If we don't even know how many carers there are, how can we ensure they receive appropriate support? Yet family carers are the lynchpin in the delivery of our social care system: even if they are not the primary carers, they must be on hand to

54 ONS, Disability and Housing UK 2019.
55 Skills for Care, *The State of the adult social care sector and workforce in England 2022,* October 2023.
56 Ibid.
57 Ibid.
58 The King's Fund, *Social Care 360: expenditure*, 2 March 2023.
59 NHS Digital, *Personal Social Services survey of adult carers in England*, 2021-22.
60 ONS, *Unpaid care, England and Wales: Census 2021,* 19 January 2023.
61 Carers Week, *I care: Carers Week report on unpaid carer identification*, June 2023.

arrange for (and often pay) formal carers, oversee their schedule of shifts, let them into the house, monitor the quality of their work.

The profile of the average family carer is unenviable. They are more likely to be poor, [62] feel lonely, and develop health issues.[63]

The cost of living crisis is affecting them disproportionately, with over a third reporting they are having to cut back or do without food or heating.[64] Over two-thirds (68 per cent) of carers reported being worried about their ability to save and plan for the future.[65]

One in five carers report feeling isolated, with 29 per cent saying they were lonely "often or always".[66]

Caring also has an impact on health. More than a quarter of family carers (27 per cent) report having a disability, while almost a third report "bad" or "very bad" mental health issues.[67] Carers of adult children with disabilities experience poorer physical and mental health than carers in general.[68] Nearly six in ten family carers live with someone who is disabled,[69] whose caring needs are likely to be even greater than someone who is older – calling for a 24/7 commitment in some cases, or even two carers at times.[70] Although Disability benefit is supposed to cover additional costs associated with disability (PIP) and recognise that disabled people may not be able to work (disabled element in UC), parents with an adult disabled child often need to subsidise them, as Government entitlements are not enough.

Despite the significant challenges they will face, 12,000 people become unpaid carers every day.[71] Almost half (48 per cent) are looking after someone living under their own roof and 55 per cent after someone living outside their household. Parents are the main recipients of informal care. [72]

The majority of family carers are of working age with those who devote less than 20 hours to caring being on average 52 years old. [73]

Some groups deliver more care than others - those on lower incomes spend more time caring for others than their wealthier counterparts;[74] BAME people are more likely to provide 20+ caring hours/ week; and women are more likely to care for a family member, with DWP data identifying 2.5 million female family carers versus 1.7 million males.[75] This gender gap is greatest when individuals are of working age.[76]

Female carers are also more likely to be disadvantaged in comparison to male carers: they make up 69 per cent of those in receipt of the Carer's Allowance. As Emily Kenway, author of "Who Cares?", told the CSJ: "We are going to have homeless 80 year old women who are in that situation because they loved someone enough to care for them, and that has pushed them into penury."[77]

62 Sebastien Peytrignet, Fiona Grimm, Charles Tallack, *Understanding unpaid carers and their access to support*, The Health Foundation, 12 April 2023.
63 Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
64 Carers UK, *The State of Caring 2023: The impact of caring on: finances*, October 2023.
65 Ibid.
66 Sebastien Peytrignet, Fiona Grimm, Charles Tallack, *Understanding unpaid carers and their access to support*, The Health Foundation, 12 April 2023; Carers UK, *State of caring 2022: A snapshot of unpaid care in the UK,* November 2022.
67 Carers UK, *State of caring survey 2022.*
68 Ibid.
69 Rachel Casey, *Unpaid care and poverty: unpaid carers' priorities for change through participatory co-design* Joseph Rowntree Foundation, 9 June 2023.
70 Interview with Claire Bolderson, 11 May, 2023.
71 Carers UK, *State of caring 2022: A snapshot of unpaid care in the UK,* November 2022.
72 DWP Family Resources Survey, Financial Year 2020 -2021, 12 May 2023.
73 DWP Family Resources Survey, Financial Year 2020 -2021, 12 May 2023; Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
74 International Longevity Centre UK, *One hundred not out: a route map for long lives*, 7 December 2023.
75 DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022*, 21 July 2023.
76 Gerald Ferrant, et al., *Unpaid Care Work: the missing link in the analysis of gender gaps in labour outcomes*, OECD Development Centre, 2014.
77 Interview with Emily Kenway, 30 May, 2023.

To some degree, this gender gap in the sector can be explained by few men self-identifying as "carers", and therefore few access formal support services – yet many are taking care of spouses, children and vulnerable family members. Indeed, among those over 85 years old, men now represent 59 per cent of carers.[78] Men's failure to recognise their caring role may be due to the social care sector predominantly employing women, with men accounting for only 16.9 per cent of social workers.[79]

Whether male or female, the proportion of carers who feel they are receiving "encouragement and support" has fallen year on year, and most recently from 34.6 per cent in 2018-19 to 31.5 per cent in 2021-22.[80]

Entitlements

Regardless of their finances or the level of care they provide, any family carer is entitled to a Carer's Assessment through their LA. This is a consultation that gives them the opportunity to voice their needs and concerns. If they qualify for help (in most LAs this depends on a needs assessment) and the council will pay for some/all of their support, they are entitled to a personal budget to pay for anything that has been agreed in the carers' support plan. The assessor (either from the Local Council or a local organisation chosen by the Council) will make a series of recommendations to meet the needs described – including signposting to local charities offering support or exercise to boost mood and health.[81]

But, as is true of many aspects of the current social care system, too many potential recipients (one in four) are unaware of the existence of the Carer's Assessment.[82] Moreover the CSJ has heard from frontline workers about the lengthy waits that their clients have encountered when applying for an assessment (the same was true for the assessment of the individual they cared for).[83] The Association of Directors of Adult Social Care (ADASS) found in 2022 that 600 individuals a day were joining the growing waiting lists for assessment in England; the "postcode lottery" that characterises so many elements of formal care applies here as well.[84]

Analysis by the Nuffield Trust reveals an 11 per cent drop between 2015/16 and 2020/21 in the numbers of carers in receipt of 'direct support'; access to breaks also declined during this period, by 42 per cent.[85]

Meanwhile, the number of unpaid carers who after a carer's assessment by the LA receive only information, advice or are signposted to other services grew by more than 36,000 between 2015/16 and 2020/21.[86]

Their struggle is a terrible injustice, given that unpaid carers save the tax-payer £162 billion according to Carers UK by caring for those who otherwise would have to rely on state or paid-for care.[87]

78 Carers UK, *Caring into later life: The growing pressure on older carers*, 2015.
79 Social Work in England, *State of the Nation 2023*, 9 March 2023.
80 NHS Digital, *Personal Social Services Survey of Adult Carers in England,* 2021-22.
81 Simon Bottery, *Home Care in England: Views from commissioners and providers*, The King's Fund, 11 December 2018.
82 Carers UK: State of caring 2022, *A snapshot of unpaid care in the UK*, November 2022.
83 ADASS, Association of Directors of Adult Social Care, Survey: *People waiting for assessments, care or reviews*, 4 August, 2022.
84 Ibid.
85 Charlotte Paddison, Nadia Crellin, *Falling Short: How far have we come in improving support for unpaid carers in England?*, Nuffield Trust, 10 October 2022.
86 Ibid.
87 Maria Petrillo, Matt Bennett, *Valuing Carers, 2021*, Carers UK and Centre for Care, University of Sheffield

Who needs care?

Even before Covid-19, boroughs faced an adult social care funding gap of approximately £130 million in 2020/21.[88] Post-pandemic, LAs have reported a significant rise in people needing LA support for the first time, driving 70 per cent of directors of adult social services to say they don't have enough money. [89]

One million 15-24 year olds and 2.8 million 25-44 year olds are disabled; this rises to 5.3 million among older people.[90] Access to care is patchy, with 80 per cent of people with mobility difficulties and 55 per cent of older people who have difficulty with an activity of daily life reporting they have not received formal or informal support, according to a recent analysis of the English Longitudinal Study of Ageing (ELSA).[91]

The Open University's series, Five Pillars for Ageing Well, highlighted the lack of good nutritional habits, hydration, physical activity, social and cognitive stimulation – which risk contributing to poor outcomes among the older population.[92]

The most disadvantaged are the most likely to need care: latest ONS[93] figures show a 19-year difference in healthy life expectancy between the least and most deprived areas of the country. A higher proportion of residents (18 per cent in the least deprived vs 13 per cent in the most deprived) in the most deprived local authorities (including Blaenau Gwent, Hartlepool and Blackpool) are claiming disability benefits while 54 per cent of women and 38 per cent of men aged over 65 in the most deprived local authorities need some form of adult social care compared to 26 per cent of women and 15 per cent of men in the least deprived local authorities.[94]

Given that the average amount local authorities spend on social care [95]per adult is lower in more deprived areas, it follows that those on low incomes are more likely to rely on a family carer.

Most minority ethnic groups in England have higher proportions of older adults with long-term conditions compared with the white British group.[96] These minority groups are also more likely to live with their children: 44 per cent of older adults from ethnic minority backgrounds receive care from a child they live with, compared to 18 per cent of white older adults.

88 London Councils, *Key Asks for the recovery of the Adult Social Care sector in London,* February 2021.

89 Ibid.

90 Esme Kirk-Wade, *UK Disability Statistics: prevalence and life experiences*, House of Commons Research Briefing, 23 August 2023.

91 Sarah Abdi, Luc de Witte, Mark Hawley, *Exploring the potential of emerging technologies to meet the care and support needs of older people: A Delphi Survey*, Geriatrics, *6*, 19, 2021.

92 Jitka Vseteckova, et al, *Ageing well Public Talks,* Open University 2021-22.

93 ONS, Health state life expectancies, UK, 2018 to 2020, 2021.

94 Constituency Data: Disability, 2021 Census, House of Commons Library, 5 April 2023; Esme Kirk-Wade, UK Disability Statistics: prevalence and life experiences, House of Commons Research Briefing, 23 August 2023; Sarah Bedford, Daniel Button, *Universal Quality Social Care: Transforming Adult Social Care in England*, New Economics Foundation, Women's Budget Group, January 2022.

95 NHS Digital, "Adult Social Care Statistics in England: An Overview", 17 November 2022.

96 Ruth Elizabeth Watkinson, Matt Sutton, Alex James Turner, *Ethnic inequalities in health-related quality of life among older adults in England: secondary analysis of a national cross-sectional survey*, The Lancet, 28 January 2021.

Demographic trends and projections

The UK ranks 16th in the International Longevity Centre's global "Healthy Ageing and Prevention Index".[97] The low ranking reflects our ageing and unhealthy population: people can currently expect to live for more than a fifth of their lives in poor health. More than one in five (22 per cent) individuals reported a disability in 2020 to 2021.[98]

With the number of older people set to increase much faster than the number in the age groups most likely to offer care, the LSE [99] has projected that by 2035 there will be demand for 8 million unpaid carers but only 6 million will be available.

Other demographic trends should also concern policy makers. By 2040, 6.2 million will live alone – half of them aged 80+.[100] Data shows that parents, currently, are the main recipients of informal care. [101] But if children are doing so much of the caring, what happens to the rising number of individuals who are childless? There is a risk that as they age, this proportion of the population will not be able to rely on the most common form of informal care. [102] The changing composition of families includes the rise of "silver splitters", those who divorce or separate in their fifties or later.

The CSJ has identified family breakdown as one of the five pathways that lead into poverty. Families can deliver support, physical, emotional and financial and relieve the sense of isolation [103] that individuals alienated from their families, or without families, cannot rely upon. Moreover without family support, older people and those with disabilities will have to pay (or pay more) for their care, or rely on ever-shrinking state-funded services. For low-income individuals, this can spell real financial hardship.

Evidence from the USA suggests that, with remarriage as well as family breakdown, relationships and responsibilities become more equivocal, with adult children feeling less able to support divorced fathers, for example.[104]

Already a higher proportion of childless older people receive more formal care (12 per cent) than those with children (7 per cent).[105]

In addition, there is evidence of an increasing number of family members living geographically further apart -- the dispersal of generations is driven by young people moving for education and work opportunities.

These trends are having, and will continue to have, significant implications for care-giving.

97 Carl Spiers et al, *Caring for older people as a social determinant of health*, Older Adults and Frailty Policy Research Unit, June 2022.

98 DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022*, 21 July 2023.

99 Andrew Harrop, Ben Cooper, *A national care service for all,* Fabian Society, 8 June 2022.

100 Ibid.

101 DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022* , 21 July 2023.

102 ONS, Data and analysis from Census 2021, *The number of people reaching old age without children*, 4 May, 2021.

103 ONS, Data and analysis from Census 2021, *The number of people reaching old age without children*, 4 May, 2021.

104 I-F Lin, et al., *The Roles of Gray Divorce and Subsequent Repartnering for Parent–Adult Child Relationships*, The Journals of Gerontology: Series B, Volume 77, Issue 1, pp 212-23, January 2022 .

105 ONS, Data and analysis from Census 2021, *The number of people reaching old age without children*, 4 May, 2021.

Our national survey

The CSJ commissioned Opinium to conduct a national survey of 1530 unpaid carers in November 2023. More than half (57 per cent) of respondents provided more than 9 hours of care a week. The care they delivered included emotional or mental health support (50 per cent), running errands (49 per cent), domestic chores (49 per cent), medical support (33 per cent), transportation (33 per cent), digital literacy (24 per cent), and financial help (22 per cent).

Alarmingly, our survey reveals that many family carers are finding the challenge of combining paid employment with their caring responsibilities is beyond them: 41 per cent of our respondents currently in work are either likely to reduce their hours or give up work altogether in the next year. Almost a quarter (23 per cent) of those aged 16-34 were likely to give up work altogether, while 16 per cent of those over 34 were likely to. Interestingly, older participants were less likely to say they will give up work altogether (7 per cent). Women (61 per cent) were more likely than men (39 per cent) to give up paid employment because of their caring responsibilities. Three in five of all unpaid carers (61 per cent) said that their care duties currently prevented them from taking up paid work or as much paid work as they'd like to.

Yet of the 61 per cent of those who said they could not work, the majority (65 per cent) said that they would take up paid employment if they could, while a similar proportion of those in part-time work (64 per cent) said they would like to increase their hours if they could. With the "right support" in place, three in five (59 per cent) would take up paid work, and almost seven in ten (69 per cent) part-time workers would increase their hours.

This report explores what that support should be; its cost; and the savings it would deliver.

Chapter Two:

Fiscal Benefits

Government, both central and local, has a role to play.

Central Government

The individuals who are the focus of our report are women (mostly) and men motivated by love and duty to care for a family member. They would balk at the suggestion that they need any inducements to undertake a task they view, as we have heard repeatedly in our interviews, as "rewarding" "an honour" and "my most important role". That many carers feel no need for external validation does not change our duty, however, to celebrate individuals who care, and offer them the best support possible, so that they may lead fulfilling lives. As a society, we should send the message that we value the most vulnerable among us – and those who care for them.

This is not just a moral imperative; it is a matter of self-interest. As noted earlier, government's oft-repeated mission to address economic inactivity can in part be achieved by supporting those unpaid carers who at present are staying out of the labour market. Almost 400,000 individuals [106]are currently economically inactive because of their caring responsibilities but, as our CSJ-Opinium national survey shows, the majority would willingly return to paid employment with the right support in place.

Fiscal Benefits

Changes to our tax and benefits system – including expanding eligibility, interaction between benefits and improving take-up -- could go a long way in supporting struggling carers.

The financial consequences of becoming a family carer can be life-changing.[107]

In many cases it means having to give up or scale down paid employment, yet even a small reduction in pay will have a significant impact on low-income households.[108]

The earnings of family carers fall by an average of £134 per month (7 per cent) after they begin caring, and continue to do so. Five years later, their pay is £804 per month (34 per cent) lower on average than before they started caring.[109]

106 DWP, *National statistics:Family Resources Survey: financial year 2020-2021*, 12 May 2023.

107 Sebastien Peytrignet, Fiona Grimm, Charles Tallack, *Understanding unpaid carers and their access to support*, The Health Foundation, 12 April 2023.

108 Carers UK, State of caring 2023: The impact of caring on: finances, November 2023; DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022*, 21 July 2023.

109 Tarek Al Baghal (ed.), Understanding Society Innovation Panel Wave 10: Results from Methodological Experiments, No 2018-06, May 2018.

Moreover the carer who reduces their hours of work or drops out of the labour market altogether compromises their pension. The unemployed and the under-employed are not covered by auto-enrolment and are missing out on employers' pensions contributions. Yet our current pensions system is predicated on the idea that the state pension is not sufficient for most individuals to enjoy a decent standard of living in retirement and that workplace contributions are critical as a complement. Policy needs to better support individuals to stay in paid employment.

The most recent Carers UK national survey of carers found that, in England: 39 per cent of carers were receiving Carer's Allowance; 16 per cent were receiving Universal Credit, of which 10 per cent were receiving Universal Credit with Carer Element; 22 per cent were receiving Council Tax Reduction/ Rate Relief.[110]

Carer's Allowance

Currently, to be eligible for the Carer's Allowance (£76.75 per week) the recipient must earn less than £139 per week and provide at least 35 hours' unpaid care. The person cared for must be in receipt of certain disability benefits, such as the Personal Independence Payment (PIP) or Disability Living Allowance (DLA), or the Attendance Allowance (AA).

The Carer's Allowance costs the government £0.9bn a year and 1.3 million individuals, 69 per cent of them women, are in receipt of this benefit.[111]

The earnings threshold tends to be uprated with inflation rather than average earnings, penalising paid work when wages rise faster than prices.[112] This means that carers are limited in their ability to undertake paid work while continuing their caring, which, as our survey showed, many of them wish to do.

In their recent annual survey of more than 10,000 carers, Carers UK found that 45 per cent of recipients of the Carer's Allowance reported that they were struggling to make ends meet.[113]

The CSJ suggested that the earnings threshold of the Allowance be raised and the benefit itself be raised. We carried out a cost-benefit analysis of this proposal, as per below:

Costs and benefits where:

- Carers Allowance earnings limit rises to £250 per week; and
- Carers Allowance for non-dependent adults increased by £5 per week and that for dependent adults increased by proportionately equivalent amount (a little under £3 per week); and
- 15 per cent of those working below 16hrs; working above 16 and below 21hrs; and above 21hrs; would move to working 16hrs, 21hrs and 36hrs respectively.

By raising the earnings limit to £250 per week, 270,000 additional working age carers in receipt of disability and incapacity related benefits become eligible for Carers Allowance across the UK.

110 Carers UK, *State of caring 2023, The impact of caring on: finances*, November 2023.
111 DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022,* 21 July 2023.
112 Joseph Rowntree Foundation, *The caring penalty*, 18 July 2023.
113 Carers UK, *State of caring 2023: The impact of caring on: finances*, November 2023.

Our proposal would see an increase of the award by £5 per week for non-dependent adults and by the equivalent proportional rise for dependent ones. This would apply to all 1.15m claimants (this includes the 270,000 new claimants) now on the benefit.

There also is an indirect assumption based on polling that of those working below 16hrs around 15 per cent move into 16hrs of work at National Minimum Wage (NMW), of those working above 16 and below 21hrs some 15 per cent move into 21hrs of work at NMW, and of those working above 21hrs about 11 per cent move to 36hrs of work at NMW.

The result of raising the earnings threshold and increasing the award by five pounds is that the cost to the exchequer of the new Carers Allowance (and the non means tested benefits expenditure of which it is a subset) rises to about £950m; however, over £500m is lost in the interaction with lower receipts of means tested benefits, tax credits and Universal Credit. This leaves extra welfare spend at circa £400m (in 2021-22 prices). As a result of more people getting into work, there is an increase of £80m across Income Tax and National Insurance (in 2021-22 prices). This means net fiscal cost-benefit in-year is within £300-£340m (in 2021-22 prices).[114] (For absolute upper end scenario please see Appendix 2).

To boost income for family carers who are not in paid employment, we recommend that the DWP should explore moving the Carer's Allowance recipients with the lowest 20% of household income to the UC system, where they will receive the carer element in addition to the Personal Allowance, thereby protecting the most disadvantaged carers from penury. Moving to the UC system should take approximately five weeks

Many who need help with care will qualify for a disability benefit – Personal Independence Payment (PIP) when they are below pension age and Attendance Allowance if they are of pensionable age – that is not means tested. These benefits can ease the financial pressure on their family carers, too, by reducing the outlays they would otherwise have to make. Attendance Allowance, however, has a very low take up rate.[115] One reason, according to Paul McGarry, head of the Greater Manchester Combined Authority Ageing Hub, "is that some people really worry about speaking to DWP in any form because they think it will affect their benefits."[116]

An additional concern carers have raised about Attendance Allowance is that to be eligible the individual they care for has to have been in need of care for six months. The delay risks needs escalating and leaving the carer struggling for six months without much-needed financial support.

Recommendation:

The DWP should raise the Carers Allowance earnings limit to £250 per week; and increase Carers Allowance for non-dependent adults by £5 per week and that for dependent adults increased by proportionately equivalent amount (a little under £3 per week).

114 IPPR tax-benefit model.

115 DWP, *Income-Related Benefits: Estimates of take-up data for financial year 2017/18*, February 2020.

116 Interview with Paul McGarry, April 13 2023.

Recommendation:

The DWP should explore moving the Carer's Allowance recipients with the lowest 20% of household income to the UC system, where they will receive the carer element in addition to the Personal Allowance, thereby protecting the most disadvantaged carers from penury.

Recommendation:

The DWP should roll out a communications campaign to improve take-up of Attendance Allowance and Pension Credit.

Recommendation:

The DWP should reduce the six-month waiting period for the Attendance Allowance to three months, bringing it into line with other disability benefits.

The Pension Credit is another benefit that has poor take-up, yet could support carers and those they are looking after. About 2.5 million older people are entitled to receive Pension Credit to top up their retirement income, yet around two in five aren't claiming it. [117] In 2022–23 the weekly thresholds were £182.60 for single people and £278.70 for couples. On average, single people receive £61 a week in Pension Credit and couples receive £85 a week.[118] Lone households are significantly more likely to be in relative income poverty than couple households: while the rate of poverty stands at 14 per cent for couples, it climbs to 23 per cent for single men and 27 per cent for single women.[119]

Research commissioned by Independent Age in 2020 showed that, at that time, increasing Pension Credit uptake could lift more than 400,000 older people out of income poverty, and halve severe income poverty to 4 per cent.[120] The same study, conducted by Loughborough University, calculated that if everyone entitled to Pension Credit received it, the government would save £4 billion on health and social care costs.[121]

The low take-up of these crucial benefits highlights the need to identify and register all family carers and support their navigation of the social care system.

117 Thomas Wilson, Phil Mawhinney, Shelley Hopkinson, *Credit where it's due: A briefing on low uptake of Pension Credit: The context, the issue, and what action must be taken*, Independent Age, November 2022.

118 Ibid.

119 Ibid.

120 Ibid.

121 Thomas Wilson, Phil Mawhinney, Shelley Hopkinson, *Credit where it's due: A briefing on low uptake of Pension Credit: The context, the issue, and what action must be taken*, Independent Age, November 2022.

International comparisons

Italy

8 million family carers: 17.4 per cent of population. [122]

3 days paid leave per month for short term care plus up to two years of paid leave to care for disabled children or relatives.Congedo Straordinario Biennale Retribuito supports those who live with the recipient of care: 100 per cent of employees' wages are paid in full by the social security agency INPS.

Indemnity di accompagnamento (attendance allowance (IA)), is a fixed monthly fee (currently €527) paid to the families of people who need care and support, regardless of income. IA was originally introduced in 1980 for those supporting disabled people but was soon extended to carers for those aged 65 and older. In 2012, the Italian National Institute of Statistics reported that about 1,530,000 older citizens had benefited from this monthly fee.

Italy defines a differentiated access to the care leave for different relatives, with priority for spouses.

For long-term leave models, Italy (2.7 per cent) reports the largest share among the EU of eligible employees who use a care leave.

DA.L.I.A: government funded one stop shop for information and training for carers seeking to stay in or return to employment.

Canada

7.8 million family carers: 25 per cent of population aged 15 and older.[123]

8 per cent received federal tax credits, and 6 per cent received funds from a government programme.

Caregivers provide more than 2/3 of care required at home.

Provincial governments fund home care and other support programs and services for people who receive care and set some criteria, but need is assessed by regional authorities and services are delivered by local agencies.

Provincial governments fund respite and other support programs and services for people who provide care and set some criteria, as above.

The Canada Caregiver Credit (CCC) is a non-refundable credit that provides a maximum of $7,348 to caregivers of dependent relatives, or up to $2,295 for the care of a common-law partner, spouse or minor child. Non-refundable credits reduce the amount of tax paid each year.

122 Francesco Diodati, *Il riconoscimento della fatica della cura: Invecchiamento e caregiving in Emilia-Romagna*, Dipartimento delle Scienze Umane, Universita degli studi di Milano-Bicocca, 2020-21.

123 Daniel Hango, *Support received by caregivers in Canada*, Insights on Canadian Society, 8 January 2020.

The Family Caregiver Benefit is available to employees caring for someone who is critically ill or injured and can be paid for up to 15 weeks. These are paid as up to 55 per cent of a person's earnings, to a maximum of $638 per week. Caregivers are eligible during the 52 weeks following certification by a medical practitioner, providing they worked at least 420 insured hours in the 52 weeks prior to the claim.

France

8.3 million family carers: 12.7 per cent of population

Six months unpaid leave with social insurance for employees in companies of over 15 workers.

Family Leave Act grants employees statutory right to work part time for two years in companies with over 15 workers; and reduce their working hours by a minimum of 15 hours for a maximum of two years.

In France care leave models are used by less than 2 per cent of the eligible population.

State-funded loans available for carers working part time which has to be repaid when carer goes back to fulltime.

Care Support Payments for short term leave of up to 10 days for acute care needs paid through long term care insurance – usually covers up to 90 per cent of earnings.

Chapter Three:

Registration and Navigation

Registration

Most people do not plan to look after a vulnerable family member. An accident, a health crisis or a sudden degeneration of an existing condition, catapult them into becoming a family carer.[124] For many, tradition demands individual self-sacrifice for the welfare of the wider family.

Feeling confused and often overwhelmed, the family member risks struggling through a complex system of appointments, assessment interviews and form-filling. In many cases, they will face financial losses and logistical hurdles. Their claims may be challenged, or rejected outright. They may not be familiar with local charities and voluntary groups that support carers with anything from day centres to free transport; and they may seek emotional support.

Moreover, they are often invisible, as many "informal" carers do not recognise themselves to be carers: they take their role for granted. The absence of an official register compounds the challenge of identifying a carer, whether formal or informal. This makes data collection very difficult and risks compromising the welfare of a valuable cohort who may be forfeiting benefits and entitlements simply because they are invisible to the NHS, the DWP and their Local Authority.

Currently, Home Improvement Agencies offer advice regarding welfare and benefits; as do charities such as Age UK and MENCAP. Some employers are also delivering support for their employees struggling to navigate the social care system: the Air Concierge Service offered by the Phoenix Group insurance provider is one example.

But for most family members the first port of call will be the GP or hospital: this is where they first understand that their vulnerable spouse, parent or child has caring needs.

New duties in the Health and Care Act 2022 require health professionals to involve carers, especially in hospital discharge.[125] Yet family carers have told the CSJ that GPs, consultants and other health professionals routinely ignore their presence, even when they are accompanying the patient to and from their visits to the surgery or hospital. This is confirmed by Carers UK research, which found that 30 per cent of carers felt their physical and mental health needs were not taken into consideration by healthcare professionals.[126]

124 Thomas Wilson, Phil Mawhinney, Shelley Hopkinson, *Credit where it's due: A briefing on low uptake of Pension Credit: The context, the issue, and what action must be taken*, Independent Age, November 2022.

125 Gov.UK, *Health and Care Act 2022*, Chapter 21.

126 Carers UK, *State of Caring 2021 report,* November 2021.

Although some GP practices do have a carer's register and include a marker for patients who are carers in their records, the statutory duty on health professionals should be extended, so that they be required to establish whether the individual accompanying an older adult, or someone with disabilities to the surgery/hospital, is their family carer and, if so, ensure they register with a national Family Carers' Register. Their details can in this way be shared with adult social care services and social prescribing link workers. Registered family carers would receive formal accreditation with associated benefits. These would include priority on council and housing association housing lists when they want to move closer to the recipient of their care (see our Housing chapter); consideration from GPs/ counsellors when they accompany their relative to appointments; signposting to specialist support.

Recommendation:

Introduce a Family Carer's Register to allow national and local government, as well as community organisations , to identify and support this cohort.

Navigation

Many family carers are also forfeiting benefits and support because they do not know how to navigate the complex social care system.

To ease the carer's navigation of the complex social care system, we propose the publication of a Local Offer for Adult Social Services; and a One Stop Shop for Carers.

All Local Authorities are required to publish information about services in their area for children and young people who have Special Educational Needs or Disabilities (SEND) and services outside their area that local children and young people with SEND are entitled to use. This is known as a "Local Offer".[127]

Jess McGregor, Director of Adult Social Services at Camden Council, proposes that LAs be required to publish a statutory "Local Offer" of adult social services.[128] This would enable carers to understand what services they could avail themselves of, and what services the friend or relative they were looking after was entitled to. Social prescribing would be folded into the Local Offer – as would navigation.

Recommendation:

All Local Authorities should be required to publish a statutory Local Offer for Adult Social Services, similar to the one they are required to publish for children and young people with SEND.

127 See for example, Manchester City Council, Local Offer, 2022.
128 Interview with Jess McGregor, 2 June 2023

The government acknowledged that navigating the system is a full time job in its recent White Paper, "People at the Heart of Care: Adult Social Care Reform."[129] The White Paper pledged to create a website providing simple explainers about social care reform. Our interviews with family carers found, however, that when seeking support, they prefer a one on one conversation with someone who will listen to their concerns as well as guide them through the labyrinth of benefits and entitlements. Peer to peer support, with families in similar caregiving situations, can serve as a useful transfer of knowledge. Other mechanisms could include patient and caregiver support groups, workshops, group retreats, and shared respite care.

Case Study: Carol

"I looked after my mother who had dementia. I managed every aspect of her everyday life which was, at times, overwhelming. It made me realise that you only get what you want when you shout! It also brought home to me that I was without children: who would do for me what I was doing for my mother? The answer was no one. I decided that I should become more pro-active about ageing... I live in a very tight-knit neighbourhood in South London – we are a lively, feisty group that has had to take on developers several times, and have grown into a strong community. During Covid we were looking after our older residents – doing the shopping and picking up prescriptions. So I decided to tap into this pandemic spirit and set up what I call the "Elders" group. The idea is to support one another into a healthy old age. We realised from the outset that we didn't know anything about what support was already out there – we didn't know about social prescribing, or the Integrated Care Board, or even about benefits our family might be entitled to as carers. It is such a complicated and fractured system, we need a directory.

Interview with CSJ, 12 September 2023

Case Study: Jonie Hawksley

"Social workers are not trained to help you navigate the system yet for most disabled adults your social worker is your only contact with local social services. They need to be better informed, and better trained: signposting is so important… We only knew about what the support we could receive from our local charities because of our parents' WhatsApp group – and we only met other parents through hospital visits. Navigation should instead be part of a GP surgery.

"GP is the first port of call and assess the needs and then should refer us to social worker, who should then refer to the specialist dietitian, physiotherapist, etc. but also to local facilities/ activities. Unfortunately the GPs are snowed under and in any case their priority is not quality of life but life or death conditions.

"Social workers should say there is a local Mencap group around the corner, this is what they offer. Instead, they don't seem to know about half the local support. And when they are good, they stay in post less than a year, so it doesn't help."

Interview with CSJ, 2 June 2023

129 DHSC, *People at the Heart of Care: adult social care reform white paper*, 18 March 2022.

Family carers should not be burdened with finding their way through a labyrinthine social care system: they have enough to contend with. They need a One Stop Shop for Carers, where individual health professionals/social prescribing link workers clearly explain the fiscal benefits, community support services, national and local government entitlements, available to family carers. As well as a dedicated, one on one meeting, there should be checks-ins along the carer's journey, as and when circumstances change, for example when dementia takes hold, or when moving from the family home becomes imperative.

The initiative, which would represent a significant step towards the crucial integration of health and social care, would be complemented by peer to peer groups. Digital support should also be put in place, but digital inclusion should not be taken for granted among low income households and among older individuals. For example, among those over 65, 25per cent are not online. [130]

Surveys of family carers [131]have highlighted that lack of information about available support was a barrier to having their needs met. A One-Stop-Shop for carers will allow more working age carers to access support so that they may stay in, or return to, paid employment while looking after a family member.

The same service can be delivered in hospitals, too.

An NHS Trust and Foundation Trust could fund the One-Stop-Shop through the Apprenticeship Levy, which represents 0.5 per cent of the pay bill for organisations with a pay bill of £3 million or over.[132] The NHS pays £200 million into the apprenticeship levy every year*:* many trusts have thus accrued significant levy pots which can be spent on apprenticeship training at any level. Apprentices spend 80 per cent of their time learning skills on the job, and 20 per cent of their time learning at college or university.

Family carers would self-refer or be referred by GPs, consultants, or hospital staff. Health professionals in the One Stop Shop for Carers would register them, entering their details on a database shared within the wider Integrated Care System. This data-sharing would spare carers having to repeatedly explain their circumstances. It would also protect the family member they care for from falling through the gaps as they are moved between different care settings.

Finally -- and crucially -- the One Stop Shop would reassure family carers that they are valued.

Recommendation:

Introduce a One Stop Shop for Carers that guides the family carer through the social care system. Major hospitals could fund this through the NHS Apprenticeship Levy. In GP surgeries, it would be run by social prescribing link workers. One Stop Shops would facilitate data sharing across an ICS, helping to progress the integration of health and social care.

130 Homes, H; Burgess, G., *Digital exclusion and poverty in the UK: How structural inequality shapes experiences of getting online*, Journal of Digital Geography and Society, 2022.

131 Carers Uk, *State of Caring 2023, The impact of caring on: health*, November 2023.

132 NHS England, Integrated Urgent Care / NHS 111 Workforce Blueprint: Apprenticeship Scheme, 2018.

Chapter Four:

Domiciliary Care

Since the pandemic, more and more people prefer care in their own home.[133]

Many will have to pay for this themselves. Only those with under £23,250 in savings are eligible for this means-tested benefit (house value is not taken into account in the assessment).

Domiciliary care is indispensable for families who provide unpaid care, complementing their role and providing them with a few hours' respite. It is also key for reducing pressure on health services: 21 per cent of Delayed Transfer of Care (DTOC) days in England in 2019/20 were due to individuals waiting for a care package in their own home. The cost to the NHS of this delay is estimated to be £30m.[134]

Many hospitals have "reablement" or "after care" teams who will visit for up to six weeks following a hospital stay. [135] They are free of charge and usually the team consists of two carers or one nurse and one carer (depending on needs as assessed by hospital discharge team). The teams also offer respite to the family carer.[136] This support, however, is temporary. Those individuals in need of care at home, whether to substitute or complement their family carer, must rely on domiciliary care.

The sector is in a perilous state: there is a shrinking work force, with vacancy rates reaching 14.1 per cent in October 2022, just as the Department for Health and Social Care have predicted that 57 per cent more adults aged 65 and over in England will require homecare in 2038 compared to 2018.[137]

Local authorities provide domiciliary care, commissioning mostly from independent (private and voluntary) sector service providers. Providers include for-profit, non-profit and third-sector organisations. Outsourcing and use of external providers mean that standard forms of employment do not apply.[138] Zero-hour contracts, low pay and long traveling times for which they are not paid have contributed to the exodus from this workforce.

Service providers meanwhile argue that they are forced into these insecure working arrangements because of councils' spot contracting and the resulting low profit margins. They also report that their commissioning contracts from LAs are too low to cover costs – indeed, many providers are handing back contracts to LAs.[139]

133 YouGov UKHCA, Public Care Survey, July 2021.

134 Skills for Care, *The state of the adult social care sector 2022*, 2022.

135 Social Care Institute for Excellence, *Reablement: a guide for carers and families*, September 2020.

136 Suzanne Hughes, Sarah Burch, *I'm not just a number on a sheet, I'm a person': Domiciliary care, self and getting older, Health Social Care Community, 28(3): 903–912 May 2023.*

137 Skills for Care, *Domiciliary care services in the adult social care sector,* 2021-22.

138 Carol Atkinson, Sarah Crozier, *Fragmented time and domiciliary care quality*, Business School, Manchester Metropolitan University, 2019.

139 ADASS 2019, The King's Fund, 2018-9 quoted in *Innovation in UK Independent homecare services: a thematic narrative review*, 2020.

Commissioners have focused on cost and efficiency, which has led domiciliary carers to deliver very short care visits (eg an average of 30 minutes). [140] The requirement to do more in less time risks compromising care quality.[141]

The domiciliary care sector has attracted other criticisms from users: the timing of visits is unreliable, there is no continuity in terms of personnel, and many care workers are unwilling to discharge any kind of duty, however minor, that is not explicitly part of their contract. [142] Complaints to local councils are too often unanswered, as one parent of an adult with complex needs reported: "We have formed a Parents Active group that meets regularly and our meetings are awash with evidence of a lack of transparency, openness and respect in the way the Council deals with residents and their inquiries. Time after time, with their situations desperate, they meet a brick wall. It was shocking that among our small group, two or three residents were seeking help from the Local Government and Social Care Ombudsman or were in mediation. The amount of work and stress for any individual to get to that point is enormous. At the end of the day, it is not about money, but about how Council officials treat residents."[143]

Cost is an issue, however. Overnight home care usually costs £17 an hour while day time care is on average £18-20 an hour. Such pricing prevents many family carers from drawing on the support available, with significant impact on their own welfare as well as their relative's.

LAs' failure to deliver a domiciliary care service that is both comprehensive and high-quality risks accelerating the need for a state-funded place in a care home which is far more expensive, as the King's Fund has argued: "free domiciliary care would pay for itself if it delayed entry into residential care by four months".[144]

A handful of Councils are piloting innovative schemes for domiciliary care services: "The issue is that we don't need more people, we just need to treat the people we have better. 43% turn-over is simply not good enough," John Bryant, Head of Integration and Development at Torbay Council told the CSJ.[145] Under his lead, the Council has introduced a scheme to upskill and increase the numbers of domiciliary carers.

140 Lucina Rolewicz, Camille Oung, Nadia Crellin, Stephanie Kumpunen, *6 Practical lessons for implementing technology in domiciliary care: Learning for commissioners and policy makers*, Research Summary, Nuffield Trust, September 2021.

141 Carol Atkinson, Sarah Crozier, *Fragmented time and domiciliary care quality*, Business School, Manchester Metropolitan University, 2019.

142 Ibid.

143 Interview with the father of a disabled adult child

144 Laura Bennett, Matthew Honeyman, Simon Bottery, *New models of home care*, The King's Fund, December 2018.

145 Interview with John Bryant, 27 July 2023.

Case Study: The Torbay Model

Interview with John Bryant

Torbay is 25 years ahead of the rest of the country in terms of our ageing population. To meet demand for care, I suggested a new model. I would redefine the role of domiciliary carer by upskilling them so they become what I call 'enhanced wellbeing practitioners.' Drawing together GPs and domiciliary carers, we introduced a Kit4Care: blue-toothed technology that allowed domiciliary carers to take blood pressure, oxygen levels, temperature and pulse. This gives readings, captures statistics relating to the cared for person's condition(s) which goes back to a clinical hub or GP practice. It's key to avoiding deterioration and prevention, as the minute the individual's statistics change there can be an intervention.

It's vital that we give people not only competence but the confidence to undertake these additional responsibilities. The training needs to be kept within a clinical and well-regulated environment.

The development of the role, whilst taking pressure of the system and getting better outcomes for people is to generate appetite among domiciliary care workers –'I want to do that too.'

The kits can be used to support the safe discharge of patients in at-home settings, where they can be monitored and reported on by trained practitioners with digital skills and tools to monitor and report as part of a multi-disciplinary health and care team.

From a small Test of Merit, run with goodwill and good-heart by GPs and care providers, I was able to raise £250k for a scaled proof of concept… my aim is to give the domiciliary carer competencies to flourish.

Interview with CSJ, 27 July 2023

Free domiciliary care

In Scotland, domiciliary care is free to anyone who needs it, without means testing. This has had promising results: despite driving increased demand for domiciliary care, by "supporting people to live at home, helping to prevent costly hospital admissions, and delaying the need for residential care, the system may have resulted in lower total government expenditure".[146]

Although the Scottish model may have led to improved outcomes, Hammersmith and Fulham Council is unique in England in delivering free home care to their residents.

146 Simon Bottery, Michael Varrow, Ruth Thorlby, Dan Wellings, *A fork in the road: Next steps for social care funding reform,* The costs of social care funding options, public attitudes to them – and the implications for policy reform, The Health Foundation, 2018.

Case Study: Hammersmith and Fulham

Interview with Councillor Ben Coleman

We decided years ago that having to pay for domiciliary care is a tax on old age and disability. We realised that people who pay for their care are only getting the support they can afford rather than the support they need.

We are offering more care per head than any other council in England. It does get more and more difficult with every funding round as budgets are cut and the proportion of older and disabled increases. It costs us approximately £1 million per year but if you balance the loss and look at the numbers of people who remain at home longer rather than enter residential care it makes sense: we discharge approximately 25% more people home from hospital and have seen a reduction in demand for residential care. Looking at the costs per unit -- £15k for home care, £20k for direct payments, £60k to keep someone in residential care.

We believe in doing things *with* residents and not *to* them. The council is implementing across its services the recommendations of our local "Disabled People's Commission", which said we should co-produce with Disabled residents everything the council does that affects them on the "nothing about us without us" principle. This is challenging but part of our determination to be the best council for Disabled people.

We have also a senior leadership team who all have "Independent Living" as part of their responsibilities and who lead co-production with residents. We encourage Direct Payment from council to residents to design and organise the support they want. For instance we have support to find personal assistants, and then how to be an employer of a PA, how to budget accounts and more. We are currently focusing on improving the quality of care at home from our commissioned providers (more flexibility, consistency, etc).

We had four main providers of services, now increased to twelve, and we offer provision of care "bridging" when there is a gap between carers and someone needs support to be discharge from hospital.

We pay our staff travel time and London Living Wage and we check with all contractors that this is really being paid. You have to manage contracted services, and we meet with our providers regularly and monitor contracts. We introduced regular meetings with domiciliary carers too, and ask them, so what does the rota feel like? Are you being paid for your travel time? Are you being paid LLW? Do you know who to ring when an issue arises? A Quality Assurance Framework is indispensable.

We often have other councils coming to see our model – but so far no one else has decided to adopt our approach. It has to be said, Hammersmith and Fulham council do cover an affluent area, and our demographics when we started with free domiciliary care did not have as many older residents as there are in, for instance, Bournemouth or Eastbourne. So we do not stand there and tell others what to do – every council has its own particular needs.

Interview with CSJ, 18 November 2023

As Councillor Ben Coleman admitted to the CSJ, delivering free domiciliary care represents a significant expenditure for a Local Authority. But in its survey of 1,530 unpaid carers, the CSJ found that 10 hours of free domiciliary care support would enable 40 per cent of carers providing 10-19 hours of care a week to return to work or to work more.

Based on estimates from the Homecare Association[147], assuming pay at the National Living Wage, the minimum total cost of such care would be around £26 per hour once other costs are factored in (e.g. travel time and expenses, training costs and management costs).

The total cost per person would therefore be around £13,520 per annum. If this free care were offered to the 10 per cent of adults with the most serious needs, it would be provided to people being looked after by around 350,000 unpaid carers of working age in England, according to 2021 Census results.[148]

The estimated annual cost of this policy would be around £4.7 billion, based on the above assumptions. Table 1 below shows the estimated economic and fiscal cost benefit analysis for this option after taking account of the employment effects suggested by our survey. Based on survey results, scaled to reflect England population estimates, 10 hours of free domiciliary care would increase employment by around 43,000, while around 15,000 unpaid carers already working would be able to increase their hours of work from part-time to full-time. The table shows estimated GDP and fiscal impacts for this policy option in its first year of operation based on these assumptions and separate CSJ analysis of Family Resources Survey (FRS) data for the benefit savings for unpaid carers moving into work.

Table 1: Economic and fiscal cost-benefit analysis for 10 hours/week free domiciliary care option

£ BILLION PA	ECONOMIC COSTS AND BENEFITS	FISCAL COSTS AND BENEFITS
Cost of policy	4.7	4.7
GDP (gross earnings from employment) increase	1.5	
Income tax and NI increase		0.4
Benefit savings (Carers Allowance, Income Support/ Universal Credit and Housing Benefit)		0.3
Net benefit/cost	**-3.2**	**-4.0**

We can see that the policy could boost GDP by around £1.5 billion, offsetting just under a third of the total cost of delivering ten hours of free domiciliary care. This costing does not, of course, take into account the very significant welfare benefits to recipients: though harder to quantify in financial terms, these are potentially transformative in terms of the health and well-being of both the family carer and the recipient of their care.

In terms of the fiscal analysis, the offsetting tax revenues and benefit savings for unpaid carers supported to work more would add up to an estimated £0.7 billion, reducing the net cost to the public finances to around £4 billion pa. In addition, supporting care at home has been shown to reduce demand for (more expensive) residential care.[149]

147 Homecare Association, Homecare Association Minimum Price for Homecare 2023-24, December 2022.
148 This calculation is made in order to control costs.
149 Benita Pusch, Ruthe Isden, *Behind the headlines: the battle to get care at home*, Age UK, 2018.

Recommendation:

Government should deliver 10 hours free domiciliary care a week to the 10 per cent adults with most needs. There are significant economic and fiscal benefits due to supporting unpaid carers to work more, which reduce the net cost of the policy, although they cannot offset it totally. This however needs to be considered alongside the purpose of the policy, which is to improve the wellbeing of care recipients and to ease the mental and physical burden on unpaid carers.

Case Study: Japan's caring vouchers

With the world's longest life expectancy and a low birth rate, Japan has long had to address the demographic challenges represented by an ageing population. One scheme, "Fureai Kippu", or caring vouchers, has proved a particularly popular multi-generational domiciliary care scheme. The vouchers allow volunteer members to earn credits for caring for an older or disabled individual which they can then exchange for their own care later in life or the care of a relative. [150] As a member of this time bank system, the volunteer can earn credits in one part of Japan and send them home to their parents to use, getting another scheme member to care for them; or alternatively they can keep the credits to be redeemed years later, when they themselves need a carer. The scheme supports older people to live independent lives, integrated within their local community. It has also been shown to stoke social capital,[151] connecting one generation to the next in a virtuous cycle of mutual support. There were more than 910 time banks recorded across Japan before 2012. When the service recipients do not have sufficient time credits to exchange for the service, they have to pay a modest fee to the organisations rather than the care providers. The system relieves the pressure [152]on formal service provision and on community service resources.

Different funding models

Families can use different ways of funding at-home care. Cash for care schemes -- direct payments, Personal Health Budgets and Individual Service Funds – have become more popular with recipients of benefits because they allow greater choice and control over care arrangements and as a result can reduce pressure on family carers. These schemes only fund personal care, and only within a limited budget. Direct payments, such as those being offered by Hammersmith & Fulham, and personal health budgets, are approved through a council assessment to purchase services chosen by the family carer or their relative from a provider of their choice. Direct payments are budgets managed either in the form of pre-paid cards or cash direct into the bank accounts of those in need of care; for carers, these direct payments can cover the cost of health and wellbeing support, from gym memberships to CBT sessions. Together with personal health budgets direct payments are managed by the LA; ISFs are paid directly to a provider for care for an individual to meet their needs.

150 Hayash,M, "Japan's Fureai Kippu Time-Banking in Elderly Care: Origins, Development, Challenges and Impact", *International Journal for Community Currency Research*, Vol. 16, p37, 2012.

151 Ng, T.K.C., Fong, B.Y.F., Leung, W.K.S., "Enhancing Social Capital for Elderly Services with Time Banking" ref. in "Ageing with Dignity in Hong Kong and Asia", Quality of Life in Asia, vol 16. Springer, Singapore. 2019.

152 Ng, T., Yim, N. & Fong, B, "Time banking for elderly in Hong Kong : current practice and challenges ",CAHMR Working Paper Series No. 2, Issue 1, 2019.

It should be noted that a recent evaluation of these cash for care schemes found that they did not have a transformative impact on care recipients. [153] Family carers, however, have reported that they enable greater flexibility and control regarding care-giving, and provide welcome support. This is especially true when direct payments and personal budgets are used to fund a personal assistant to complement the family carer in terms of respite and companionship. The care recipient is responsible for the personal assistant's pay, taxes, contract and pension and needs to arrange and pay for any training and supervision as well as any necessary items (gloves, aprons, etc.)

Care Co-operative

Research underlines the importance of "a relational, person-centred care delivered by consistent, regular formal carers".[154] Participants who developed a trusting relationship with their carers spoke of experiencing security, familiarity and friendship. This was particularly important for individuals living on their own.

A Care Co-operative is a members-owned organisation that provides care for individuals in receipt of Direct Payments or Personal Health Budgets (provided for care of dependants). A group of "members" and their Personal Assistants (PAs) team up to cover each other's care needs. It is subject to regulation by the Care Quality Commission (CQC). Its size allows members to "know" the PAs that might work for them while being able to sustain a team of PAs that can cover sickness and holiday absences. Members of care co-operatives have reported that by pooling resources they achieved greater efficiency and social connections.[155]

Buurtzorg Model (The Netherlands)

The model was developed in 2007 and consists of a team of 10–12 nurses who manage their own case work and decide care provision and delivery for 50–60 patients in a local area. They deliver the kind of clinical care that community nurses deliver, supporting with washing, eating, dressing and toileting), reablement. Each client will have the same team member taking care of them throughout. Nurses arrange appointments directly with clients and co-produce personalised careplan with them. Nurses encourage clients to reach out to informal support networks. Client cases discussed and co-managed at weekly team meetings. A small number of back-office staff deal with finances and administration, supported by comprehensive IT system.

Buurtzorg adopted a flat per-hour payment method for its services. Nurses are entitled to decide the amount of care needed for each patient. They also train family carers to support the patient's ability to live independently.

Adapting the Buurtzorg model to Uk has proved challenging. A pilot in West Suffolk evaluated by King's Fund found in 2017 that the recruitment crisis in nursing, and the lack of adaptive IT infrastructure in health and social care had left the team of nurses struggling with self-management; it also exposed a lack of thorough training and support for the nurses.

153 James Woolham, et al, *Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment,* Cambridge University Press, 22 January 2016.

154 Suzanne Hughes, Sarah Burch, *I'm not just a number on a sheet, I'm a person': Domiciliary care, self and getting older, Health Social Care Community, 28(3): 903–912 May 2023*.

155 Jonathan Oliver, *A Social Care Cooperative: Doing care differently*, University of Hertfordshire, February 2023.

Chapter Five:
Housing

The Government's recent 'People at the Heart of Care' White Paper [156] places housing at the heart of an adult social care strategy, pointing out that older people, and those with a disability, are more likely to spend more time confined indoors. With almost half (48 per cent) of carers looking after someone living under their own roof, [157] and 38 per cent of people with a disability living with family, appropriate housing is also crucial to the carers' experience. [158] Even when they are not living with the recipient of their care, knowing them to be living in suitable accommodation frees the carer of constant worry. In some cases this frees them also to step into, or back into, paid employment should they wish to.

Providing suitable housing for the most vulnerable would not only ease pressure on family carers but also on the social care system and the housing market. The cost to the NHS alone, as a result of poor and ill-suited housing, is estimated to be £1.4bn across England.[159]

Over half (54 per cent) of households in the social rented sector and just under a third of private renters have at least one household member with a long-term illness or disability;[160] 37 per cent of households [161] who own outright include someone with a disability; and one million owner-occupied households living in poverty are headed by someone aged 55 or over. [162] Housing for these individuals must meet very specific needs.

Currently, in most cases, it does not. Poor planning policies at a local level and a failure to reach development targets at a national level have created a housing shortage. A limited supply of, and an ever-increasing demand for, housing allows developers and private landlords to ignore calls for improving their stock, as demand for housing far outstrips supply. Our working group, which includes representatives of carers' charities, stressed that although the National Planning Policy Framework places obligations on local planners and policy makers to conduct an adequate Housing Needs Assessment when devising a Local Plan, too many have little understanding of the special needs of older and disabled residents.

156 DHSC, *People at the Heart of Care: adult social care reform white paper,* 18 March, 2022.
157 DWP, *National statistics: Family Resources Survey: financial year 2021 to 2022*, 21 July 2023.
158 Mencap, *Funding supported housing for all,* April 2018.
159 National Housing Federation, Older Person's Housing Group, 2022.
160 DLHUC, English Housing Survey 2021 to 2022: national statistics headline report, 15 December 2022.
161 Centre for Ageing Better, *Housing - The State of Ageing 2022*, 2022.
162 DLHUC, *National statistics English Housing Survey 2021 to 2022: headline report*, 15 December 2022; Centre for Ageing Better, *Housing - The State of Ageing 2022*, 2022.

Low Quality Housing Stock

The lack of suitable housing has a significant impact on family carers who are fearful for their loved one's safety and therefore reluctant to leave them alone at home. This limits opportunities for paid employment.

In 2022 15% of homes failed to meet the Decent Homes Standard and 8 per cent had a Housing Health and Safety rating Category 1 hazard (representing a serious and immediate risk to a person's health and safety).[163]

Almost 1 in 5 homes headed by someone aged 60 or older is in a condition that endangers the health of the people who live there.[164] The poorest among them are most likely to experience issues such as poor insulation or inaccessible entryways and bathroom facilities in their homes.[165] One in four parent carers find their disabled child's housing unsatisfactory and 61 per cent of local authorities admit that local housing arrangements do not meet the needs of people with a learning disability.[166]

In July 2022 the Government pledged to raise the accessibility standard for new homes, to benefit those with a disability and their carers; but it has yet to commit to improve the choice of housing for the older population and there is no national policy requirement for Local Authorities to include age-friendly principles in their local plans.[167] While the NPPF asks that "the size, type and tenure of housing needed for different groups in the community should be assessed and reflected in planning policies…", there is no similar requirement for age-friendly spaces, transportation links, or health infrastructure such as GP practices, pharmacies, hospitals.

Insufficient housing stock

Housing stock (especially social housing stock) fails to meet present needs. The Conservative Party manifesto pledged to build 300,000 new homes every year by the mid-2020s. The Rt Hon Michael Gove, then Housing Minister, scrapped the commitment in December 2022.[168]

Councils and developers disagree about the barriers to building accessible (category 2 or 3) homes. A recent survey found that LAs complain that developers challenge planning policies, on the basis that meeting additional specifications risks reducing their profits.[169] Developers meanwhile express frustration at the failure by Local Authorities to create a business-friendly environment: a lack of transparent and long term planning has left developers feeling uncertain and therefore unwilling to commit to investment.[170] They point out that Government's planning policies for England, set out in the National Planning Policy Framework, calls on Local Authorities to publish local plans explaining what they envisage for the future, preferably with a 15-year time frame.[171] Yet less than half of LAs have published a local housing plan.

163 DLHUC, *English Housing Survey 2022-3*, 14 December 2023.
164 Centre for Ageing Better, *Housing - The State of Ageing 2022,* 2022.
165 Ibid.
166 Mencap, *Funding supported housing for all,* April 2018.
167 Centre for Ageing Better, *Locked out: A New Perspective on Older People's Housing Choices*, August 2023.
168 UK Parliament, Hansard, *Planning System and Levelling-up and Regeneration Bill* debate, 6 December 2022.
169 Centre for Ageing Better, *The State of Ageing in 2020*; Equality and Human Rights Commission, *Housing and Disabled People: Britain's Hidden Crisis*, 2017.
170 Les Mayhew, *The Mayhew Review: Future-proofing retirement living -- Easing the care and housing crisis,* International Longevity Centre UK, 2023.
171 DLUHC, *National Planning Policy Framework*, 20 December 2023.

Lord Best, Chair of the APPG of Housing and Care for Older People, told the CSJ that insufficient housing stock is keeping more than 4 million older people who would like to move trapped in their homes. [172] He pointed out that the Mayhew Review had found that retirement housing – such as extra care schemes -- helps older people stay healthier for longer. Yet currently only 10 per cent of Homes England grants to housing associations, charities, private developers and Local Authorities are allocated to retirement housing.

Recommendation:

Homes England should increase the proportion of their grant allocated for retirement housing.

The planning system

Although the National Planning Policy Framework sets out the government's plans for housing, Local Authorities can set their own rules, through local planning codes, or "local plans". These plans differ between the over 300 local authority districts and, as we have seen, are often unpublished, leaving would-be investors in limbo.

Local authorities also need a new classification system.

While care homes are classed as C2, and therefore do not need to provide affordable housing either on site or through contribution, retirement housing is classed as C3, which comes with the requirement to provide affordable housing. In the course of our research the CSJ have heard from developers and providers that this requirement often makes retirement housing financially unviable.[173] Given that it already entails greater building and operating costs than typical residential schemes, as well as a much greater proportion of non-saleable communal areas, this extra requirement makes retirement housing even less attractive to would-be developers.

Most local plans ignore the challenges associated with retirement housing, leading to poor assessment of planning applications. Retirement community operators report that they routinely appeal planning decisions, a process that is both costly and time-consuming.[174]

Recommendation:

The Government should revise the National Planning Policy Framework to explicitly require all local plans to include a specific policy and target for new wheelchair accessible homes (known as M4(3) in building regulations), and where no local target is set, to require 10 per cent of new homes to meet the standard.

172 Interview with Lord Best, May 24, 2023; Centre for Ageing Better, *Locked out: A New Perspective on Older People's Housing Choices*, August 2023.
173 Interviews with CSJ "Family Cares" Working Group, March-September 2023.
174 Interviews with "Family Cares" Working Group, March-September 2023.

Recommendation:

Government should introduce a new planning use class that takes into account the very specific nature of retirement housing, removing constraints on building new retirements homes.

The Older People's Housing Taskforce has provided an important opportunity for joint work in this area. Our CSJ Working Group fed into the Taskforce, which reported to both the Department for Levelling Up, Housing and Communities (DLUHC), and the Department for Health and Social Care (DHSC), (See Appendix 3).

Front line workers from carers' charities, those supporting the aged, and those supporting individuals with disabilities have told the CSJ that most Local Authorities lack data about the needs of the most vulnerable residents in their area and thus fail to make adequate housing plans.[175] To address this issue, the CSJ joins the Centre for Ageing Better in calling on all Local Authorities to organise focus groups that include older residents, residents affected by disability, as well as their carers.[176] Existing surveys (including by the Centre for Ageing Better, Carers UK, Care UK, etc) have highlighted the need for the right location, with infrastructure that enables mobility, spontaneous social interactions, and proximity to essentials such as GPs, pharmacies, parks and shops: this is integral to a sense of "home" for the more vulnerable and their carers.[177]

Focus groups that include this cohort will give a better understanding of their number and their needs, to inform local housing plans and ensure they are well targeted. Government can learn from the example of Greater Manchester's Ageing in Place Pathfinder, which invites local residents to collaborate on a strategy to improve residents' quality of life as they grow older and in need of more support.[178]

Recommendation:

Local Authorities should invite older residents, those affected by a disability, and their carers, to participate in discussion groups to inform planning decisions.

The National Model Design Code aims to give local planning authorities (and developers) a toolkit of principles to consider in designing new developments.[179] The Code, updated in 2021 by the DLUHC, covers public and private spaces, including streets and parks, buildings and street network. 14 LAs have taken part in pilots to create their own local design code, produced by multi-disciplinary teams including architects, urban designers and Local Planning Authority officers – but also representatives of the local community, to ensure residents' needs are met.[180]

175 Centre for Aging Better, *Locked out: a new perspective on older people's housing choices*, August 2023.

176 Ibid.

177 Ibid.

178 Greater Manchester Combined Authority, *The Ageing In Place Pathfinder,* 21 September, 2022.

179 Ministry of Housing Communities and Local Government, *National Model Design Code Part 2 Guidance Notes,* June 2021.

180 Matthew Carmona, Wendy Clarke, Brian Quinn, Valentina Giordano, *National Model Design Code (NMDC) Pilot Programme Phase One, Monitoring & Evaluation,* UCL, The Bartlett School of Planning, March 2022.

As the Design Code is rolled out nationally, government should strengthen the guidance for Local Authorities on the access requirements by including specific reference to the HAPPI design principles. These ten principles include: space and flexibility; daylight in the home and in shared spaces; balconies and outdoor space; adaptability and 'care ready' design; positive use of circulation space; shared facilities and 'hubs'; plants, trees, and the natural environment; energy efficiency and sustainable design; storage for belongings and bicycles; external shared surfaces and 'home zones'. Prof Alison Bowes, professor in Dementia and Ageing at Stirling University, told the CSJ the HAPPI criteria are critical for retirement homes and homes for those affected by blindness or dementia, as "they recognise that healthy ageing calls for specific housing elements".[181]

Recommendation:

Government should ensure its NPPF guidelines to local authorities specify the inclusion of the ten HAPPI principles to the design of new build developments.

Serious Game

The roll out of the Design Code presents an excellent opportunity to introduce the "Serious Game", an initiative piloted in Southwark, which brings together policy-makers, developers, service deliverers and the older population to decide how best to address local housing needs over a 12 year period. Housing is understood as more than a physical space: it is the facilitator of social connections and independent living. The initiative, designed by the University of Stirling, aims to familiarise decisionmakers with "the needs of an ageing population", as Prof Vikki McCall, Senior Lecturer in Social Policy and Housing at the University of Stirling, told the CSJ.[182] She explained that "by integrating the different stakeholders whose responsibility is to create a more age-friendly environment… our model of a fictional town "Our Town" can be contextualised to any existing town and can be adapted to include those with a disability as well as family carers too."

Stakeholders are given budget constraints (reflecting real-life budget cuts) and demographic constraints (reflecting real-life issues such as an increasing number of individuals with disabilities, and a surge in the ageing population). The inter-disciplinary team draws together their data, breaking down the silos that persist between housing, health and social care. Projecting into the future, the "Game" reflects real-world demographic pressures (increase in the ageing population but also in those who report a disability) and how priorities need to shift to meet these changes. The "Serious Game" can be used to measure, and ensure, a town's "friendliness" to the ageing and the disabled population – and those who care for them.

181 Interview with Prof Alison Bowes, 13 July, 2023.
182 Interview with Prof Vikki McCall, 7 September, 2023.

Current building regulations include three levels of accessible housing:

- Category 1 -- M4 (1) the minimum standard, with flush threshold, space to circulate, toilet at entrance level – but no concern about adaptability
- Category 2 M4 (2) "age-friendly" housing, featuring adaptable walls (for hand rails), and wide staircase for installing stairlifts
- Category 3 M4 (3) wheelchair-friendly home.

97 per cent of Local Authorities told a recent survey by the Centre for Ageing Better that their need for accessible homes will increase in the next 10 years, with a quarter of local authorities surveyed describing their need for accessible homes as severe.[183]

This calls for the Secretary of State to make changes in planning regulations, so that the new minimum standard for accessible housing becomes Category 2 M4(2), which features easily adaptable lay-out and structural elements.

Recommendation:

The CSJ echoes the Centre for Ageing Better in calling for accessible and adaptable homes (known as M4 (2) in building regulations) Category 2 housing to become the new minimum standard for new-build homes.

The Housing List

Each local authority draws up its own rules for deciding the order of priority on its record of qualified households – or housing list. These allocation schemes, published on their website, [184] prioritise anyone with a disability or age-related conditions. But not their family carer, unless they live in the same house. This policy should change: it is in the interest of the LA to enable family carers to live close to the recipient of their care as close proximity reduces pressure on council-funded domiciliary care and NHS resources; prevents health conditions from escalating and needing more intensive and expensive interventions; addresses isolation, which is likely to affect the older population and those affected by a disability, compromising their welfare. [185]In addition, proximity would reduce pressures on the carer, who otherwise has to travel, which is expensive and time consuming; or live together with their family member, which is not always suitable.

Recommendation:

Local Authorities' housing lists should prioritise family carers seeking to live close to those they care for.

183 Centre for Ageing Better, *The State of Ageing in 2020.*
184 DLUHC, *Allocation of accommodation: guidance for local authorities*, 27 October 2023.
185 Ibid.

Home Adaptation Grants and Disabled Facilities Grants

Unsafe and inadequate housing is one of the biggest barriers to family carers' participation in the labour market, because they are reluctant to leave those they look after in an unsafe home.[186]

More than 80 per cent of the housing stock we will be living in by 2050 is already built,[187] the Centre for Ageing Better has found. Ensuring existing housing stock can be adapted is therefore an urgent need and in July 2022 the Government committed £500 million annually towards a Disabled Facilities Grant, to adapt homes to suit residents' needs – including ramps, stair lifts, etc. [188] In England and Wales, the council will pay for adaptations that cost under £1,000. In some cases, it will grant a means tested Disabled Facilities Grant (DFG) for more expensive home adaptations which include widening doorways, installation of stairlifts, as well as smaller changes like using a shower chair to make personal care easier.[189]

But the process of adapting a home for its disabled or older residents can be too slow and too patchy, with each LA having different policies around adaptations as well as varied means of delivering of Disabled Facilities Grants.[190] Care-users and front line workers in some of the 650 charities that make up the CSJ Alliance report a postcode lottery exists for adaptation services: where a resident with minor disabilities in one LA will be granted immediate assistance in making their home more accessible, a resident in another LA who has the same or more serious disabilities, will be forced to wait for months, with an attendant deterioration of their condition.[191]

This is a public health issue, as properly adapted homes keep the vulnerable in a familiar environment, and facilitate the carer's role, with positive outcomes for both.[192] This is a spend now to save later measure: people stay in their own home about four years longer, on average, once it is suitably adapted, according to Rosamond Roughton, Director for Care and Transformation at the Department of Health and Social Care, thus saving LA budgets the cost of a place in a state-funded care home.[193] Every £1 spent on home improvements to reduce falls leads to £7.50 worth of savings for the health and care sector while every £1 spent on improving warmth in homes occupied by vulnerable households yields £4 in health benefits.[194]

Obtaining planning permission for a granny flat, or for other home extensions with the purpose of housing a vulnerable relative can be daunting – and all too often unsuccessful. The government's Autumn Statement took a step to address this with the Chancellor's announcement of a consultation "on a new Permitted Development Right to allow any house to be converted into two flats provided the exterior remains unaffected."[195]

Our exclusive CSJ-Opinium survey suggests that around 17,000 family carers would move from economic inactivity into employment if the Home Adaptation grant were increased to £2,000, with around 7,500 undertaking part-time work and 9,500 full time work. Around 6,500 family carers would increase their hours of work from part-time to full-time. Three times as many women as

186 Centre for Ageing Better, *Homes for Life: guide to accessible homes,* 2020.
187 House of Lords, *Ageing: Science, Technology and Healthy Living*, Science and Technology Select Committee, 1st Report of Session 2019–21
188 Department of Health and Social Care, *Next steps to put people at the heart of care*, 4 April 2023.
189 Centre for Ageing Better, *Homes for Life: it's time to build the homes we need*, 2022.
190 Vikky McCall, *Inclusive Living: ageing, adaptations and futureproofing homes*, Ubiquity Press, University of Stirling, 2022.
191 Interviews by the CSJ, May-October 2023.
192 Phillippa Carnemolla, Catherine Bridge, *A scoping review of home modification interventions – Mapping the evidence base, Indoor and Built Environment*, 28 February 2018.
193 House of Lords, *Ageing: Science, Technology and Healthy Living*, Science and Technology Select Committee 1st Report of Session 2019–21
194 Centre for Ageing Better, *Homes for Life: It's time to build the homes we need*, 2022.
195 Autumn Statement November 2023, Summary, 22 November 2023.

men (14 per cent vs 5 per cent) found this policy would enable them to go from zero to part time employment. We based our cost benefit analysis on the £2,000 adaptation grant being given to 5 per cent of individuals looked after by working age unpaid carers each year, which equates to around 175,000 grants per year.[196] Under this assumption, the estimated total cost to the Exchequer would be around £385m pa, including a 10 per cent allowance for management/administrative costs.

The benefits of this for GDP and tax revenues are calculated assuming median earnings for these work categories based on data from the 2023 Annual Survey of Hours and Earnings by the ONS (around £35,500 full-time and £12,500 part-time earnings pa).

The table below shows estimated GDP and fiscal impacts for this policy option in its first year of operation based on these assumptions and separate CSJ analysis of Family Resources Survey (FRS) data for the benefit savings for unpaid carers moving into work. See annex 3 for a fuller explanation of our methodology.

Table 2: Economic and fiscal cost-benefit analysis for home adaptation grants option (first year)

£ MILLION	ECONOMIC COSTS AND BENEFITS	FISCAL COSTS AND BENEFITS
Cost of policy	385	385
GDP (gross earnings from employment) increase	653	
Income tax and NI increase		167
Benefit savings (Carers Allowance, Income Support/ Universal Credit and Housing Benefit)		138
Net benefit/cost	**268**	**-80**

We can see that, even in the first year, the positive impact on GDP from higher employment outweighs the cost of the policy: the net economic benefit is clearly positive at an estimated £268m. This would be true even if the employment response was significantly lower than the CSJ survey suggested, bearing in mind that benefits should be measured over the lifetime of the assets created (which might be 5 years or more for home adaptations such as stairlifts or walk-in showers).

The estimated net fiscal benefit is negative at around -£80m in the first year, but the payback period for the policy would be only around 15 months based on the estimates in Table 2, far less than the plausible lifetime of the assets created. This result would be robust even if the employment response was, for example, only half as great as the CSJ survey suggested.

In summary, the home adaptation grants policy would appear to have a very favourable economic and fiscal cost-benefit ratio, even before considering other benefits such as improved welfare of the people being cared for due to being able to stay in their own homes, safely, for longer.

Work coaches in Job Centres would be tasked with administering the grants to those cared for by eligible job-seekers, on a discretionary basis. The recipient of care would be included in the grant proposal and associated discussions. The CSJ has submitted a small-scale pilot project design to the DWP, to test the impact of home adaptation on the employment outcomes of 220 job-seekers.

196 This calculation is made in order to keep expenditure within the fiscal envelope.

Recommendation:

DWP should administer a Home Adaptations Grant of £2,000 to 5 per cent of individuals looked after by working age unpaid carers each year (this equates to around 175,000 grants per year).

Home improvement agencies

Home Improvement Agencies (HIA) are not-for-profit organisations also known as Care and Repair services and Stay Put services – because they allow people with a disability or those who are older to stay in their own home.[197]

Over 200 agencies, run by charities, LAs or housing associations, cover more than 80 per cent of Local Authorities. Once the LA assessment finds that the individual is eligible for assistance the agency worker can get estimates for any necessary adaptation work, helping them and/or their family carer to apply for local council or Disabled Facility Grants (which, as noted earlier, can be a slow and complicated process of multiple form-filling). The HIA key worker will ensure that the contractors who carry out necessary works are reputable and reliable, and will supervise work to completion. Some HIAs also have handymen on their books to undertake small jobs, such as fitting rails. The HIA worker will act as a navigator of the social care system, too, signposting to financial experts, for instance, and/or local specialist support. Some councils have their own handyperson service, while charities like Age Uk also deliver the service.

A Social Return on Investment analysis of a Care and Repair scheme in West Lothian found a social return of £4.53 for every £1 invested, finding that the scheme reduced falls and accidents in the home, increased ability to remain living at home, increased sense of security and safety, reduced cost of housing elderly and disabled people, reduced time spent gaining access to clients' homes, reduced cost of provision of care services in the home, reduced delay to hospital discharge process.[198]

A number of HIAs are working closely with hospital discharge teams to arrange adaptations for those patients waiting to return home after a stay in hospital. Given the pressures on NHS hospitals, this invaluable service should be supported.

Recommendation:

All hospital discharge teams should work closely with a Home Improvement Agency or with home improvement services in their area, including LA housing teams, housing providers and voluntary sector organisations to help patients return to a home which meets their needs.

197 Vikky McCall, *Inclusive Living: ageing, adaptations and future-proofing homes*, Housing Learning and Improvement Network, 18 November 2022.

198 Care & Repair, West Lothian; Horizon Housing, *Social Return on Investment Analysis*, June 2013.

Chapter Six:

Specialist Housing Schemes

When a family carer cannot meet their relative's needs, they should be able to choose among housing alternatives that deliver specialist care. All too often, however, the carer will find these schemes characterized by low levels of supply and/or low quality, rendering them unsuitable for their relative's welfare. Many family carers have no choice then but to keep their relative at home.

The three most common specialist housing schemes catering for those who are older and/or affected by disabilities are extra care models, sheltered housing, and supported living.

Extra care model: purpose-built retirement villages – council-funded and privately-funded. Full professional care staff looking after residents, but outside care can be bought in. A recent evaluation by the Housing Learning and Improvement Network found evidence that housing for older people delivered significant cost-benefits to the NHS and local authority adult social care. [199] It found that extra care housing, by reducing the number of residents' visits to a GP, ambulance callouts, and by improving their quality of life could be viewed "as a preventative alternative to residential care for many people. Lifetime savings to the taxpayer per person from delaying or preventing this move could be as much as £5,000."

Research has found that the cost to Local Authority commissioners of providing care and support through the extra care model is around 17.8 per cent less (roughly £1,222 per year) per person than providing the same care in the wider community. One provider estimates that at least £3000 is saved annually per resident for the NHS and other stakeholders where they offer activities to address loneliness.[200]

199 Housing Learning and Improvement Network, *The health and social care cost benefits of housing for older people,* June 2019.
200 National Housing Federation, *Older Person's Housing Group*, 2022.

Case Study: Wigan and Homes England Collaboration

Wigan Council has collaborated with Homes England to deliver a successful integrated housing health and social care scheme that has regenerated an area of council owned land on an estate that had been affected by anti-social behaviour. Homes England gave a £3,257,630 grant for the £12,533,178 extra care housing scheme that includes 51 affordable rent apartments as well as 18 affordable rent bungalows whose residents do not require extra care. The Former Sandalwood Drive scheme, which meets needs of older residents with support service available 24 hours a day, is designed to be dementia friendly and flexible, with the basic design accommodating older people who are well and providing for additional changes when required. This scheme is located close to local amenities such as shops and bus stops. The communal facilities within the scheme offer an opportunity to create a 'Community Hub' engaging with public third sector organisations operating in the area. This included apprenticeships and workshops for students at the local Wigan College, with sessions on CV Writing & interview skills as well as site visits for construction students.

Sheltered housing: usually bungalows, flats, maybe 6-8, warden on site. Residents organise for the care themselves. 0.6 per cent of people living with a disability live in sheltered housing, following council assessment. Rental is most likely from housing associations and councils; buying is from private providers. Service charges can be high.

Sheltered housing is seldom included in any housing development. Yet an assessment of social value calculated by Demos in 2017 found that the government could save £486m per year through sheltered housing, which reduces inpatient stays, prevents falls and tackles loneliness.[201]

Supported living: 3-4 people with disabilities share a flat and organise care for the group. Central government pays for this out of Housing Benefit or UC, so LAs are very keen on this alternative. 16 per cent of people living with a disability live in supported accommodation. Claire Bolderson led a BBC investigation into Supported Living in 2023. [202] It found that "Too often the care is low quality, yet the tax payer is stuck with massive bill.

"Our alarming investigation found that there has been a steep rise in the number of statutory notifications to the CQC about unexpected serious injuries and even deaths over the last 8 years in supported living. 2041 deaths (up 40 per cent) over 8 years and 3700 serious injuries (up 279 per cent) over the same period."

"In Supported Living, the tenancy is covered by housing benefit which comes from central government funding – this explains why this option is so popular with councils… Tenants get disability and other benefits and that pays for their bills: there is no cap on housing allowance for the disabled."

The challenge, Claire Bolderson told the CSJ, lies in the lack of regulation. While all residential care homes must register with the CQC, the Commission has no right of entry into people's homes, leaving these houses without any inspection. "This is particularly dangerous when many individuals with high support needs cannot speak." [203]

201 Claudia Wood, *The Social Value of Sheltered Housing*, DEMOS, June 2017.
202 BBC Radio 4, File on Four, *No Place Like Home: the inside story of supported living*, 12 February, 2019.
203 Interview Claire Bolderson, 11 May 2023.

Recommendation:

The Care Quality Commission should be able to evaluate Supported Living accommodation.

The threshold for access to specialist housing schemes varies with each LA – and many are so high as to exclude families with real needs. In addition to high thresholds, patchy supply and quality also limit access to these schemes.

Investors in specialist housing claim they are forced to operate at a disadvantage: affordable housing enjoys special planning status, but specialist housing, which also delivers social benefits, does not. For example, there is no requirement to include older people's housing in Local Plans. The Mayhew Review [204] found that specialist retirement housing helps older people stay healthier for longer, especially when they have access to care. This reduces pressure on the NHS, and postpones long-term and expensive residential care that LAs would have to fund. The Review [205]called on Government to build 50,000 new units a year to meet demand, which far outstrips supply -- a "meagre" 7,000 currently built annually.

Recommendation:

Retirement housing should have the same special planning status as affordable housing, given its clear and demonstrable social value.

Multigenerational Living

A recent Pew research Centre report reveals that the number of Americans embracing multigenerational living has spiralled, with over 59 million individuals now living in multi-generational homes.[206] 27.9 per cent highlight the importance of providing care for older relatives.

In England and Wales the ONS revealed that the number of families with adult children living with their parents rose 13.6 per cent between the 2011 Census and Census 2021 to nearly 3.8million.[207]

Multi-generational living can provide shared care under one roof, with the older relatives looking after grandchildren or an adult disabled child, while younger relatives look after the older. This virtuous circle could bring benefits to all age groups, yet receives little support from local government or housing policies.[208] Again, housing lists could be used as an incentive to care, with councils and housing associations prioritising the family with three generations under one roof.

204 Les Mayhew, *The Mayhew Review: Future-proofing retirement living -- Easing the care and housing crisis,* International Longevity Centre UK, 2023.
205 Ibid.
206 D'V. Cohn, et al, *The Demographics of multigenerational households,* Pew Research Centre, 24 March, 2022.
207 ONS Census 2021, *Number of multi-generational households by household tenure,* 25 April, 2023.
208 Matter Architecture, *Rethinking inter-generational housing.*

Recommendation:

The DLUHC rules around Housing Registers so that all councils prioritise a family with three generations under one roof in their housing lists.

Chapter Seven:
Community

> *"Family carers need to feel supported by their community. Trusted relationships are built at a neighborhood level and grass root groups familiar with who is in need, who is caring for those in need, and what local resources are available to them are best placed to establish these relationships."*
>
> Julie Charalambous, Calderdale SmartMove Yorkshire

From social life to job hunting, the support family carers need is often found in the neighbourhood rather than the hospital or social services. Central and Local government should do more to sustain the voluntary and community sectors.

Case Study: Emilia Romagna region, Italy

Interview with Manu Portal, social worker

The regional council introduced a new law (Legge Regionale No2) in 2014 that explicitly recognises the role of family caregivers and their right to support – not just in looking after their relative, but more generally in their daily life.

The council is clear in its messaging about family carers as "everyday heroes" [209] on its website. This sets the scene for a more positive approach to care-giving: you are not alone, there is a wider community to support you.

Local health and social care services, community groups, and charities are integrated through a personalised "plan" (Piano Assistenziale Individuale (PAI) that identifies the carer's needs and matches them with local services. These can include information and training for the carer; an explicit role in decision-making about the medical/social care their relative requires; and monitoring of the carer's own health as part of a preventive strategy that guarantees support in case they fell overwhelmed by their situation.

In 2019 the region allocated 7 million euros to support family carers, offering a means-tested Cash Allowance as part of the PAI given to families living with an older relative or one with disabilities. The local authority also delivers respite care during vacation times or any other time when the family cannot take care temporarily of their dependent child, parent or spouse. Respite care services cover up to 30 days yearly for each family, which can be split over the year; and temporary residential respite care after hospital discharges.

209 Bologna Today, *Eroi del quotidiano*, 17 June 2023.

Crucially, the Emilia-Romagna Fund has commissioned voluntary groups to develop programmes to promote local social networks. Two popular charities are supporting parents of children with disabilities. Because so many in these situations are concerned about their children's wellbeing, when they themselves will no longer be around, "Durante e Dopo di Noi" (During and After Us) is a charity that not only signposts to services and benefits, it also includes counselling sessions and practical strategies for planning care for the disabled once their relatives can no longer do this. The Aut Aut Association in Modena is a peer to peer group for parents of children with autism. It draws them together for mutual support and raising the profile of the issue. The association organises trips and excursions, "Saturday nights together" and summer camps so the young people can enjoy some independent experiences (and parents have respite, as therapists are on hand).

Interview with CSJ, 4 December 2023

The CSJ, with its Alliance of 650-strong small charities, has long championed the work of grassroot groups, which deliver support at a local level for local needs. Voluntary and charitable organisations, for whom "care" is a mission statement, complement and often replace the welfare state in delivering support. Their impact is especially felt in poorer communities, where needs are greater and money is more scarce, yet research by New Philanthropy Capital [210]showed that in areas designated as priority for the Government's Levelling Up fund, there's a third less local charitable activity than in wealthier areas.

Their size allows grassroot groups to deliver personalised care. As Claire Turner of Carers Leeds told us: "We know that community support can be person-centred in a way that statutory services seldom are. If you are caring for your dad and he loves cricket, we find a volunteer who can watch cricket with him while you go out to the cinema."[211]

Residents engage with local voluntary groups more readily than with government and social services, which they are more likely to see as punitive authority figures or suspect of tick-boxing indifference. "Many of the people we work with," Julie Charalambous, who runs Calderdale SmartMove in West Yorkshire told the CSJ, "they become nervous around statutory services such as social services. Clients often don't want 'a stranger to walk into my home'.[212] Being a charity means we are acceptable to them and we can send in a support worker to sit beside them, listen to their stories… because we are not authority figures."

Too often, however, Local Authorities hinder rather than promote small charities. The impact of budget cuts is widely felt, and charity leads and key workers interviewed for this report have complained that voluntary groups risk being sidelined by statutory services when it comes to obtaining funds from the council.

LA contracts often require copious form filling and cumbersome bureaucracy, which can be managed by large organisations with development officers, but tend to discourage small grassroot groups.

210 New Philanthropy Capital, *Building Blocks for Growth*, May 2023.
211 Interview with Claire Turner, 20 June, 2023.
212 Interview with Julie Charalambous, 7 June, 2023.

Promoting community support means promoting greater local autonomy. As Patricia Hewitt's Independent Review of Integrated Care Systems argued, local needs should be a priority: "some areas have different levels of deprivation and different groups that suffer greater inequalities, and… some local people have different priorities for health and care."[213] The review called for ICSs, which vary in size, from those covering 750,000 individuals to those covering over 3 million, to be bench-marked against one another, in order for best practice to come to light – and be copied.

Shared Care Records (ShCR) which include health data and care plans for each individual within an ICS, can be accessed by NHS professionals. Hewitt calls for social care providers, voluntary organisations that deliver community and mental health services, LAs and individuals and their carers to have access, too.[214] "Having better access to data is crucial for place-based care", Helena Herklots, CBE, Older People's Commissioner in Wales told the CSJ.[215]

The Greater Manchester Combined Authority is promoting the 20 minute neighbourhood principles, which includes cycling infrastructure and ensuring the "walkability" and wheelchair friendliness of new and existing places.[216] One element is about creating "opportunities… indoor or outdoor leisure or be active… and places to sit and rest regularly within private and public spaces such as playgrounds, designed to meet the needs of those with mobility issues".[217] Welcoming public spaces encourage impromptu exchanges and connections, and can prove key in addressing loneliness and isolation.

Community spaces are especially important in low income areas. "Here, welcoming carers to a place where they can meet peers, engage across the generations, or simply get an hour's respite, can prove transformative," Helena Herklots, CBE, Older People's Commissioner in Wales told the CSJ: "if you live in a poor area you are likely to lack good transport, safe roads and green spaces, even pavements. An asset-poor community can keep the carer and their family member trapped indoors or wary of venturing out. Digital platforms can help but we have seen that a physical space in the community is far more important. Digital among the older population, especially among lower income groups, doesn't usually appeal."[218]

Care homes can also provide a community space where carers and those they support can socialise, learn, find respite. This is the vision of West Sussex County Council, which collaborated with three local care homes to design a toolkit for community engagement. The toolkit highlighted some of the opportunities to share the care home settings with local community groups, for example, toddler groups, Men in Sheds and Scouts. While care homes can be used as multi-generational spaces, they can also encourage relationships between residents from other care homes.

213 Patricia Hewitt, *The Hewitt Review: An independent review of integrated care systems,* 4 April 2023.

214 Ibid.

215 Interview with Helena Herklots, 14 April 2023.

216 GM Housing Planning and Ageing Group, *Creating Age Friendly Developments: a practical guide for ensuring homes and communities support ageing in place,* November 2023.

217 Ibid.

218 Interview with Helena Herklots, 14 April 2023.

Respite care

Carers need respite from what is an often all-consuming, non-stop schedule of household chores, personal care, GP visits, and medicine administration. "Respite means a place where you feel it is safe to leave your loved one for a couple of hours or a day or two, so I can see a friend, see a film, or just catch up on sleep" Jonie Hawksley told the CSJ.[219]

"People would be more confident to step up if they knew that they don't have to do this 24/7. We need to know that the support is there to enable us to help the widower next door, without having to take on the sole responsibility for his care," Claire Turner of Leeds Carers told us.[220]

But respite care is expensive: according to the UK Care Guide (2023), the average price for a week's stay at a residential respite care centre can be between £1,000 to £5,000 per person depending on the level of care support needed. An individual service such as day care or overnight support may cost up to £300 per day (this is the equivalent of four weeks' worth of Carer's Allowance).

The CSJ introduced the concept of a Family Hub in its landmark 2007 report, "Breakthrough Britain".[221] The multi-agency hubs adopt a "one front door approach" that erases stigma. They can deliver both universal services, such as Health Visitors and birth registration, and targeted services such as Domestic Abuse support or housing advice. The bottom-up model ensures that families in the area can find the support they need. The Government pledged to roll out the hubs nationwide, starting with £301.75 million for 75 councils where hubs would deliver support for young families.[222]

Extending the family hub offer to include activities for older and/or disabled adults would provide a valuable opportunity for respite for their family carers. The hubs could draw on the support of local voluntary groups to engage older individuals or those with disabilities.

Jess McGregor, Director of Adult Social Services at Camden Council, agreed that this would address loneliness and respite care – for both carers and those they are looking after.[223] "Most people are still uncertain about Family Hubs – but they could be the answer. We need a national campaign to publicise their offer."

Recommendation:

extend the Family Hub offer to include support for older people or individuals with a disability, to offer respite for their carers.

Community groups and charities are also playing a pivotal role in providing respite for carers with low-cost, innovative schemes that merit wider take-up.

219 Interview with Jonie Hawksley, 12 March, 2023
220 Interview with Claire Turner, 20 June, 2023
221 Centre for Social Justice, *Breakthrough Britain,* Chairman's Overview, July 2007
222 HM Government, *Family hubs and start for life programme guide*, August 2022
223 Interview with Jess McGregor, 2 June 2023

Case Study: Bolton Dementia Support Group

Interview with Dave Bevitt

Dave Bevitt runs Bolton Dementia Support Group. "Ours is a membership organisation with 225 carers. We organise events for carers and the dementia team and have experts coming to talk every week. We deliver a 12 week course. We try to drive home the point that people with dementia go to the GP too late – and when it's not picked up early with a diagnosis the condition escalates.

Having a member of your family develop dementia is scary, and the system at present leaves you feeling unsupported. The NHS memory assessment team will assess, then offer medicine, then deliver a six week course that gives information about dementia and how to manage it -- but then that's it, you are left on your own.

We know that for partners, especially, it is a 24/7 job. So we have introduced a Memory Café, which operates twice a week. One is at a Crown Green bowling club and has about 80 dementia patients and the same number of carers turning up at a time. We get an entertainer and play music, which has been shown to have a huge impact on those affected by dementia. They listen to the Beatles and rock and roll music, and these become truly joyful events. Volunteers run the events which gives carers an opportunity to come speak about the challenges they are facing. When they are in our groups they feel they are not alone. As for the dementia patients, they are transformed by the experience: they come in using a stick, within minutes of the music striking up, they are dancing and laughing. It's a fabulous experience. We know that carers need respite – just an hour makes a difference – but we also know that it is a huge challenge when those with dementia get so anxious with strangers. So continuity of volunteer staff is key."

Interview with CSJ, 20 June 2023

In the course of our research we have encountered some promising collaborations between grassroot charities, and between the voluntary sector and local authorities. These models of best practice should be adopted more widely.

In Yorkshire, Calderdale SmartMove benefits from collaborating with other charities to deliver support to carers. "We have a good relationship with the (Calderdale) Council with regular meetings– but, like everywhere, there is no money, and no services available outside of the contracted services to provide social activities for older people. As a result, we tend to work in partnership with other charities to provide the support. For instance, we refer clients to the Archway Project which organises a "Past Times" get together every Monday afternoon – it's a 1950s style session where they'll lay on tea dances, bingo, a quiz as well as a hot meal. It's so popular, but the issue is providing the transportation. That's a key ask – if I could wave a magic wand, it would be to fund free transport and community centres. The people we are working with are often withdrawn – they need to socialise, to feel part of the community again. These are people who used to talk over the back fence, who played bowls and went to bingo night."

Leeds Council has given the organisation Carers Leeds, which runs networks across 35 neighbourhoods, small grants to be distributed among neighbourhood groups that cater for specific cohorts such as ethnic groups. "We gave Time for Carers, for instance, a £250 grant for carers to take

a break," Claire Turner, CEO of Carer Leeds told the CSJ. [224]"For a small charity, even a small amount of funding can be crucial – it helps with printing leaflets, putting the kettle on… They have to give us a receipt, that's all. It makes no sense that asking for a £4,000 grant takes up as much times as asking for £400,000. When even modest funding can make a big difference at a local level, commissioners should consider simplifying the contracts expected of smaller charities: these groups simply cannot afford the kind of development offices that big organisations have."

Simpler contracts should be followed by longer term ones. Trusted relationships are at the heart of charitable organisations, and explain their success. But trust needs time to build, especially for the most vulnerable.

The Family Toolbox Alliance in the Wirral [225]has benefited from their council's long-term vision. Wirral Borough Council's funding contract was a minimum of 5 years with 4 more on the table, which enabled the Family Toolbox to address the challenges of Birkenhead, where 35% of residents live in deprivation, life expectancy differs by 11.8 years between its poorest neighbourhoods and its wealthiest (only 11km away). "The Council trusts us and does not burden us with unnecessary paperwork, or metrics to meet," Ben Gilchrist of Caritas Shrewsbury told us.[226]

Carers Leeds has obtained a five year contract from the council. "We are lucky" Claire Turner, CEO, tells the CSJ, "that Leeds Council is backing us with a longer term contract than usual. They recognise that relationships need time to develop into trusting collaboration." [227]

Recommendation:

In their commissioning Local Authorities should issue longer term (four year minimum) contracts and issue reporting requirements that are manageable for small voluntary organisations and grassroot groups.

Wirral Council has invited representation for the voluntary sector on its committees. This has given the Toolbox an opportunity to address both health and social care needs among their community. Already, the charities have supported 7854 beneficiaries, ranging from disadvantaged families of young children to a group of older volunteers and carers who "drop in" at the Toolbox headquarters, offering advice and joining in activities in the cheerful, noisy set of rooms that serve as the Family Toolbox headquarters.

The success of the Family Toolbox in the Wirral validates the vision behind the Integrated Care Partnerships, which, as the Hewitt Review highlighted, supports voluntary organisations to deliver more personalised and holistic care by integrating health and social care.

Jitka Vseteckova, lead academic from the school of Health, Wellbeing and Social Care at the Open University, is leading the co-production of training materials for community assets for the Integrated Care Across Northamptonshire (iCAN), a programme to improve the quality of care for older people and people with disabilities. The programme, she told the CSJ, aims to keep individuals at home "if

224 Interview with Claire Turner, 20 June 2023.

225 Collaborating charities are Caritas Shrewsbury, Ferries Family Groups, Foundation Years Trust, Involve Northwest, Koala Northwest, Shaftesbury Youth Club and WEB Merseyside.

226 Interview with Ben Gilchrist, 13 April, 2023.

227 Interview with Claire Turner, 20 June 2023.

it is the right place for them" and to do so relies on a system-wide collaboration across councils, community trusts, community groups and voluntary sector.[228] Driven by the voluntary organisations, Carers in Northamptonshire, and Northamptonshire Health and Care Partnership, the programme relies on a team in the community to "move quickly to prevent the need for hospitalisation but also to put support in place for those who need to return home from hospital… for prevention at a national level we need health and care working together. Family carers in Northamptonshire know that early help is available to them – before crisis hits."

Case Study: Greater Manchester Ageing Hub

Greater Manchester is the UK's only Age-Friendly City-Region as recognised by the World Health Organisation. At the Greater Manchester Ageing Hub, Paul McGarry leads an 11 people team "to respond to the opportunities and challenges of an ageing population in our city region. We believe in community-led support whether it is for the carer of an older spouse or the mother of an adult with learning difficulties. Mayor Andy Burnham is personally committed to this agenda," Paul McGarry told the CSJ, "and is ensuring that our team is strong and includes staff from many local charities who are seconded here."[229]

Greater Manchester Ageing Hub convenes an interdisciplinary Housing, Planning and Ageing Group made up of policymakers, developers (both for and not for profit), architects, academics and older people themselves to work specifically on increasing the quality and quantity of age-friendly homes across the region.

Several key projects were developed based on needs identified within the group including Rightsizing, Creating Age-Friendly Developments and Design for Life.

For an age (and disability) friendly community, though, housing is just one element. Community infrastructure has to be safe and inclusive. "Too many people with mobility issues – age or a disability – were not setting foot outside because they were frightened by the uneven paving, or lack of public benches, or of public toilets. These features are a key part of place." As is, he pointed out, "free transport. This takes organisation and investment. We use school buses during the day and have started volunteer driving schemes which have the extra benefit of giving purpose to drivers too."

Neighbourhood action plans have been delivering community activities ranging from a moveable nightclub for the over-60s through a new version of meals on wheels to inter-generational volunteering. For carers specifically, the 'Live Well' social prescribing services are facilitating contact between carers with shared experience. They also link those in need of support with the community's social interventions, including lunch clubs, exercise classes, and musical events. "We know that isolation is often the number one challenge for carers and with different activities, rooted in the community, we are trying to foster a sense of belonging and confidence," Paul McGarry told the CSJ "They encourage people to be physically active and socially connected: for carers especially who often don't look after themselves because they are looking after someone with greater needs, engaging in these groups can have clear health implications-- reducing falls, reducing obesity and promoting health checks."

228 Interview with Jitka Vseteckova, 7 June 2023.
229 Interview with Paul McGarry, 26 May 2023.

Finally the Hub is studying best practice not only across the UK but also abroad – with visits and exchanges with policy makers from Norway to Singapore.

Case Study: Driving Miss Daisy

This accompaniment service may be contracted by hospitals as part of their discharge strategy but also may be directly contracted by carers and/or the recipients of their care. Drivers, trained and certified in Emergency First Aid and safeguarding and dementia-aware, and driving bespoke, adapted vehicles, will transport the client with mobility issues to hospital, for a shopping trip, out of town. Every journey is tailored to meet the particular needs and requirements of each client. Most clients are booked by family carers – though some will self-refer, according to Sarah from Driving Miss Daisy Portsmouth, while a few have been referred by social workers.

In Portsmouth, Driving Miss Daisy has 15 regular clients on their list, who need weekly support. "Drivers will not only transport clients but also accompany them to hospital visits and take notes; ensure that they have all they need with them before they leave home; ensure the home is warm and put the kettle on for them."

Some drivers are asked to provide some company when the family carer is out – "they might take them out for a walk or drive them and stay with them the entire time during an event like a funeral or a wedding," according to Sarah.

The service, which has been delivering since 2014, is evenly divided between support for older people and people with disabilities. There is a minimum charge of £20, with fees depending on the service provided and the time required.

Drivers are employed by the charity: "They are carefully screened and we make sure they have the proper training. We have 4 drivers during the week and one for weekends, and we rarely have a day when no one is being driven."

Another impressive scheme, Shared Lives, has been scaled nationally – though our research found many of our front line workers and carers were unaware of it. The scheme trains and vets carers, then pairs them with an individual – either an adult with learning disabilities or an older person -- with needs. Some carers move in, some visit regularly while others provide care in their own home. The schemes gives families respite care, and have supported 12800 individuals to date. Funded by LAs or NHS, Shared Life schemes are registered with the Care Quality Commission which rates them as the highest form of care in England, with 96% of schemes being rated good or outstanding.[230] Carers who take part in this scheme are self-employed and receive fixed payment. Compared to other forms of regulated care for people with learning disabilities, Shared Lives costs £26,000 less per year.[231]

230 Social Finance, *Community-based care for vulnerable adults*: *The Shared Lives Incubator: Learnings Addendum*, 27 June, 2022.
231 Social Finance, *Community-based care for vulnerable adults*: *The Shared Lives Incubator: Learnings Addendum*, 27 June, 2022.

Chapter Eight:

Employment

> *"Good work is good for your health."*
>
> *Working Well Programme, Greater Manchester Combined Authority*

One in seven employees in the workplace are also family carers,[232] with responsibilities ranging from assisting with feeding and mobility to running errands and carrying out administrative duties.

Employers should prize this cohort. The additional skills honed by caring – patience, diligence, organisational capacity, flexibility, ingenuity -- transform the ordinary employee into an extraordinary asset. In addition, by working to retain experienced employees, employers can reduce the cost of recruitment and skilling their workforce. The Work Institute has calculated that the cost of replacing an employee costs a third to 200 per cent of that employee's earnings.[233] Meanwhile, unplanned absences by carers cost the UK economy around £3.5 billion a year.[234]

Given that carers are 1.6 times more likely to be in work if they use paid-for support services, it is in their employer's interest to ensure that their staff has access to appropriate support. [235]

Currently, this is not always the case, and the stress of juggling work and care is leading 600 employees a day on average to leave employment.[236] The CSJ-Opinium survey of 1530 working-age family carers found that 41 per cent of unpaid carers currently in work are either likely to reduce their hours or give up work altogether in the next year; three in five of all unpaid carers (61 per cent) say that their care duties currently prevent them from taking up paid work or as much paid work as they'd like to. Of concern is the age of these groups: while 23 per cent amongst those aged 16-34 said they would give up work altogether among older participants closer to retirement the proportion was only 7 per cent.

Two thirds of those not currently in work (65 per cent) said they would take up paid employment if they could, while a similar proportion of those in part-time work (64 per cent) said they would like to increase their hours if they could. Employers face an urgent challenge: how to bridge the gap between the family carer's desire to undertake paid work and their ability to do so.

232 Carers UK, *Juggling Work and Unpaid Care – a growing issue,* 2019.
233 William Mahan, *The Cost of Replacing an Employee*, Work Institute Blog, 20 August 2022.
234 Carers UK, *State of Caring 2023 - The impact of caring on: finances*, October 2023.
235 Leonard Cheshire Charity, *Care for Equality*, 2021.
236 Carers UK, *Juggling Work and Unpaid Care – a growing issue,* 2019.

Barriers to paid employment

In "Beyond the Great Retirement", Phoenix Insights (part of the Phoenix Group insurance provider) undertook fresh research to understand the causes of, and the potential solutions for, the surge in the UK's economic inactivity.[237] Their national survey found that among over 50s the median wealth for those who are economically inactive because they are looking after their family or home is well below the median for all those aged 50-64 (£137,000 vs £758,000). "This suggests" the report concluded, "that it is more likely that this group are being forced to leave the labour market due to domestic pressures than because they would like to concentrate on family life and feel they can afford to."

Five years after taking on their caring role, 31 per cent of family carers are no longer in paid work.[238]

Combining paid employment and caring holds many challenges. The Health Organisation found travel/commuting had proved difficult for family carers in paid employment, in terms of time and cost [239]. This was particularly true for those who lived in rural communities – where, often, they found transportation was inadequate. Being at a distance from their relative affected their ability to respond quickly in an emergency.[240]

The unpredictable nature of caring often complicated the employees' working schedule, and made it difficult for them to predict how long their leave should be.[241] This could spark conflict at work, with employers and colleagues either ignoring or not understanding the carer's circumstances. In turn, their colleagues' reactions could lead carers to doubt their ability to stay in their job.[242]

The earnings of family carers fall by an average of 7 per cent after they begin caring, and continue to decline.[243] Disrupted employment leads to cumulative disadvantage, notably in pension and retirement.[244]

Carers with lower qualifications are at a particular disadvantage: the combination of lower qualifications and being a carer for ten or more hours a week resulted in being six times less likely to be in paid employment, an earnings penalty of £12,000 a year; they also had significantly lower mental and physical health scores. [245] For low-income carers even a small reduction in their pay will have a huge impact.[246] Employees working in lower-skilled roles have fewer resources and therefore fewer choices when it comes to balancing care and employment responsibilities.[247]

237 Phoenix Insights, *Beyond the Great Retirement: Understanding and tackling economic inactivity amongst the over 50s*, Phoenix Group, 6 March 2023.

238 Joseph Rowntree Foundation, *The Caring Penalty*, 18 July 2023.

239 Sebastien Peytrignet, Fiona Grimm, Charles Tallack, *Understanding unpaid carers and their access to support*, The Health Foundation, 12 April 2023.

240 Alice Spann, et al., *Challenges of combining work and unpaid care, and solutions: A scoping review*, Health Social Care Community, 28(3):699-715, May 2020.

241 Ibid.

242 Ibid.

243 Tarek Al Baghal (ed.), Understanding Society Innovation Panel Wave 10: Results from Methodological Experiments, No 2018-06, May 2018.

244 The carer who leaves paid employment will not be covered by auto-enrolment and will miss out on employers' pensions contribution. The independent review of the state pension age made specific mention of carers as a group of concern. (https://www.gov.uk/government/publications/state-pension-age-independent-review-final-report).

245 Nicola Brimblecombe, Javiera Cartagena Farias*, Inequalities in unpaid carer's health, employment status and social isolation,* Health Social Care Community, 12 November 2022.

246 DWP, "National statistics: Family Resources Survey: financial year 2021 to 2022", 21 July 2023.

247 Lesley Deacon, Philip Nicholson, and Kim Allen, *A Neoliberalist Solution for a Neoliberalist Problem:* The *Neoliberalist normalisation of psycho-social support for parent-carers*, University of Sunderland, 2016.

Carers on lower incomes are less likely to have the option of flexible working and more likely to find negotiating flexible working time arrangements with their bosses more challenging: only 13 per cent of working carers had formally requested flexible working of their employers.[248]

The impact on women's employment of caring for adult family members is almost as significant as raising children, with more than a third of women (36 per cent) having to reduce their hours in the workplace, compared with a quarter (24 per cent) of their male colleagues.[249] And women are three times as likely as men to be in part time work – in many cases because of caring responsibilities.[250]

An analysis of Britons aged 50–75 years concluded that full-time working women providing family care for a partner/spouse were more likely to leave the labour market, while caring for parents/grandparents or others had no impact on their employment. [251]

Minority ethnic carers who must meet cultural expectations also have limited choice in their role: for example, female, Asian carers may experience pressure to drop out of employment or reduce hours to fulfil their caring role.[252]

Three-quarters of working carers, both male and female, said that, to varying degrees, their paid work had made it difficult to provide care at home. More than one in four (28 per cent) reported that at least once a week they felt too tired, when they returned home from work, to manage their caring responsibilities.[253] Unsurprisingly, providing care for ten hours or more per week increases the likelihood of employees, particularly women in their fifties, leaving the workplace.[254]

Perhaps unsurprisingly, given the 24/7 nature of their role, carers living with the person they care for are more likely to give up work than those who don't.[255]

The longer a carer has been disengaged from the labour market, the harder it is for them to re-engage. Individuals who had had to leave the labour market due to their caring responsibilities found returning to work a challenge. They reported concern about the gap in their career, and recognised the impact on their pension.[256]

Employers

It is in employers' interest to support the carers in their workforce. They otherwise risk reduced work productivity, increased absenteeism, reduced employee engagement and morale, and high staff turnover rates.[257] As one employer (who wished to remain anonymous) told the CSJ, "If we as employers don't engage with carers and design policies that give them some flexibility, they will feel alienated and under-valued and the temptation will be to just sign off sick."

248 Greig Cameron, *Low-paid employees miss out on flexible working: A lack of trust by employers is blamed for the divide,* The Times, 15 May 2023.

249 Ibid.

250 Carers UK: State of Caring 2022, *A snapshot of unpaid care in the UK*, November 2022.

251 Ibid.

252 Nicola Brimblecombe, Javiera Cartagena Farias*, Inequalities in unpaid carer's health, employment status and social isolation,* Health Social Care Community, 12 November 2022.

253 Ibid.

254 Attracta Lafferty, et al, *Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role,* Community, Work & Family, 26:3, 292-311, 2023

255 Nicola Brimblecombe, Javiera Cartagena Farias*, Inequalities in unpaid carer's health, employment status and social isolation,* Health Social Care Community, 12 November 2022.

256 Ibid.

257 Attracta Lafferty, et al, *Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role,* Community, Work & Family, 26:3, 292-311, 2023.

Many employers fail to identify the carers in their workforce, which prevents them from putting in place the right policies and guidance to support this group.[258]

How can employers better support their working carers?

New legislation coming into force next year offers new hope and new rights for carers in the workplace, benefiting both them and their employers. But tweaking the legislation and backing it up with powerful government-led messaging could bring even greater benefits.

The Carers' Leave Act, which received Royal Assent in May 2023, will be enacted in 2024 affecting the nearly 2 million employees who are family carers.[259] The landmark workplace law introduces a new and flexible entitlement to one week's *unpaid* leave per year for employees who are providing or arranging care for a relative or dependant, available from the first day of their employment. Employees who are carers will be protected from dismissal "or any detriment because of having taken time off".

The CSJ-Opinium survey of 1,530 working age carers, carried out in November 2023 (publication date: January 30, 2024), found that 40 per cent of respondents who were not in paid employment felt that five days' paid leave would enable them to go back to work.

Surveys show that carers feel ignored in the workplace; this entitlement would go some way to providing formal recognition of the invaluable contribution they make to the workplace.[260] Many employees with caring responsibilities do not identify as carers and therefore do not know what entitlements they are eligible for.

Recommendation:

The CSJ calls for a government-led public health campaign, carried out across both traditional and social media, messaging the five days of unpaid carer's leave and – once agreed upon -- the five days paid carer's leave.

Recommendation:

Given the need of support for family carers, and the economic advantages of such legislation, the CSJ urges Government to introduce a statutory five days paid leave for employers with more than 10 employees.

Working carers have reported that they do not know about existing support and how to access it: over half of respondents (64 per cent) in the Phoenix Insights survey "did not know whether provision was sufficient which highlights a potential lack of awareness of the support that is on offer from employers." [261]

258 Ibid.

259 Gov UK, *Carer's Leave Act*, 2023.

260 Carers UK, *Carers' employment rights today, tomorrow and in the future,* November 2023.

261 Annie Austin, Justin Heyes, *Supporting working carers - How employers and employees can benefit*, CIPD, The University of Sheffield, June 2020; Phoenix Insights, *Beyond the Great Retirement: Understanding and tackling economic inactivity amongst the over 50*, Phoenix Group, 6 March 2023

Case Study: Phoenix Group

Interview with Gill Lees, Head of People Policy, Phoenix Group

In response, we introduced a Carers' Network of employees. It's a peer to peer system that is being used a great deal – it has its own dedicated page on our internal site so it is easy to find.

The Network publicises available policies and forms of support and, by finding colleagues with similar experiences, enables employees to identify themselves as carers.

The Carers' Network feeds back anonymously where policy needs to change or be adapted, for instance helping managers and employees to review the terminology of policy write-ups.

When you are struggling because you have caring responsibilities, you may not turn to HR as an initial point of contact, but you will find it helpful to speak to colleagues who may have experienced what you are living through.

In addition we have had a stand-alone carer's leave policy for a number of years now, that allows for ten days paid leave and 5 days unpaid. As of earlier this year, we have introduced a new benefit, the "Carer Concierge" service. Our colleagues can find it on our internal website and it signposts them to support within the workplace and beyond. The service offers a free confidential telephone advisory service that can help carers understand the options and support available to them, from understanding and navigating the Care Home field to at home help. The Concierge team can allocate a dedicated expert to the employee carer, too, to help navigate any aspect of the care journey, arranging care home tours or helping with benefit applications.

Managers don't need special training they just need to be made aware that their colleagues could be in this situation. We don't expect them to be care experts but we do expect them to support colleagues and use the variety of time off and flexible working options we have designed.

Typically the age group we need to be conscious of is the over 50s, especially among women: this is a group that is more likely to leave employment for caring responsibilities because balancing both roles becomes too much for them to cope with. However, we recognise that people of all ages and genders have caring responsibilities.

When work culture is good, the employer is not just looking at support for carers in an isolated fashion, only designing specific policies -- they also look beyond, to give more holistic support.

We know that employees can be concerned about asking time off, they don't want to be seen as a bother. Creating a culture that allows colleagues to share and ask for support is key.

Interview with CSJ, 13th November 2023

Recommendation:

Government should encourage employers to introduce a Carers' Network as a means of identifying and supporting their carer employees.

Evidence shows that as well as encouraging a more inclusive and engaging work environment, these policies are in the employer's own self-interest.[262] Working carers who believe their employer is carer-friendly are less likely to:

- consider reducing their hours or giving up their job altogether;
- find it difficult to concentrate at work;
- have taken sick leave to provide care;
- have taken unpaid leave to provide care.[263]

New legislation will enshrine the right for employees to request flexible working from day one of a new role and the government have given this their support, indicating this could come into place from 2024. This will not only support family carers – it will boost employers' productivity too, saving businesses up to £4.8 billion a year in unplanned absences and a further £3.4 billion in improved employee retention, according to a report by Carers UK.[264]

Flexible work is regarded as the most popular incentive back to work for carers and their colleagues alike: in their survey for "Beyond the Great Retirement", Phoenix Insights found that 64 per cent of respondents would return to work if flexible work were available.[265]

Case Study: Singapore

The lessons from Singapore are especially interesting because the country shares the same demographic profile as the UK, with almost one in five of the population 65 or over. The country decided more than a decade ago that employment policy should address the challenge inherent in an older (and more vulnerable) workforce. By introducing career plans and up-skilling programmes for these employees, the Singapore strategy extended their working life, even if only part time -- enabling their family carers to stay longer in their workplace too. The government has given out job redesign grants to employees aged over 50 in 2500 companies. Meanwhile the "Structured Career Planning" involves regular, structured career conversations with employees over 45 about skills upgrading and opportunities. They can benefit from a Skills Future Mid-Career Support Package to move into new occupations for career progression.

The National Silver Academy has enabled over 99,000 seniors to learn new skills from more than 1,000 courses offered – including "Social media marketing", "Growing your own food" and "Forest Therapy". The Academy also showcases volunteering opportunities for seniors within 750 companies /corporations.

The results have been remarkable: employment rate between 2010-2022 for 65+ has gone up from 17.1 per cent in 2010 to 31.0 per cent in 2022. Among 55-64 year olds it has grown from 59 per cent in 2010 to 70.6 per cent in 2022.

Reference: Living Life to the Fullest, 2023 Action Plan for Successful ageing, Singapore

262 CIPD, The University of Sheffield, *Supporting working carers: How employers and employees can benefit,* 2020.
263 CIPD, The University of Sheffield, *Supporting working carers: How employers and employees can benefit,* 2020.
264 Carers UK, *Juggling Work and Unpaid Care – a growing issue,* 2019.
265 Phoenix Insights, *Beyond the Great Retirement: Understanding and tackling economic inactivity amongst the over 50s,* Phoenix Group, 6 March 2023.

Ministry of Health

A mid-career MOT, which involves a one on one conversation signposting to upskilling courses, alternative pathways within the workplace, and mental and physical health check-up when necessary, would boost all employees' confidence – but in particular the carer employees. The MOT would be employee-led, allowing them to explore options for professional development, pension and retirement. The CSJ would echo the ILC in calling on government to require that all businesses employing more than 50 staff must provide this, while smaller businesses would be accessing the MOT through Job CentrePlus for their employees who have been benefit claimants.

Recommendation:

businesses employing more than 50 staff must provide a mid-career MOT, while smaller businesses would be accessing this through JobCentres Plus.

Supporting family carers who seek to enter or re-enter the workplace should be a priority for local government as well as the Treasury and employers. In Manchester, the Combined Authority launched its Working Well: Work and Health Programme in 2018 to support the long term unemployed and those affected by a disability or other health conditions into work.[266] The £64 million programme is set to assist 28,500 individuals, 6 per cent of them family carers, until 2026.

Case Study: Working Well

Paul McGarry of the Greater Manchester Ageing Hub told the CSJ that "If you have been a carer and stepped out of the workforce for years, it's daunting to go back. So a specialised service of intensive counselling can really help you."

The initial "Working Well" pilot, co-funded by the Greater Manchester Combined Authority and the DWP, helped over 600 job-seekers into work, 6 per cent of whom were carers. Many continued working for 12 months or more. It also bestowed additional benefits, "improved health and reduced antisocial behaviour were also positive outcomes seen in the programme."[267]

Working Well offers all participants individually tailored, integrated support from their own key worker to re-enter the labour market. This can include health, skills and employment support. While similar to the Universal Support model, the Working Well programme aims to include also job-seekers who are not recipients of Universal Credit. Job-seeking family carers in the Manchester Working Well programme will have been referred by health and/or social care teams.

266 Greater Manchester Combined Authority, *Working Well: Pioneer*, 2024.
267 Ibid.

The key worker connects with the job-seeker but also with an Integration Coordinator who signposts them to the local specialist services in each of the ten boroughs that best meet their needs. Key workers' caseloads are kept low, at around 60 clients each, to ensure that they can provide intensive and bespoke support to all their clients. A personalised action plan is developed for each WW client, and a bespoke package of support is then created in response. Two providers, Ingeus and Big Life, delivered the pilot programme in Greater Manchester for performance-based payment. Depending on whether the clients had found a job and how long they stayed in the job, the two providers could earn up to £2880 per client.[268]

Together with DWP and the Center for Ageing Better the Combined Authority is now looking at the German model "Perspective 50+" which put in place a privately commissioned job centre to recruit older workers.

In its mission to ☒get people back to work☒, Government has invested £2.5 bn in a ☒back to Work☒ plan, run under the auspices of both the Department for Work and Pensions and the Department of Health and Social Care. They will test the WorkWell programme in 15 areas around the country, enabling employers, Job Centres, social workers and charities to refer individuals for assessment so that they may be supported by life coaches, GPs, social prescribers etc. The programme will start in 2025, run by the Integrated Care Systems.

The WorkWell programme has its roots, as its name suggests, in the Working Well Programme in the Greater Manchester Combined Authority. This included carer participants, many of whom successfully entered the workplace and stayed in employment for a year. The 15 ICS that will be in charge of establishing the new WorkWell programme in their localities also could ensure that family carers represent a proportion of those referred for support by life coaches, GPs, social prescribers, etc. If successful, this model could be scaled nationwide, enabling thousands of family carers to re-enter paid employment. As we have noted, there is real appetite among family carers to participate in the labour market, and the WorkWell initiative could facilitate this. Moreover, this cohort, by virtue of their caring responsibilities, has honed the skills to ensure they can contribute to any workplace -- organisation, self-discipline, drive, etc.

Recommendation:

The DWP should encourage the 15 ICS testing the new WorkWell programme to include family carers in their initiative.

268 Department for Work and Pensions, *Early Impact Assessment*, Greater Manchester Working Well. January 2018.

Case Study: Aviva

Interview with Anthony Fitzpatrick, Head of Employee Relations and Global Policy

"We have aimed to normalise caring responsibilities by removing the barriers and the stigma just by talking about it, keeping a regular flow of communication, recognising that there can be specific challenges, for instance, you are a male carer how does that feel? We want people to feel that at Aviva they can come forward and speak about their role as carers… we want a caring culture.

"Since the start of 2022, 1,435 colleagues have taken carers leave.

"We recognise that you don't leave your carer commitment at the office door when you step into the office…. We know that these circumstances can be really difficult. We have developed a pool of resources that are available on our employee portal that also help people with a range of issues to find additional help and support to help families find the right care services. That can be anything from day care, night care, respite, sheltered accommodation, residential and nursing care.

"We give 35 hours of paid leave per year. Or pro rata. We also enable employees to have unpaid leave and holidays at short notice. And also crucial is the fact that we operate hybrid working – that makes an impact.

"We have established a Carers' Hub, to help design policy and procedure. We keep the language user-friendly so that the Carer Hub is easily accessible.

"We always start by saying, 'Talk to your leader, he or she is the primary interface between you and your organisation… Develop the "workplace adjustment passport" with your leader: in this document you work out what you need, short medium and long term.' For instance, 'I have an elderly relative who has had a fall, so every Wednesday afternoon I need to accompany her to a physio therapist, or every Friday the nurse comes round and I need to be there.' The ownership of that document sits with the colleague. That living document is reviewed once a year.

"Our carer employees can use Aviva's Employee Resource Group -- a one stop shop for people.

This is a great way for people to share and to stay connected and we have continued to really keep the momentum behind carers and caring through regular communications and personal testimonials – these can be very powerful indeed."

Interview with CSJ, 14th November 2023

Aviva is a member of the Employers for Carers coalition of over 230 employers that has introduced a Carer Confident scheme to recognises companies that support their staff with caring responsibilities. The criteria include transparent policies and guidance that are widely communicated within the workplace, practical support and peer support, and helping the carer employee identify themselves.

This initiative should be encouraged as a key tool in the campaign to end economic inactivity.

Recommendation:

Government should encourage more employers to sign onto the "Carer Confident" scheme by communicating it more widely, linking it explicitly to the campaign to end economic inactivity.

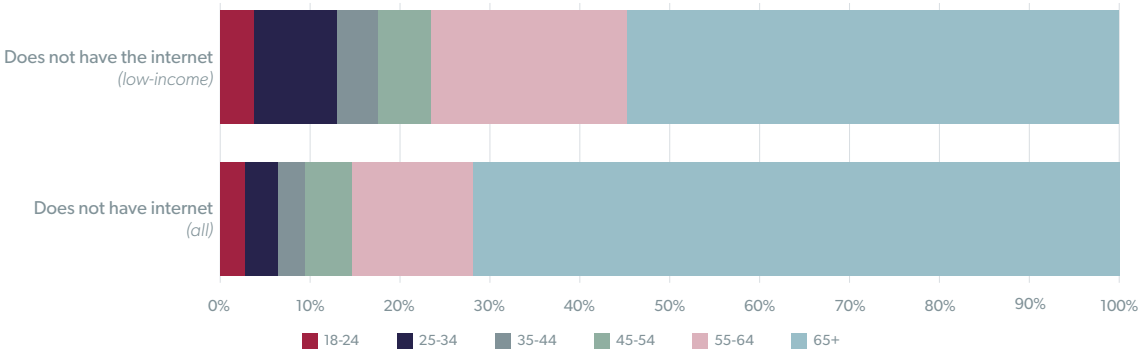
With the right support in place, paid employment can help protect family carers from the potentially negative impact of caring, providing respite and social interaction, as well as financial security. [269] As we have shown, some employers are already exhibiting best practice and their example should be followed.

269 Alison Pearson, *Who cares about the carers? A call to action on behalf of mothers of disabled children*, Frontiers in Sociology, Vol.8, 2024.

Chapter Nine:

Digital tools and technology

Inexpensive and accessible digital tools could revolutionise family carers' experience. But the social care sector, according to the Nuffield Trust, currently "has had very little exposure to digital technologies". [270] One reason is that older people, who are more likely to be the recipients of care, are far more likely to be digitally excluded. [271] Across the UK, 3 million people are offline[272]. In an analysis of the British Household Longitudinal Survey (Understanding Society) collected by the University of Essex, the CSJ found that just 62 per cent of those aged over 65+ own a computer and 75 per cent of those who are unemployed own a computer: both these figures are below the national average. While over 65s represent the majority of those who lack access to the internet at home, 29 per cent are of working age. In addition, 42 per cent of those on low incomes without access to the internet at home are of working age. [273]



Graph above reflects updated figures from the CSJ 2023 report, "Locked out", using Wave M Jan 2021- May 2023 for this analysis.

Perhaps unsurprisingly, only 41 per cent of family carers report that using technology makes their care responsibilities easier.[274]

270 Lucina Rolewicz, Camille Oung, Nadia Crellin, Stephanie Kumpunen, *6 Practical lessons for implementing technology in domiciliary care: Learning for commissioners and policy makers*, Research Summary, Nuffield Trust, September 2021.

271 Centre for Social Justice, *Left out: how to tackle digital exclusion and reduce the poverty premium*, August 2023.

272 Office for National Statistics, Dataset "Digital exclusion and equality in the UK", 30 January 2023.

273 Ibid.

274 Joseph Rowntree Foundation, *The Caring Penalty,* 18 July 2023.

Yet telecare could prove transformational: the 2010 Carer Strategy described one of the main aims of telecare as being to allow carers to be away from the recipient of their care, making it easier for them to remain in employment. [275] New technologies proved crucial during the pandemic, allowing for arms-length care and supervision.

They could be particularly value to carers on low income: this cohort is more likely to face economic challenges because they are less likely to be able to carry out remote working.

The Government has committed to delivering gigabit broadband to 85 per cent of UK buildings by 2025, and set out targets for 95 per cent of the UK to be covered by a 4G signal by the same year.[276] It has pledged £150 million of additional funding to drive wider adoption of technology and extend digitisation across social care.[277] Its 2014 Digital Inclusion Strategy accelerated and increased internet penetration nationally but since then, LAs have reduced their investment in the adoption of, and training in, such interventions.[278] The cost of digital technology remains prohibitive for low-income households. Family carers have reported other challenges, too: for many, innovative technology remains unfamiliar, and they fear the training necessary would prove time-consuming and/or expensive. Research shows that "an important reason for carers being unable to use telecare successfully was that carers lacked information and knowledge about telecare and its functions." [279]

As a result, some technologies -- robotics, exoskeletons, and drug release mechanisms – have had a low take up.[280] The same is true of technologies with graphic user interface, and multiple buttons: individuals with age-related conditions and those with disabilities may find these innovations beyond their capability. Even in terms of smartphones, 65.8 per cent of family carers use them, a much smaller proportion than the rest of the population (92 per cent). [281]

Integrating innovative technologies with other elements of care giving can be also a challenge. For health and wellbeing checks to become part of a carer's schedule, for example, timings have to take into account the GPs' availability – not always feasible. The transportation of some heavy or bulky equipment can also prove an obstacle for carers who travel on foot or by public transport.[282]

275 Nicole Steils, John Woolham, Malcolm Fisk, Jeremy Porteus, Kirsty Forsyth, *Carers' involvement in telecare provision by local councils for older people in England: perspectives of council telecare managers and stakeholders*, Ageing and Society. 2021;41(2):456-475, 8 October 2019.

276 Hannah Holmes, Gemma Burgess, *Digital exclusion and poverty in the UK: How structural inequality shapes experiences of getting online,* Digital Geography and Society, Volume 3, 2022.

277 Ibid.

278 Lucina Rolewicz, Camille Oung, Nadia Crellin, Stephanie Kumpunen, *6 Practical lessons for implementing technology in domiciliary care: Learning for commissioners and policy makers*, Research Summary, Nuffield Trust, September 2021.

279 Nicole Steils, John Woolham, Malcolm Fisk, Jeremy Porteus, Kirsty Forsyth, *Carers' involvement in telecare provision by local councils for older people in England: perspectives of council telecare managers and stakeholders*, Ageing and Society. 2021;41(2):456-475, 8 October 2019; Carers UK, *State of caring 2022*, November 2022.

280 Junxin Li et al, *A personalized behavioral intervention implementing health technologies for older adults: A pilot feasibility study*, Geriatric Nursing, Volume 41, Issue 3, pp 313-9, May-June 2020.

281 Egan J Kieran, *Understanding Current Needs and Future Expectations of Informal Caregivers for Technology to Support Health and Well-being: National Survey Study,* JMR Aging, 25 July 2022; Nick Baker, *Uk Mobile Phone Statistics 2023*, U Switch, 13 November 2023.

282 Lucina Rolewicz, Camille Oung, Nadia Crellin, Stephanie Kumpunen, *6 Practical lessons for implementing technology in domiciliary care: Learning for commissioners and policy makers*, Research Summary, Nuffield Trust, September 2021.

Case Study: Japan

Interview with Prof Taichi Ono, Japanese National Graduate Institute for Policy Studies

Technology is integral to Japan's social care, Prof Taichi Ono told the CSJ. The country's demographic profile is of concern to Japan's government, with population decreasing 12 years in a row. Wearable devices using robotics technology provide power assistance to caregivers so that they may raise or lower the person they are looking after in their bed/chair. For carers who are working part time away from home or are not living with their loved ones – which is a growing trend also in Japan -- there are platforms using robotics technology, used for home care and equipped with a fall detection sensor and external communication function. Addressing loneliness – and freeing the family carer from providing 24/7 companionship – they have introduced pet robots such as the OHaNAS, a talking sheep who engages users in conversation, plays word games, and responds to touch in various ways. Similarly, Robi Jr., a compact-sized communication robot, uses more than 2,000 phrases and is promoted with the slogan, "Motto nakayoshi"("get closer"). Even our toilet designs are focused on carers: they can wash and dry their older relatives or those with disabilities at the press of a button, without injuring their back.[283]

Interview with CSJ, 14 September 2023

The UK has yet to mirror Japan's widespread adoption of digital technology to support family carers, but progress has been made – much of it accelerated by the pandemic.

Personalised Health

The ever-wider adoption of "personalised health", whereby the individual can purchase apps or wearable technology to self-administer medical tests, and chart their own health and ageing profile prevention has been shown to reduce hospital readmission and improve the health outcomes of older people. [284] This technology is widely available and allows carers to track daily activity, and monitor vital signs.[285] Personalised health gives the vulnerable individual and their carer greater agency, allowing for early intervention.

Information can be provided in a wide variety of formats – through computer, tablets, or cell phones and handheld devices – to best suit the carer.10

Technology-enabled care services such as home health monitoring tools (smart home cameras) and therapeutic robots (as per the Japan case study) can ensure a home becomes a safe space for the vulnerable resident.[286] Knowing that the recipient of their care is under "remote supervision" allows a family carer to enter or re-enter the workforce.

283 Maitreyi Bordia Das et al , *Silver Hues: Building Age-Ready Cities,* International Bank for Reconstruction and Development/The World Bank, 2022.

284 Sarah Abdi, Luc de Witte, Marc Hawley, *Exploring the Potential of Emerging Technologies to Meet the Care and Support Needs of Older People: A Delphi Survey,* Geriatrics 6, 19, 13 February 2021.

285 John Thomas, *Review of Digital Technology Solutions to Support Caregivers,* University of Strathclyde, Glasgow. 2020.

286 Government Office for Science, *Future of an Ageing Population*, 2009.

"Hospital at Home"

Digital technology encourages clinical homecare, which since Covid-19 has become increasingly popular [287]. Delivered by trained healthcare staff including pharmacists and nurses, clinical homecare enables patients and their family carers to build a relationship with a particular key worker as part of a wider integrated team. This can ease pressure on carers while also improving adherence to treatment and, as a result, patient outcomes.[288] A recent study showed that caring for a select group of vulnerable people at home can improve patient outcomes, while reducing pressures on hospitals.[289] The same study also reported higher levels of patient satisfaction with "hospital at home" care.

For family carers who are juggling work and looking after a frail or disabled adult, clinical homecare can spare time-consuming trips to hospital for an appointment – trips that can cause stress and anxiety for patients and carers alike.[290]

To extend the reach of clinical homecare, government should accelerate the proper integration of health and social care across the country, as the Hewitt Review recommended: patient health records need to be joined up, linking prescribing systems and clinical systems, pharmacy (ordering, invoicing, patient medication records, repeat prescription records), homecare provider systems, and financial systems. Too many areas of the NHS still fail in data sharing, hindering effective prevention.[291] The Integrated Care Systems have a budget of around £113bn – and the Hewitt Review recommended a target of 1% investment in prevention within ICS areas.

Digital Inclusion

To take advantage of the opportunities offered by technology however, Government needs to remove the barriers to devices and data and improve digital capability. To tackle limited data access for the lowest income consumers, the CSJ has proposed that the Department for Work and Pensions "consistently advertise social tariffs to eligible Universal Credit recipients. [292] We further recommend reducing VAT on social tariffs pending a guarantee from providers that savings will be passed to consumers. We also recommend asking providers to improve their social tariff speeds to match average speeds and take steps to help consumers compare commercial and social speeds to demonstrate their comparability."[293] At 100 per cent take up this would cost the Treasury circa £116 million – though actual take up would fall well below this.

Recommendation:

Reduce VAT on social tariffs to 5 per cent

287 Richard Sloggett, *Care closer to home - The role of clinical homecare in the revolution of patient care*, Future Health, March 2022.
288 Ibid.
289 NHS England, *Reducing length of stay*, 2019.
290 Richard Sloggett, *Care closer to home - The role of clinical homecare in the revolution of patient care*, Future Health, March 2022
291 Ibid.
292 Centre for Social Justice, *Left out: how to tackle digital exclusion and reduce the poverty premium,* August 2023.
293 Centre for Social Justice, *Left out: how to tackle digital exclusion and reduce the poverty premium*, August 2023.

Recommendation:

Encourage providers to improve their social tariff speeds to match average speeds

Digital innovations, especially when inexpensive and user friendly, could potentially reduce costs significantly and long-term for government at a national and local level. Crucially, they could also offer family carers the opportunity to return to paid employment, knowing that their relative has access to digital support and can be monitored remotely.

Chapter Ten:

Changing the culture

During the pandemic, people across the country stood on their doorsteps to clap for carers. This show of gratitude for the heroic work carried out by formal carers was a promising departure from decades of under-investment and under-appreciation. Unfortunately, the display of goodwill proved short-lived.

We neglect this remarkable group, even though, beyond lockdown, carers have supported our most vulnerable citizens through illness, disability, and old age. We fail to recognize those whose unstinting support is unpaid – the extraordinary spouses, parents, children, siblings who have been sparing the rest of us an enormous and costly task, all the while displaying qualities that as a country we should cherish, such as charity, selflessness, loving duty, patience.

For many family members, the journey into care is sudden and bewildering, involving medical terms and social care services that are wholly unfamiliar. It also often forces them into a humiliating position: while the rhetoric about caregivers is increasingly about "partners in care", carers have reported directly to the CSJ that they feel many service users complain of being "talked down to", made to feel "stupid or helpless or both".[294] Claire Bolderson in her research on social care charging, attributes this to the "very unequal relationship between care service users and LAs."[295] The state, she points out, expects carers to undertake the physical, emotional and financial support of their vulnerable family member, but fails to recognize them as best placed to know the needs of those in their care.

Even luminaries in the medical field overlook the family as a source of care: in his 267 page Annual Report on Health in an Ageing Society, Chris Whitty, the Chief Medical Officer includes only three paragraphs on family carers.[296]

Undermining family members in this way risks quashing their confidence or leaving them feeling the system is their foe not their friend. As Jonie Hawksley told the CSJ Working Group, "I know what my son's needs are, and I shouldn't have to take on the state to secure the right support for him."

A cultural shift

Our Working Group and the stakeholders who engaged with our research call for a wholesale cultural shift that engages government, business and public services – including our education system. We should prepare all adults for caregiving, explaining that everyone of us at some point is likely to be a carer, in need of some basic skills and adequate support.[297]

294 Unstructured interviews conducted by CSJ, March-November 2023.

295 Claire Boulderson, *Social Care Charging*, Social Policy and Social Research Department, UCL, November 2023.

296 Chief Medical Officer's Annual Report 2023:Health in an Ageing Society, 2023.

297 Richard Schulz, Scott Beach, Sara Czaja, Lynn Martire, Joan Monin, *Family Caregiving for Older Adults,* Annual Review of Psychology Vol 71:635-659, January 2020.

This should start in school. Multi Academy Trusts could follow the example of the housing associations that offer skills development like IT, interview skills and CV writing for local family carers as part of their community outreach. This invaluable up-skilling can be signposted by the Universal Support Work Coach when a family carer meets with them.

Schools should provide information about the rewards and challenges of a role that, given demographic trends and health service innovations, is becoming ever more necessary. The curriculum can highlight caregiving as a fundamental human value through PHSE classes, and welcome speakers with lived experience to describe the rewards and challenges of looking after a family member affected by age or disabilities.

Through their careers advice schools could encourage students to see caregiving as a highly rewarding profession that can increasingly rely on being in demand, long term. Crucially, this is a profession that ffers strong sense of job satisfaction.[298] Schools can also recommend experience as a carer – in a formal or informal setting -- as part of their students' CV-building.

Challenging stereotypes

Schools should be conscious that care-giving is a viable professional career or lifestyle choice to all students and not just female ones. Traditionally, caregiving has been perceived as "woman's work", with three in five carers being female, but the rise in demand for family carers due to the demographic changes will challenge this assumption.[299] Men's intervention however has not always been gratefully received, as David Goodhart notes in his forthcoming book "The Road Home": *"Even those men who do have social skills are sometimes not welcome in jobs requiring physical intimacy with the very old, very young, or disabled…"*

When men in formal care account for only 16.9 per cent of social workers it is not hard to see why men are less likely to identify as "informal" carers and to access the support services they are eligible for. [300]

Yet many men already take care of spouses, children and vulnerable family members; among those over 85 years old, men now represent 59 per cent of carers.[301] The care that they deliver often differs from that undertaken by their female counterparts: while women carry out tasks such as bathing, washing, feeding etc, men are more likely to provide help with Instrumental Activities of Daily Living (IADL)' which entails accompanying to medical appointments, cooking and providing financial advice.[302]

There is evidence also that men engage in "professionalisation" of caregiving tasks by applying skills from previous employment, such as management or technology.[303] This suggests that men are likely to feel more at ease with caregiving as technology plays an ever-increasing role in these tasks.

298 Caring Times, *New research reveals strong sense of job satisfaction among UK carers,* 8 June 2023.

299 Yvonne Prinzellner, et al, *Care–life balance: a new normal for men too?,* International Journal of Care and Caring, *7*(3), 563-569. Retrieved 30 November, 2023; Eurofound, *Long-Term Care Workforce: Employment and Working Conditions,* Publications Office of the European Union, Luxembourg, 2020.

300 *Social Work in England: State of the Nation 2023*, 9 March 2023.

301 Carers Uk, *Caring into later life: The growing pressure on older carers,* London, 2015

302 Yvonne Prinzellner, et al, *Care–life balance: a new normal for men too?,* International Journal of Care and Caring, *7*(3), 563-569. Retrieved 30 November, 2023.

303 Yvonne Prinzellner, et al, *Care–life balance: a new normal for men too?,* International Journal of Care and Caring, *7*(3), 563-569. Retrieved 30 November, 2023.

In the meantime, healthcare professionals need to be more aware of men's reluctance to identify as carers and to seek support. This will lead to more accurate assessments and therefore to more timely support or interventions.

Listening to family carers

Healthcare professionals need to take into account the sense of marginalization that many family carers struggle with. GPs and primary care givers, often the first point of contact for a carer, are well-placed to change the impression that only patients matter.[304] When a relative is accompanying a vulnerable individual on their GP visits or counselling appointments, the health care professional should automatically follow a protocol around checking on the health and well-being of the caregiver. Once they have identified the family carer, they should register them (as noted earlier) and signpost them to specialist support when necessary.

We have heard from family carers that their concerns regarding their relative's condition, and suggestions they may make for its improvement are routinely ignored by social care workers as well as health care professionals. This short-sighted approach must be challenged.

Recognising the impact family carers have on the outcomes of vulnerable individuals, Skills for Care have developed a framework to improve collaboration between formal carers and families.[305] The framework has been adopted by some adult social care employers, but should become standard.

Recommendation:

Promote collaboration between families and health and social care professionals the Department of Health and Social Care should introduce a protocol around speaking with family caregivers and registering their concerns and suggestions regarding the care for their relative.

Upskilling Carers

Family carers, both male and female, report feeling ill-prepared for looking after their relative's medical conditions and treatment. [306] Even delivering simple healthcare such as dressing a wound or administering a finger prick test to monitor a diabetic patient's blood sugar can be daunting. Feeling out of their depth, and concerned for the welfare of the individual they are caring for, they will automatically contact their GP or other health professionals – adding pressure on the already overwhelmed sector.

Promoting a true culture change for informal carers requires the elevation of formal care: a sector characterised by low pay and few prospects for professional development is unlikely to inspire new entrants.

304 Jasneet Parmar, et al., *Family Physician's and Primary Care Team's Perspectives on Supporting Family Caregivers in Primary Care Networks,* Int. J. Environ. Res. Public Health 2021.

305 Skills for Care, *Working with families friends and carers,* 2019.

306 Alexandra Davidson, et al., *Family Carers' Experiences and Perceived Roles in inter-professional collaborative practice in primary care,* Health Expectations, 9 July 2023.

A health and social care partnership that would give domiciliary carers the opportunity to progress within the NHS would enable domiciliary carers to access training and employment opportunities in an NHS hospital. Carers could train alongside community nurses and then be able to apply for hospital and community work, whether as occupational therapists or as nurses.

Upskilling of family carers, too, where appropriate -- on administering medications, operating medical equipment and navigating pathways for accessing primary healthcare IPCP teams -- would boost confidence as well as competence.

Family carers have said learning about the diagnosis and progression of the condition was only the first step, and that they would need to also learn the critical role of being the key link in communication between the patient and healthcare professionals but also social services.[307] In many instances, too, family carers need to act as advocates for their relative(s). Research shows that knowing that they have the skills to understand and manage the complexities associated with their relative's condition, lends them the confidence to be an effective advocate – whether for someone affected by disabilities or age-related frailty.[308]

Currently, online training (much of it free) is available to carers, covering topics ranging from communication to mental health awareness and positive "risk-taking". In Wales, for example, family carers can sign up for "What about me?", a personal development course developed by The Open University and Carers Trust Wales, designed to help carers recognise their skills and experiences.[309]

We should ensure that family members as well as formal carers have the opportunity to learn skills to boost their self-confidence, and secure a better profile and higher status.

Upskilling carers will facilitate their role while enabling them to implement a preventative strategy that reduces the need for formal care and more intensive interventions.

The NHS budget for Training and Development within trusts and foundation trusts should invest in training programmes delivered by nurses to family carers in non-medical interventions. The transfer-of-knowledge, from a clinically registered practitioner to a family carer, boosts carers' self-confidence and extends their caring capacity.

Recommendation:

Trusts and foundation trusts should use their budget for Training and Development to fund training schemes for family carers in non-medical interventions.

Recommendation:

Trusts and foundation trusts should use their budget for Training and Development to fund training for domiciliary carers to gain access to hospital or community employment opportunities.

307 Alexandra Davidson, et al., *Family Carers' Experiences and Perceived Roles in inter-professional collaborative practice in primary care,* Health Expectations, 9 July 2023.

308 John Thomas, *Review of Digital Technology Solutions to Support Caregivers,* University of Strathclyde, Glasgow, 2020.

309 Open University in Wales, *Support for carers*

Case Study: Barefoot Counsellors

Interview with Anil Patil, Founder

Training family carers in counselling gives them an important skill while also providing crucial mental health support – for themselves as well as those they look after. This is the principle espoused by Carers Worldwide with their Barefoot Counsellors scheme, currently engaging 150,000 women in India, Nepal and Bangladesh. Taking a community approach, the scheme trains family carers in self-care, resilience and community wellbeing. Over five days' training (or 45 hours online) the programme offers peer to peer learning as well as professional-led exercises. Upon completion of the programme, the carer receives a joint certificate from MIND India and the Public Health Foundation of India.

"More than any certificate, the benefit for these women comes from knowing that someone is interested in their life." Anil Patil, CEO of Carers Worldwide, told the CSJ, these carers feel invisible, hidden behind a curtain. They are the wounded healer. In the countries where we work no one has heard of the term carer: it is simply an unquestioned role for mainly women.

We draw them together into emotional support groups which are run and managed by carers themselves. They make the arrangements to be able to get one hour off so they can take part in our groups. We have made a Health and Wellbeing Toolkit because we found that 81 per cent of the women we are training have mental health issues -- remember, they are not just carers, they are mothers, wives, daughters. Over the years (Barefoot Counsellors has been running since 2012), for those who are part of our programme that 81% has come down to 9 per cent.

"We work with 15 charity partners. We would be keen to bring our programme to the Nepalese community in Reading or Winchester; or to Leicester, with its sizeable Indian community."

Interview with CSJ, 3 June 2023

Caring: a protected characteristic

The Equality Act [310] made it illegal to discriminate on grounds of nine 'protected characteristics' including ethnicity, nationality, religion and sex. . This extends legal protection against discrimination – when in the workplace, using public services, purchasing or renting property, etc. While the primary driver for this legislation was to protect individuals, the secondary consequence has been to raise public awareness of the protected characteristic. Carers who undertake to look after a family member have reported to the CSJ repeatedly [311] that they feel overlooked, marginalized and misunderstood by support services, health professionals, and employers. This wrong must be addressed – and an amendment to the existing legislation (the Equality Act of 2010) would go some way in achieving this.

310 Legislation Gov UK, Equality Act 2010.
311 Unstructured interviews conducted by CSJ, March-November 2023.

Recommendation:

Amend the Equality Act 2010 to include being a carer in its list of protected characteristics.

Finally, celebrity should not be discounted as a means to change culture. Prominent role models in the media can raise care to an admirable and celebrated role, as Kate Garraway and Timothy West have shown. Government could encourage family carers through a traditional media and social media campaign that celebrates these "everyday heroes". This positive narrative will validate the extraordinary efforts of family, friends, and neighbours, young and old, to help the most vulnerable in our society. It will also promote the invaluable qualities that these carers personify, such as selflessness, patience, self-discipline, and thoroughness. Recognising the value in the carer's experience, more and more young (and older) will recognise that to care for a relative or friend is not a death sentence, nor is it the first step to penury, but a widely admired role.

Chapter Eleven:
Conclusion

Demand for care will increase dramatically over the next few years. This development will take place in a context where the formal social care sector is shrinking because of low wages, scarce professional development opportunities, and local authorities' budget constraints. The ensuing gap between demand and supply of care will need to be filled by family carers.

Our reliance on this cohort should compel us to make their lives more manageable. For those of working age, we should ensure that their caring responsibilities do not preclude holding down a paid job – especially as, the CSJ-Opinium survey shows, so many 16-64 year old carers want to return to work or increase their hours at work.

This report has shed a light on the barriers they face in attempting to enter or re-enter the labour market. Challenges such as a complex benefits system, digital poverty, poor housing, and unhelpful employers are driving family carers away from paid employment. Indeed, 41 per cent are thinking about reducing their hours or leaving paid employment entirely within the next year, our national survey finds.

This trend will have significant negative consequences. Cutting short working life compromises family carers' earnings and pensions, which is likely to be especially damaging for low-income workers; it also dents confidence and aspiration, while reducing social connections.

The negative impact of a further increase of economic inactivity will affect the Treasury, too, as we have shown: lost earnings mean lost taxes and lost NI contributions; and in the case of family carers, these losses are all the more significant because they often come hand in hand with a rise in benefit claims.

The CSJ has asked family carers what , in their view, would help them sustain paid employment. They were clear that with the "right support in place", they would be able to hold down a job and continue to provide care. The three key policies we costed represent a sensible investment by government to deliver this support. As our cost benefit analysis shows, they should enable a significant proportion of the economically inactive working age carers to be once again part of the labour market – and share the many benefits conferred by paid employment.

Beyond easing the family carer into (or back into) a job, we should feel under a moral obligation to ensure a better quality of life for those selfless individuals who look after someone vulnerable. For too long the failures of national and local government have left this cohort struggling with unmet needs

Fortunately, solutions to our current dilemma abound – in this country and abroad. This report has showcased promising national and international schemes to be replicated and scaled. Many rely on small grassroot organisations that know best the needs of local families and the recipients of their care; these groups and charities are also small enough to be agile and instant in the assistance they deliver. Place-based support, and peer-to-peer support, can often meet needs the state leaves

unanswered. To ensure that small charities and grassroot groups are competing for local government contracts on a level playing field, commissioning needs to become a simpler process, that allows schemes to prove their worth over a longer timeframe.

Other promising schemes rely on technology, which has huge potential for supporting both formal and informal carers in terms of monitoring, administering medication, preventing accidents and crises. Among the most disadvantaged however this potential remains untapped because of cost and, critically, lack of digital inclusion. Here government must step up to fill the shameful gap between those who can get online and those who remain stuck offline.

Crucial, too, is the role of business. An employee with care experience will have honed invaluable skills and qualities, including of organisation, patience, determination, advocacy.

Employers who can keep them on board, or attract them in the first place, will benefit hugely and save themselves the costs of recruitment and training. Some of the concessions family carers are asking for will be expensive – paid carers' leave for instance; some however are free and easy to implement, such as an in-workplace carer's information hub.

Finally, communication around family caring needs improvement. Too many contributors to this report have expressed their frustration and dismay at finding themselves suddenly cast into the impenetrable maze that is our social care system, with no one to signpost them in the right direction. Communicating what an individual is entitled to, should be done clearly, and in timely fashion. But improving communication around family carers should be about recognition as well as direction. A national campaign to celebrate these everyday heroes, recognising the sacrifice that spouses, siblings, children, parents make on a daily basis, is long overdue.

Family carers play a crucial role. Without them, the most vulnerable risk suffering indignities including penury and mistreatment while state services are set to buckle under ever greater pressure. There is no more deserving a cohort for government to support.

Appendix 1

Table 1 – Key assumptions for updating of income tax loss estimates

VARIABLE	PICKARD ET AL ASSUMPTIONS	DATA SOURCES USED BY PICKARD ET AL	UPDATED ASSUMPTIONS	DATA SOURCES USED IN UPDATED ESTIMATES
Number of unpaid carers in England (16-64)	4.1 million	2011 Census	3.5 million	2021 Census
% not in employment due to caring	8.4%	HSCIC 2009/10 survey of carers in households	11.4%	CSJ/Opinium survey of unpaid carers (2023)
Number leaving employment due to caring	345,000	Rounded estimate	295,000	Rounded estimates
% of female unpaid carers	59%	2011 Census	61%	2021 Census
% of male unpaid carers	41%	2011 Census	39%	2021 Census
% of female carers leaving FT work	51%	2011 Census	52%	2021 Census
% of female carers leaving PT work	49%	2011 Census	48%	2021 Census
% of male carers leaving FT work	85%	2011 Census	80%	2021 Census
% of male carers leaving PT work	15%	2011 Census	20%	2021 Census
Male and female FT/ PT earnings	Median weekly pay of: M FT: £567 M PT: £156 F FT: £471 F PT: £172	2015 ASHE survey (ONS)	Median weekly pay of: M FT: £725 M PT: £230 F FT: £629 F PT: £246	2023 ASHE survey (ONS)**
Average income tax rate paid	17.2%	HMRC estimate for 2015/16	18.0%	HMRC estimate for 2023/24
Estimated total income tax loss	**£1.2bn**	**2015/16**	**£1.9bn**	**2023/24**

*This was from a survey of 1,530 unpaid carers commissioned by the Centre for Social Justice (CSJ) and carried out by Opinium in November 2023.

**Provisional ASHE data for 2023 published by ONS on 1 November 2023, covering the UK as a whole

Most of the assumptions in Table 1 are quite similar, with the main differences being:

- a lower estimate of the number of unpaid carers in England from the 2021 Census as compared to the 2011 Census data used by Pickard et al (3.5m vs 4.1m)
- a higher estimate that 11.4% of unpaid carers aged 16-64 were unable to work due to their caring responsibilities based on the more up to date CSJ survey of 2023, rather than the 8.4% estimate from the 2009/10 survey used by Pickard et al (note that the latest FRS data also supports an estimate for 2021/22 of around 11%, close to the new CSJ survey estimate)
- higher earnings levels in 2023 due primarily to general price inflation since 2015
- a somewhat higher average income tax rate now than in 2015/16 (18% vs 17.2%)

The net impact of these changes is a rise in the estimated income tax loss from £1.2bn in 2015/16 in the Pickard study to around £1.9bn in 2023/24.

It should be noted that a significantly higher estimated income tax loss of around £3.6bn would arise if we used the much higher 21.4% assumption on the share of carers not able to work due to their caring responsibilities from the NHS PSS survey of adult carers 2021/22. This is not directly comparable, however, as this PSS survey was for a much narrower population of carers who are known to councils. These carers tend to be significantly older (almost half are over 65) and with more significant caring responsibilities than the general population of unpaid household carers identified by the Census. As such, we cannot just apply the 21.4% estimate to this whole population of 3.5 million unpaid carers.

National insurance losses from unpaid carers not being able to work:

Modelling the impact on national insurance (NI) revenues poses some challenges and requires a number of simplifying assumptions. Nonetheless, this seems preferable to not including NI as Pickard et al did. The key assumptions used here (in addition to those in Table 1) are that:

- average NI contributions (NICs) that carers would have made if they had been able to work are approximated by the NI contributions that would be made by people in the four categories considered (male/female, split in each case into FT and PT workers) with median earnings for each category (using the same ASHE data as in Table 1)
- the median earnings of the self-employed, excluding business expenses, would be the same on average as for employees in the same categories (M/F, FT/PT)[312]
- 14% of the female carers and 24% of the male carers not working due to their caring roles would otherwise have been self-employed rather than employees (based on Census 2021 data for all unpaid carers of each sex).

We need to consider self-employed workers separately since NICs will be lower for them than employees, primarily due to there being no employer NICs for the self-employed. Thresholds and rates for self-employment NICs also differ from those for employee NICs.

Based on these simplifying assumptions, we can estimate lost NI revenues at around £1.4 billion in 2023/24 as shown in Table 2 below.

312 Note that Pickard et al also implicitly make this assumption in their income tax loss estimates, as do we in our updated income tax loss estimates.

Table 2 – Estimated revenue losses due to unpaid carers not being able to work (£bn)

	PICKARD ET AL ESTIMATE FOR 2015/16	UPDATED ESTIMATE FOR 2023/24
Employee NICs	n/a	0.53
Employer NICs	n/a	0.79
Self-employed NICs	n/a	0.11
Total NIC loss	n/a	1.4
Income tax loss	1.2	1.9
Total revenue loss	1.2	3.4

Note: columns may not add up exactly due to rounding

Additional benefit spending due to unpaid carers not being able to work

Pickard et al estimated additional benefit spending for unpaid carers aged 16-64 unable to work of around £1.7 billion in 2015/16 for England, based on analysis of data from the 2009/10 carers survey relating to Carers Allowance, Income Support and Housing Benefit.

The CSJ has produced updated estimates using data from the Family Resources Survey (FRS), which is the main source used within government for detailed benefit calculations. This also allows for comparisons over time although these are complicated by changes in the benefit system, most importantly the phased introduction of Universal Credit. These data are also for the UK as a whole, so need to be adjusted to give estimates for England only for comparison with Pickard et al.

Table 3 summarises key results of this new analysis, matched as far as possible with the Pickard et al estimates although this is not precisely possible due to the different data sources and benefit regime changes. The estimates for individual benefits are less reliable than the overall estimates, which suggest a broadly similar figure for England 2015/16 from both studies as the penultimate row of Table 3 shows (£1.7bn from the Pickard study and £1.6bn from the FRS-based analysis).

Table 3 – Estimated additional benefit spending due to unpaid carers aged 16-64 not being able to work (£bn)

	PICKARD ET AL ESTIMATE FOR 2015/16 (ENGLAND)	FRS-BASED ESTIMATES FOR 2015/16 (UK)	FRS-BASED ESTIMATES FOR 2021/22 (UK)
Income support	0.5	0.2	0.1
Housing benefit	0.8	1.1	1.8
Carers allowance (including carers premium and element)	0.4	0.6	0.9
Total benefit spending	1.7	1.9	2.8
Adjusted for England	1.7	1.6	2.4
Uprated to 2023/24 values using CPI	n/a	n/a	2.8

Sources: Pickard et al (2017), CSJ analysis of FRS data, CPI forecasts for 2023/24 from OBR (November 2023). England adjustment based on its share of total UK population (84.3% in 2021).

The corresponding estimates for 2021/22 based on FRS data show marked increases in additional benefit spending on these unpaid carers who are not able to work for both Carers Allowance and Housing Benefit, although the latter estimates are subject to considerable margins of error. Overall, however, the estimated extra benefit spending was around £2.8bn in 2021/22 for the UK as a whole or around £2.4bn for England. Uprating this to 2023/24 values using CPI suggests estimated additional benefit spending as a result of these unpaid carers not being able to work of the order of £2.8bn in the current fiscal year.

Summary

Including national insurance in the analysis, on plausible simplifying assumptions, would add around £1.4bn to the estimated revenue loss from unpaid carers being unable to work, taking the total tax revenue loss to around £3.4bn in 2023/24 based on updated assumptions and CSJ survey results on the proportion of unpaid carers not able to work.

Updated estimates using the latest available FRS data suggest additional benefit spending for these unpaid carers unable to work of around £2.8bn in 2023/24, taking the overall estimated cost to the public finances to around £6.2 billion for England in 2023/24. This compares to the Pickard estimate of £2.9bn for 2015/16 excluding national insurance losses (see Table 4 below)

Table 4: Summary of the estimated cost to the public finances of unpaid carers aged 16-64 in England not being able to work

	ESTIMATED COSTS (£BN, ENGLAND)	
	2015/16 (PICKARD ET AL)	2023/24 (CSJ)
Income tax loss	1.2	1.9
National insurance loss	Not included	1.4
Extra benefit spending	1.7	2.8
Total cost to public finances	2.9	6.2

Appendix 2

Although we acknowledge that the aspiration to get all those who left work for caring responsibilities back into work is the absolute upper end of the range of possible exchequer gain, we have also calculated the costs and benefits of this scenario.

According to the Family Resource Survey, a little over 300,000 inactive benefit claimants of Carers Allowance or equivalents in Universal Credit, or those who have caring increments in Income Support and Housing Benefit are identified. There are 400,000 inactive working age adults that said their reason for not wanting to work was caring responsibility for a disabled (or older) person in the UK.[313]

The sub benefit claiming populations had relevant benefit or increment amounts applied to them equates to an overall UK benefit bill of £2.8bn and an (England only) one of £2.4bn in 2021-22; this second number uprated returned an England only value of £2.8bn in 2023-24.

We undertook earnings and tax calculations using a similar population estimate based on 2021 Census data, split by employed and self-employed movements by male and female by full-time and part-time.

The average earnings applied to each cross-tabulated subgroup came from the Annual Survey of Hours and Earnings, which included Income Tax, Employee and Employer National Insurance personal allowance and tax rates to them. These were grossed up by population size to deliver an overall tax take of £3.4bn in 2023-24.

The net fiscal benefit across benefits and taxes is £6.2bn in 2023-24.

313 Department for Work and Pensions, *Family Resources Survey 2023*, CSJ calculations.

Appendix 3

Older People's Task Force
Submission by the CSJ on 11 September 2023

People

What are the most important issues the taskforce should seek to address? (maximum 250 words)

Many older people are uncertain about their retirement housing options. [7] This is especially true, we heard during the CSJ's interviews with charity key workers, of those on low income as well as members of ethnic communities. Not knowing about available options leaves some of the most vulnerable individuals struggling in unsuitable homes. For instance, in Yorkshire, Calderdale SmartMove told us about the low income men (many of them widowers) they worked with, who had no idea about their entitlements regarding home adaptations, the Disabled Facility Grant, and sheltered housing. In Manchester, we heard from the charity AfricanCaribbean Care Group, which explained how their clients did not seek social workers' support as they worried about how this could affect their benefits.

Do you have specific recommendations for the taskforce to consider? (maximum 250 words)

Government should promote a national level communications strategy that would set out the features (including costs) of different housing models available for older people. The campaign should, as Prof Alison Bowes, professor in Dementia and Ageing at Stirling University told the CSJ, frame future-proofing housing as something in all our interest: we all age, so we all need accessible, safe housing.

As part of this national communication strategy, the CSJ recommends a One-Stop Shop for Carers, in hospitals and GP surgeries, to deliver advice on housing options as well as local support services for those looking after an elderly family member. Individual health professionals/ social prescribing link workers would clearly explain the housing options, fiscal benefits, local voluntary services, national and local government entitlements, available to family carers and those they look after. The One Stop Shop for Carers would be delivered through social prescribing link workers in GP surgeries; while in hospitals, there would be a clear duty on the NHS Trust and Foundation Trusts to train local apprentices to help family carers navigate the social care system and retirement housing. This would be funded through the apprenticeship levy, which represents 0.5% of the pay bill for organisations with a pay bill of £3 million or over. [8]The NHS pays £200 million into the apprenticeship levy every year: many trusts have thus accrued significant levy pots.

Places

What are the most important issues the taskforce should seek to address? (maximum 250 words)

Currently, only 9% of UK homes meet the minimum accessibility standard and more than 2 million people aged over 55 are living in a home that endangers their health or wellbeing[1]. There is an urgent need for more suitable accommodation for our older population.

Retirement housing is the only form of housing that the Government has identified as being 'critical' within National Planning Policy Guidance (NPPG). More recently, the Mayhew Review recommended that the government adopt a retirement housing target of 50,000 units a year to 2040 to keep up with demand.

For this target to be reached, planning regulation needs to change. It is hindering investment in housing for our older citizens.

Do you have specific recommendations for the taskforce to consider? (maximum 250 words)

While care homes are classed as C2, and therefore do not need to provide affordable housing either on site or through contribution, retirement housing is classed as C3, which does come with the requirement to provide affordable housing. The CSJ have heard from developers and providers that this requirement makes retirement housing financially unviable. Retirement housing, they explained, already entails higher building and operating costs than typical residential schemes. It also entails a much higher proportion of non-saleable communal areas. Having to meet an extra requirement places would-be developers at a further disadvantage.

Given the demographic pressures, Government should introduce a new planning use class that takes into account the very specific nature of retirement housing. A dedicated classification would help local planning authorities better understand a sector they are as yet unfamiliar.

Similarly, Homes England should allocate a bigger proportion of their grant for retirement housing. Currently, 10% is for supported living, leaving too little for older people:[2] £40 million out of £4 billion. There are approximately 74000 housing with care units in UK – this represents only 0.9% of households aged over 65 in England and Wales. Yet The Mayhew Review [3] found that retirement housing – such as extra care schemes -- helps older people stay healthier for longer.

Products

What are the most important issues the taskforce should seek to address? (maximum 250 words)

Individuals affected by dementia, limited mobility, or blindness struggle when they venture outside the home, their family carers have told the CSJ. Town planning has routinely ignored this vulnerable cohort, increasing risks of falls or other unintentional self-harm. Too many local authorities allow retirement housing to be built on the peripheries of a town, away from the centre and its hub of activity. Such segregation cements the isolation and loneliness of the elderly; it also affects their health. Vikki McCall, Professor in Social Policy and Housing at Stirling University, told the CSJ that "healthy ageing calls for specific elements in town planning".[4] These include proximity to GPs, pharmacies, shops, green spaces; pedestrian-friendly and wheel-chair routes; and public spaces that encourage unplanned social interaction.

Do you have specific recommendations for the taskforce to consider? (maximum 250 words)

The "Serious Game", designed by Prof McCall's team at Stirling University, aims to give local planning authorities and key stakeholders, including voluntary sector, housing associations, representatives of health and social care as well as older residents' groups, a toolkit to measure and ensure their town's Age-Friendliness.

The Game, currently being piloted in Southwark, features the fictional "Hope Town", where older people, developers, policy makers and service deliverers are asked to collaborate to ensure the well-being of an ageing population. Housing is understood as more than a physical space: it is the facilitator of social connections and independent living. The inter-disciplinary team draws together their data, breaking down the silos that persist between housing health and social care. Projecting into the future, the "Game" reflects real-world demographic pressures (increase in the ageing population but also in those who report a disability) and how priorities need to shift to meet these changes. The "Serious Game" can be contextualised to any town, and can be adapted to measure how public and private spaces, including streets and parks, buildings and street networks, can meet older residents' needs.

The National Model Design Code[5] aims to give local planning authorities (and developers) a toolkit of principles to consider in designing new developments. 14 LAs have taken part in pilots to create their own local design code[6], produced by multi-disciplinary teams. As the Design Code is rolled out nationally, government should introduce the "Serious Game" to the guidance for Local Authorities. This will enable them to rate their area's "Age Friendliness".

[1] Greater Manchester Planning and Housing Commission, *Creating Age-Friendly Homes in Greater Manchester: Increasing the supply of homes for people in mid and later life*, 21 March 2022.
[2] Interview with Lord Best, 24 May 2023.
[3] Les Mayhew, *Future-proofing retirement living*, International Longevity Centre UK, 1 November 2022.
[4] Interview with Prof McCall, 7 September, 2023.
[5] Ministry of Housing Community and Local Government, National Model Design Code: Part 2 Guidance Notes, 2021.
[6] Local Government Association, *National Model Design Code Pilot Case Studies*, 2024.
[7] Brian Beach, *Future-proofing retirement housing in England*, International Longevity Centre UK, February 2021.
[8] NHS England and Health Education England, Apprenticeship Scheme, March 2018.
[9] Centre for Ageing Better, *The State of Ageing*, 2022.
[10] Ibid.
[11] Interview with Lord Best, 24 May 2023.
[12] Ibid.
[13] All-Party Parliamentary Group on Housing and Care for Older People, *Making retirement living affordable: the role of shared ownership housing for older people,* January 2023.
[14] Ibid.

The Centre for Social Justice
Kings Buildings
16 Smith Square
Westminster, SW1P 3HQ

www.centreforsocialjustice.org.uk
@csjthinktank