



HOUSE OF LORDS

Adult Social Care Committee

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Report of Session 2022–23

**A “gloriously  
ordinary life”:  
spotlight on adult  
social care**

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### *Select Committee on Adult Social Care*

The Select Committee on Adult Social Care was appointed by the House of Lords on 19 January 2022 to consider the planning for, and delivery of, adult social care services in England.

### *Membership*

The Members of the Select Committee on Adult Social Care were:

|   |  |
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| <a href="#"><u>Baroness Barker</u></a>                | <a href="#"><u>Baroness Jolly</u></a>                  |
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### *Declaration of interests*

See Appendix 1.

A full list of Members' interests can be found in the Register of Lords' Interests:

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## CONTENTS

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|  | <i>Page</i> |
|--|-------------|
| <b>Summary</b>   | <b>3</b>    |
| <b>Chapter 1: Introduction: if not now, when?</b>  | <b>9</b>    |
| Figure 1: Estimates of the value of care for adults  | 11          |
| Box 1: Language  | 12          |
| Challenging assumptions and changing attitudes   | 12          |
| The scale of the challenge: a service in fast decline  | 14          |
| A new approach to adult social care  | 17          |
| <b>Chapter 2: “Entrenched” invisibility: why does it matter?</b>   | <b>21</b>   |
| Reasons for invisibility   | 22          |
| Public understanding and personal experience   | 22          |
| The need to know more  | 23          |
| Lack of political imperative   | 25          |
| COVID-19   | 27          |
| How invisibility diminishes the service  | 28          |
| <b>Chapter 3: “The hope that things are going to get better”:<br/>the reality of adult social care today</b> | <b>30</b>   |
| What does it feel like to be drawing on adult social care today?   | 30          |
| Stigma and discrimination against older adults and disabled<br>people  | 30          |
| The forgotten purpose of adult social care   | 31          |
| Trust and power: local authorities as gatekeepers  | 34          |
| The role of friends and families   | 36          |
| Ageing without children: failing the future  | 37          |
| What does it feel like to be an unpaid carer today?  | 38          |
| What do we owe the unpaid carer?   | 38          |
| Financial, physical and emotional strain   | 40          |
| Box 2: Carer’s Allowance   | 41          |
| The inadequacy of support for unpaid carers  | 43          |
| Failing to connect with unpaid carers  | 44          |
| Navigating the social care system: a constant fight  | 45          |
| What happens if nothing changes? The risks of failing to reform  | 46          |
| <b>Chapter 4: “The greatest risk is not to change”: principles and<br/>possibilities</b>                     | <b>48</b>   |
| Changing the lens  | 48          |
| Facing reality: funding and workforce  | 49          |
| An appropriate funding settlement for adult social care  | 49          |
| Box 3: Government investment in adult social care  | 51          |
| Investing in skills: “we have a massive problem”   | 53          |
| Creating a national identity for adult social care   | 57          |
| Box 4: The Scottish National Care Service  | 58          |
| Raising a banner for adult social care   | 59          |
| Revisiting the Care Act 2014   | 62          |
| Why has the Care Act 2014 failed?  | 64          |
| Unlocking the potential of Integrated Care Systems   | 66          |
| The role of ICSs in delivering place-based approaches: the<br>challenge of rurality                          | 70          |
| <b>Chapter 5: Equal partners, better lives: co-production in practice<br/>and policy</b>                     | <b>73</b>   |
| Co-production in practice  | 73          |

|  |            |
|--|------------|
| Box 5: Strength-based approaches   | 76         |
| Valuing the local community  | 76         |
| Co-production in social care policy  | 78         |
| Box 6: Best practice in co-production  | 79         |
| Learning from the best: the role of local authorities in generating and spreading change   | 80         |
| Embracing a new narrative  | 80         |
| The workforce: a key to unlocking cultural change  | 83         |
| Sharing good practice and robust data  | 84         |
| <b>Chapter 6: Independent living: “Making It Real”</b>   | <b>86</b>  |
| Reliable advice and information: the key to achieving independent living   | 86         |
| Empowering the individual: expanding direct payments and personal assistance   | 88         |
| Box 7: Direct payments example of best practice: Hammersmith and Fulham Council  | 91         |
| Box 8: ENABLE Scotland: Best practice in enabling the recruitment of personal assistants   | 93         |
| The importance of accessible and inclusive housing   | 94         |
| Unlocking the potential of digital technologies  | 99         |
| <b>Chapter 7: Unpaid carers: “We need support, we need recognition”</b>  | <b>102</b> |
| Who are the unpaid carers? The paradox of disclosure   | 102        |
| No wrong door: Identifying and respecting carers   | 104        |
| Box 9: Identification: examples of best practice   | 105        |
| Finding solutions: keeping unpaid carers out of poverty and in work  | 106        |
| Combining work and care  | 108        |
| Box 10: International example: Germany   | 110        |
| Box 11: Employment example of best practice: West Midlands   | 111        |
| A service that cares for them: accessing short breaks  | 112        |
| Finding a way through the care system  | 112        |
| Navigating transitions   | 115        |
| Recognising the role and value of unpaid carers in the caring relationship: an unrecognised asset  | 116        |
| <b>Chapter 8: Conclusion: “When is the help coming?”</b>   | <b>119</b> |
| <b>Summary of conclusions and recommendations</b>  | <b>122</b> |
| <b>Appendix 1: List of Members and declarations of interest</b>  | <b>126</b> |
| <b>Appendix 2: List of witnesses</b>   | <b>128</b> |
| <b>Appendix 3: Call for evidence</b>   | <b>137</b> |
| <b>Appendix 4: Summary of Adult Social Care Committee visit to Real, 6 September 2022</b>  | <b>142</b> |
| <b>Appendix 5: Letter from Chair of the Adult Social Care Committee to the Chancellor of the Exchequer and Secretary of State for Health and Social Care</b> | <b>146</b> |

Evidence is published online at <https://committees.parliament.uk/committee/580/adult-social-care-committee/publications/> and available for inspection at the Parliamentary Archives (020 7219 3074).

Q in footnotes refers to a question in oral evidence.

## SUMMARY

Whether because we receive care and support, or because we provide paid or unpaid care, it is estimated that 10 million of us are affected by the adult social care system in England at any one time.<sup>1</sup> That is almost one in five people—and in a society where we live longer and with more complex conditions, we are increasingly likely to one day be included in that number. Yet adult social care continues to be largely out of sight and off the public agenda until we need it. This is in stark contrast to the NHS. Our understanding of adult social care, as a society, is partial and often flawed. We see social care as intended to support those who cannot support themselves: a burden on resources that is synonymous with decline and crisis.

These assumptions exist not only in wider society but have also framed policy at key points in history and in the present, with the consequence that adult social care has been denied the opportunity to be what it should be: a service that enables people to live fruitful, active and valuable lives. Drawing on adult social care should not be seen as a disaster, nor should it mean resigning oneself to a lower quality of life. Instead, social care needs to be about being given the extra support required to enable people to live what one witness described to us as a “gloriously ordinary life”—like any other citizen.<sup>2</sup> This can be achieved by social and economic investment that we make as a society—not least because we are all likely to draw on it eventually.

This narrative is far removed from current realities. This inquiry puts the spotlight on social care by focusing on the voices of lived experience, and we have heard that across the system, many disabled adults and older people continue to be denied choice and control over their lives. This is due to a number of issues but largely because of the lack of resources. Most adult social care is provided by local authorities. The last ten years have seen a 29% real-terms reduction in local government spending power,<sup>3</sup> which has led to an estimated 12% drop in spending per person on adult social care services between 2010/11 and 2018/19.<sup>4</sup> The quality and consistency of services has suffered acutely as local authorities have had to raise the threshold to receive support, creating high levels of unmet need and increasing the pressure on unpaid carers. It is estimated that in the first three months of 2022, 2.2 million hours of homecare could not be delivered due to insufficient workforce capacity.<sup>5</sup> The COVID-19 pandemic only aggravated these challenges.

We heard the frustration and anger of those who have to battle to access even the most basic support, and who have experienced adult social care becoming ever-more distanced from a service that might enable them to live a life of their choice.

1 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

2 Q 23 (Tricia Nicoll)

3 National Audit Office, *The adult social care market in England* (March 2021) p 6: <https://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf> [accessed 30 September 2022]

4 Health and Social Care Committee, *Social care: funding and workforce* (Third Report, Session 2019–21, HC 206) p 8

5 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 35: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

We also heard the testimonies of unpaid carers, the often invisible spouse, child, parent, sibling or friend who has to step up to provide care and support when the system is failing. We heard how exhausted carers are by the pressure to provide care that is placed on them by the assumption, held by our society and policy makers, that social care happens first and foremost in the family circle. An assumption that means the work of unpaid carers is largely invisible, unrecognised and unsupported.

Estimates show that there are between 4.2 million and 6.5 million unpaid carers in the UK,<sup>6</sup> with the actual figure likely to be much higher. The average person now has a 50% chance of becoming an unpaid carer by the time they reach 50.<sup>7</sup> Some estimates show that unpaid care could have a value of up to £132 billion per year.<sup>8</sup> Despite these significant numbers, carers feel invisible: many of them are at financial, emotional and physical breaking point, with no hope for a better future. An estimated 44% of working age adults who were caring 35 hours or more a week live in poverty.<sup>9</sup> They have to meet additional costs, ranging from extra heating to travel costs, while grappling with significant barriers to accessing any benefit.

We recognise that the Government has outlined a new vision for social care in its recent White Paper and we applaud its ambition.<sup>10</sup> We believe, however, that it falls sadly short of providing a concrete and fully resourced programme of change, which is necessary to realise these ambitions. The recent funding announcements that were made in relation to adult social care have further lessened expectations that the White Paper will be realised in practice.<sup>11</sup>

In this report, therefore, we set out the core changes that we want to see happen in adult social care, so that it becomes a progressive, visible, fairer and kinder system. Each of our recommendations constitutes a tangible step towards enabling these changes. Fundamentally, our recommendations are about building a more resilient, cost-effective, sustainable and modern service with greater efficiency as well as equality at its core.

First, we want adult social care to become a national imperative. This must be reflected in an appropriate and long-term funding settlement. Recent Government policy in relation to funding for social care has been vague and incoherent—in short, wholly insufficient to tackle the significant challenges faced by the sector. Together with funding, we want to see a properly resourced workforce strategy for social care. We also argue that the profile of social care must be raised within wider society, with a detailed, long-term national plan for

6 Department for Work and Pensions, Family Resources Survey: financial year 2020 to 2021 (31 March 2022): <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021> [accessed 29 September 2022] and Carers UK, *Facts about carers* (August 2019) p 1: [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2019.pdf](https://www.carersuk.org/images/Facts_about_Carers_2019.pdf) [accessed 28 October 2022]

7 Carers UK, *Will I Care? The likelihood of being a carer in adult life* (November 2019) p 4: [https://www.carersuk.org/images/News\\_campaigns/CarersRightsDay\\_Nov19\\_FINAL.pdf](https://www.carersuk.org/images/News_campaigns/CarersRightsDay_Nov19_FINAL.pdf) [accessed 29 September 2022]

8 Supplementary written evidence from Professor Sue Yeandle (ASC0153)

9 Joseph Rowntree Foundation and London Unemployed Strategies (ASC0116)

10 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

11 HM Treasury, *Autumn Statement 2022*, CP 751 (November 2022) p 26: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1118417/CCS1022065440-001\\_SECURE\\_HMT\\_Autumn\\_Statement\\_November\\_2022\\_Web\\_accessible\\_1\\_.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1_.pdf) [accessed 21 November 2022]



the sector and the establishment of a Commissioner for Care and Support, to show how adult social care can have such positive and transformational power in people’s lives.

As part of this change, one priority is to find out more about who receives and who provides care, under what conditions and how their situation can be improved. The adult social care system is very thin on data and we have to plug this gap urgently. We also want to see the laudable principles and vision of the Care Act 2014 implemented in practice. Much of the transformation that we call for is contained in the Act’s principles of wellbeing, choice and control. These principles have not been realised in practice, and we propose that one of the most constructive ways forward should simply be to ensure that they are.

Second, we want to see people who draw on care having the same choice and control over their lives as other people. This can only happen through the widespread adoption of co-production in social care practice, which is defined as when people who use services and carers work with professionals in equal partnerships towards shared goals.<sup>12</sup> Disabled adults and older people must be in full control of their care, and the support they receive should be tailored to their needs and ambitions. We also argue that the solutions that enable people to exercise choice and control and live independent lives, such as effective approaches to building community capacity, direct payments or accessible and inclusive housing, must be expanded.

Third, we want to see a system that is not based on the assumption that families will automatically provide care and support for each other because no other choice is open to them. This means that people should be able to choose what care they receive and from whom—and support should be available equally, whether they wish to draw on unpaid care, on paid care, or on a mix of both.

Similarly, there should not be an expectation that unpaid carers can and should provide care. This also means that if they do, there needs to be better recognition of the value of their contribution—to our society and economy—and better support for them to keep caring. Unpaid carers must be identified at the very start of their caring journey and signposted to support. They need to receive better financial compensation if their caring duties prevent them from working, and they need to be given the means to juggle work and caring if they are in employment. They must get access to more short breaks from caring and better help to navigate the system. These are urgent changes that must be implemented now. The risk of carer breakdown is already tangible.

These changes are key if we are to realise a more positive definition of adult social care. The social movement Social Care Future describes social care as follows:

“We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”<sup>13</sup>

We fully endorse this definition and believe that it should form the basis of any reform. Without a fundamental rethinking of how we understand, approach and design social care, it will not be possible to realise the huge value that care and support can bring—and as a society we will keep failing disabled adults, older people, unpaid carers, and ourselves.

12 Written evidence from the Social Care Institute for Excellence ([ASC0081](#))

13 Social Care Future, ‘A vision for the future of social care’: <https://socialcarefuture.blog/2021/04/29/a-vision-for-the-future-of-social-care/> [accessed 15 September 2022]

### Autumn Statement 2022: Implications for funding

As we were finishing our report, the Government introduced its Autumn Statement, which bears directly on our inquiry.

Social care funding reforms were to come into force in October 2023 and would have set an £86,000 limit on the amount anyone in England would need to spend on their personal care costs in their lifetime.<sup>14</sup> The Government itself described this as “a seismic change” that would have delivered on a core recommendation of the independent Dilnot Commission.<sup>15</sup> In the Autumn Statement, this fundamental reform was delayed by two years to October 2025.<sup>16</sup> It is yet another delay to add to previous ones that have frustrated attempts to relieve individuals and families from the unsustainable costs of social care.

The Chair of the Health and Social Care Committee Steve Brine MP has said that “the result will be that more people face the very real prospect of crippling bills with the cap now not coming into effect until October 2025. Though set at a level far higher than called for by this Committee, the cap represents a key plank of social care reform.”<sup>17</sup>

The Chancellor’s argument is that the money saved, together with flexibility for local authorities on council tax and £1.7 billion of new grant funding in 2024/25, will enable £4.7 billion of additional funding for adult social care services in 2024/25.<sup>18</sup>

In the context of our findings, described in this report, on inadequate assessments and care packages, we welcome the additional funding but not at the expense of further delay in the first steps towards long-term reform of the system, with the objective of enabling everyone to access appropriate support to live their life well.

This delay, as well as the other proposals for social care that were made in the Autumn Statement, make our point: they are another failure to sustainably address the challenges faced by the social care system as a whole. They reflect a vain attempt to resolve the crisis in social care merely by increasing the number of care packages, as yet unquantified, while leveraging a regressive source of funding through council tax flexibility. This does not constitute a plan to create a system that is properly funded and resourced in the long term. For example, while we welcome the commitment to a comprehensive workforce plan for the NHS, the Chancellor was silent on the need for and adult social care workforce plan. Both are needed, now.

14 HM Government, *Build Back Better: Our plan for health and social care*, CP 506, September 2021, p 16: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1015736/Build\\_Back\\_Better-Our\\_Plan\\_for\\_Health\\_and\\_Social\\_Care.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1015736/Build_Back_Better-Our_Plan_for_Health_and_Social_Care.pdf) [accessed 22 November 2022]

15 *Ibid.*, p56

16 HM Treasury, *Autumn Statement 2022*, CP 751, November 2022, p 56: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1118417/CCS1022065440-001\\_SECURE\\_HMT\\_Autumn\\_Statement\\_November\\_2022\\_Web\\_accessible\\_1\\_.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1_.pdf) [accessed 21 November 2022]

17 Health and Social Care Committee, ‘Chair of the Health and Social Care Committee comment on Autumn Statement’, (17 November 2022): <https://committees.parliament.uk/committee/81/health-and-social-care-committee/news/174503/chair-of-the-health-and-social-care-committee-comment-on-autumn-statement/>

18 *Ibid.*, p 26



The Chancellor’s statement is driven by a financial emergency, but it underlines the points we make about fragmentation, the lack of a holistic national strategy for social care, or of predictable and sustained funding. While it identifies the points of crisis, it does nothing to raise confidence that disabled adults and older people will be able to get the care and support they need to live good lives, or that the often forgotten unpaid carers who support them will be better off.

There is little detail yet as to how the money will be allocated or spent. Where is the funding going? What will it change? How will it be monitored? These are some of the questions that we asked the Chancellor and the Secretary of State for Health and Social Care, which are set out in Appendix 5.



# A “gloriously ordinary life”: spotlight on adult social care

## CHAPTER 1: INTRODUCTION: IF NOT NOW, WHEN?

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1. Why should we care about adult social care? Our answer is blunt: it concerns all of us because at some point in our lives, we are all likely to support someone we care about, or to draw on care ourselves. Adult social care affects the lives of over 10 million adults of all ages in England at any one time, including those who receive paid and unpaid care, the workforce and unpaid carers.<sup>19</sup> Social care covers a wide range of situations, from the support offered to a family providing care to a disabled child, to the personal care offered to older adults in a residential care home; from the daily drop-in service to a person with dementia receiving care at home from their children or spouse, to the personal assistant supporting a disabled adult of working age. It covers the millions of unpaid carers who support family members, often at the cost of their own health and careers. Adult social care is not about others. It is about all of us—and it is both our collective responsibility and in our best interest to ensure that it is sustainable and humane.
2. The importance of adult social care can be appreciated simply by looking at the scale of the sector. The adult social care workforce is estimated at 1.62 million filled posts<sup>20</sup>—more than the NHS, which latest headcount is at 1.37 million.<sup>21</sup> It represents a large, overlapping and complex system of relationships, institutions and agencies that impact on every aspect of daily life for those involved with it.
3. In recent years, driven by the consequences of an ageing society and the cost of residential care, the challenges of funding and staffing, the increasing demands on adult social care have risen up the political agenda. This has been illustrated by a raft of research and policy—White Papers, Government consultations, Parliamentary inquiries, reports and academic studies undertaken on topics ranging from workforce and funding to market shaping and integration with healthcare. Two recent major pieces of legislation have emerged with the objective of generating significant change in adult social care: the Care Act 2014 and the Health and Care Act 2022.
4. Tragically, despite these recent reforms, very little has improved for those who depend upon or provide adult social care. Many aspects of the system remain invisible and overlooked by the public and policy makers alike.

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19 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

20 Skills for care, *State of the adult social care sector and workforce in England* (October 2022) p 39: <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2022.pdf> [accessed 2 November 2022]

21 NHS Digital, *NHS Workforce Statistics: January 2022 (Including selected provisional statistics for February 2022)* (April 2022): <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/january-2022> [accessed 2 November 2022]

5. The reason for this might seem obvious. Unlike the NHS, which cares ‘from cradle to grave’, we collide with adult social care usually at a moment of crisis, of unexpected transition, when our lives appear to be changing for the worse. Unlike the NHS, little is known about who is in charge of adult social care, how it works, how it is paid for and what help we might get.
6. Whereas we celebrate the NHS and take pride in its history and achievements, adult social care has largely been missing from the heroic account of the welfare state. Seeking help from adult social care seems a mark of failure and dependency, and a last resort. With dependence seen as the norm for disabled adults and older people, and as long as women stayed at home to provide care and support, there appeared to be no reason to publicly acknowledge the importance and value of social care.
7. We recognise that in the past years, largely as a result of the COVID-19 crisis, adult social care has become more visible. The dramatic impact of the pandemic, particularly in care homes, has been brought to the public’s attention, at the same time shining a light on the shortcomings of the system. Reports, surveys and studies have multiplied to make the case for more significant reform. We were told by Gillian Keegan MP, then Minister of State for Care at the Department of Health and Social Care (2021-2022), that there is “no doubt” that the profile of social care has “massively changed” since the pandemic.<sup>22</sup> This new public attention is welcome, but we argue that it remains partial. In many cases, it has contributed to perpetuate a flawed understanding of who adult social care is for and what it can achieve.
8. In this vast and changing landscape, we have chosen to look at one element that exemplifies this set of characteristics that mark out adult social care. It is the element that is least visible, most fragmentary and most vulnerable, and yet it is absolutely vital to the sustainability of the whole adult social care service, but also the health service and society as a whole.
9. We have asked: who cares? The answer is, in most cases, the family at home and friends in the community: the ‘unpaid carers’. Recent analysis of data from 2001 to 2018 revealed that 65% of adults have provided unpaid care in their adult life, which increases to 70% for women. The average person now has a 50% chance of becoming an unpaid carer by the time they reach 50.<sup>23</sup> The Family Resources Survey for 2020/21 puts the number of unpaid carers at 4.2 million, which represents 6% of the UK population.<sup>24</sup> Based on data from the 2011 Census, Carers UK estimate the figure is 6.5 million.<sup>25</sup> The actual figure is likely to be higher due to the difficulty of identifying unpaid carers, in part because of the language challenges mentioned below. For example, Carers UK’s latest State of Caring Survey, which is based on polling of 3,500 people, estimates that there are around 10.6 million unpaid carers in the UK today.<sup>26</sup> Without unpaid carers, our health and social care

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22 Q 149 (Gillian Keegan MP)

23 Carers UK, *Will I Care? The likelihood of being a carer in adult life* (November 2019) p 4: [https://www.carersuk.org/images/News\\_campaigns/CarersRightsDay\\_Nov19\\_FINAL.pdf](https://www.carersuk.org/images/News_campaigns/CarersRightsDay_Nov19_FINAL.pdf) [accessed 29 September 2022]

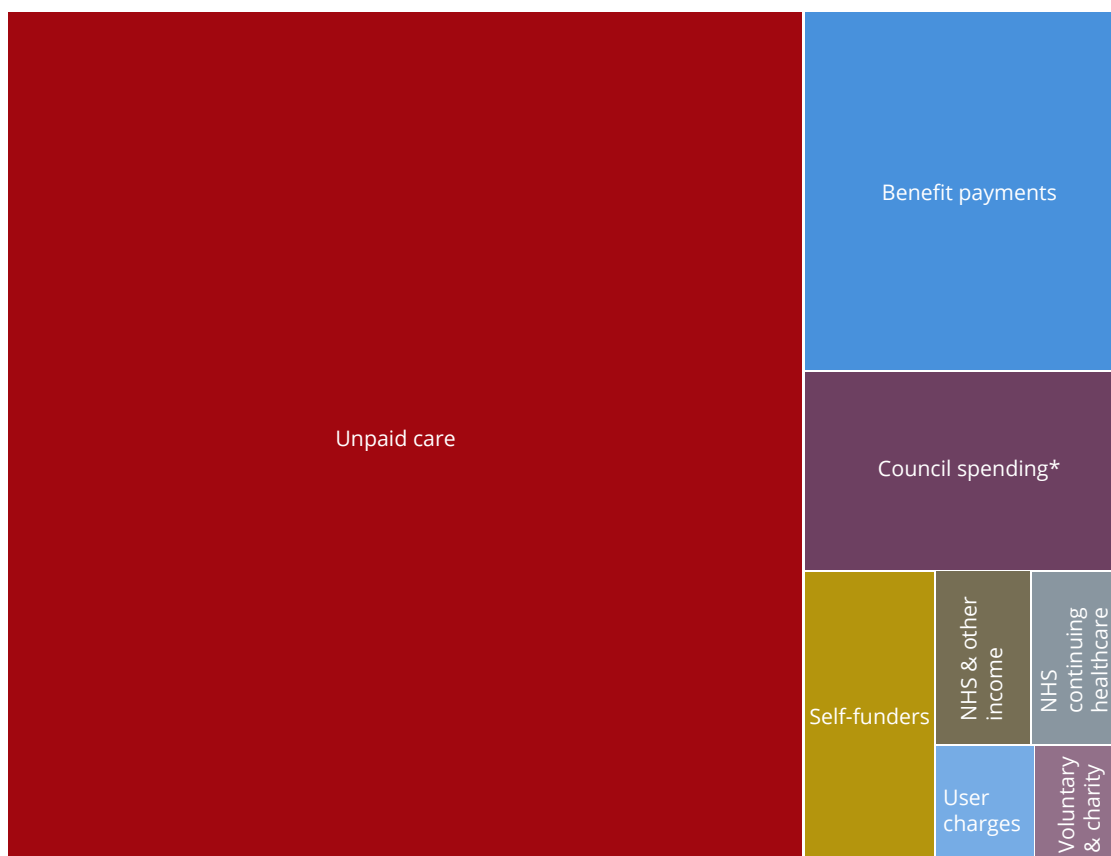
24 Department for Work and Pensions, *Family Resources Survey: financial year 2020 to 2021* (31 March 2022): <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021> [accessed 29 September 2022]

25 Carers UK, *Facts about carers* (August 2019) p 1: [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2019.pdf](https://www.carersuk.org/images/Facts_about_Carers_2019.pdf) [accessed 28 October 2022]

26 Carers UK, *State of Caring 2022* (November 2022) p 4: [https://www.carersuk.org/images/Research/CUK\\_State\\_of\\_Caring\\_2022\\_report.pdf](https://www.carersuk.org/images/Research/CUK_State_of_Caring_2022_report.pdf) [accessed 15 November 2022]

systems would collapse: as we discuss in later chapters, estimates of the value of unpaid care provided by family and friends vary between £100 billion and £132 billion per year.

**Figure 1: Estimates of the value of care for adults**



\*Council spending adjusted to avoid double-counting income from NHS and user charges

Source: Richard Humphries, *Ending the Social Care Crisis: A New Road to Reform* (Bristol: Policy Press, 2022) p 74

10. The relationship between unpaid carers and those who draw on social care is interdependent. Our report focuses on the nature of that mutual relationship and what needs to change for both to thrive.
11. These are relationships that are hugely diverse. From a wife who cares for her husband when his health starts deteriorating, to a daughter providing support to her parents with chronic medical conditions: unpaid carers are not “others”; as one witness told us, they are “like you or me.”<sup>27</sup> The term ‘unpaid carers’ is a barely adequate description of the many millions of women and men who provide care and support to disabled adults for a lifetime, or who become carers for older people who, sometimes suddenly through stroke, dementia or many other causes, become reliant on care and support. Their voices are hardly heard and they are, for the most part, invisible to those of us who are not in the same situation.

### Box 1: Language

We heard from many witnesses that the term ‘unpaid carer’ is flawed, because many do not find that this label reflects the nature of the care and support they provide. As one witness explained to us, providing care is often instinctive: she employed the analogy of “someone just literally tripping up on the pavement and you put your hand out to catch them.” Labelling this as ‘unpaid care’ was, she said, unnatural.<sup>28</sup> Another witness explained that she found the concept of being “cared for” very difficult to accept, because of the passive role it pins onto the person with care needs; when in reality, caring is a dynamic relationship, in which the person with care needs can also be and often is a source of support to the unpaid carer.<sup>29</sup> Many carers, therefore, prefer to use the word which best describes their relationship to the person they provide care for, such as ‘mother’ or ‘husband’.<sup>30</sup>

Despite its shortcomings, for the purpose of clarity, we have decided to use the term ‘unpaid carer’ or ‘carer’ throughout this report to refer to friends and families providing unpaid care. This is because it is one of the terms most frequently used in official documents and policy. It should not be confused with ‘paid carers’ or the ‘workforce’, which refers in this inquiry to professional social care staff. We recognise that this is a failure of language to grasp the complexities of the relationship between the unpaid carer and the person who draws on care; and that this is reflective of a system that does not understand, support or enhance this relationship. Chapter 6 will discuss language in more detail.

12. In short, to the question ‘who cares?’ we can answer: not enough of us—but we all should, and we should care more. Both the adult social care system and the people at the heart of the system, who draw on care or provide it, are rarely given the priority that they should. This report suggests practical measures to give adult social care the focus, attention, identity and support it deserves. This is the key to creating a fairer, kinder, more dignified and more sustainable adult social care system for all, which ensures that disabled adults and older people can live equal and meaningful lives, and that unpaid carers are supported and recognised for their extraordinary contribution.

#### Challenging assumptions and changing attitudes

13. Our society and our economy currently face extreme difficulties. There is, in our view, no better time to be ambitious, which is why the foundation of our report is to challenge the restrictive definition of adult social care that permeates our society. We argue for a transformation in the perception and role of social care—and this also includes rethinking the role of unpaid carers.
14. Despite all the changes we have witnessed since the creation of the welfare state, many of our current approaches are still based on a deficit model that tries to identify ‘what is wrong’ with people and to ‘fix them’. But our witnesses were eloquent that adult social care, on the contrary, is enabling

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28 *Ibid.*

29 [Q 142](#) (Tricia Nicoll)

30 Written evidence from Carers Trust ([ASC0097](#))



and transformative. In this spirit, we have endorsed the definition of social care that is proposed by the social movement Social Care Future:

*“We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”<sup>31</sup>*

Some people might need support to do these things, whether because they have a disability or because they have developed a health condition as they aged. Social care provides this support. This definition implies that when it works at its best, social care helps create a web of relationships and support that people can draw on to live their life with meaning, purpose and connection, regardless of their age or disability.<sup>32</sup> Some of our witnesses explained that this could simply mean getting support to go for a walk in the park or to watch the football at the weekend. In other words, social care is not only about ‘services’: it is about having a life.

15. Achieving this means challenging prevailing attitudes and assumptions, particularly around perceptions that disabled adults and older people are somehow not capable of exercising choice and control over their own lives. In setting out a different view of adult social care, our report challenges both adult social care services and those who are accountable for them across government, to remove existing barriers to independent living and to put in place a more positive vision of social care and the contributions it makes to all our lives.
16. It also means challenging the assumption which presently underpins the adult social care system that families will simply step in if someone has care and support needs. It is an assumption which has been openly promoted at the highest levels of government. In 2021, the Rt Hon Sajid Javid MP, then Secretary of State for Health and Social Care, told the Conservative Party Conference: “Health—and social care—begins at home. Family first, then community, then the state.”<sup>33</sup> It is a view that permeates the way that adult social care is delivered and steers many decisions that are made, from the Department of Health and Social Care to the social care professional through the local authority. Women are particularly affected by this assumption and are over-represented among unpaid carers. In 2019, for example, of the 1.25 million ‘sandwich carers’ in the UK who care for an older relative while also bringing up a family, 68% were women.<sup>34</sup>
17. But demographics has changed: people live longer and almost three-quarters of women in the UK (72.2%) work.<sup>35</sup> Moreover, an increasing number of families do not have children and more people are likely to be childless in the future. According to some estimates, there are currently around 1.2 million people over the age of 65 ageing without children, and this number is set to

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31 Social Care Future, ‘A vision for the future of social care’: <https://socialcarefuture.blog/2021/04/29/a-vision-for-the-future-of-social-care/> [accessed 15 September 2022]

32 *Ibid.*

33 Sajid Javid, Speech to Conservative Party Conference, 5 October 2021: <https://www.conservatives.com/news/2021/sajid-javid-s-speech-to-conservative-party-conference> [accessed 2 November 2022]

34 Age UK, *Breaking Point: The social care burden on women* (March 2019) p 3: <https://www.ageuk.org.uk/contentassets/c3dac0771e614672b363c5fe7e6f826e/breaking-point-age-uk.pdf> [accessed 2 November 2022]

35 Organisation for Economic Co-Operation and Development, ‘Short-Term Labour Market Statistics’: <https://stats.oecd.org/Index.aspx?DataSetCode=STLABOUR> [accessed 7 November 2022]

rise to 2 million by 2030.<sup>36</sup> The adult social care system has responded neither with imagination nor innovation to match those changes. This may in turn reflect the innate and human reluctance to think about how disability and ageing might change our lives—partly because if we do, we may admit that we might need social care, even though we may not know when we will need it, or how long we will need it for. Sir Andrew Dilnot vividly described how this creates extremely challenging and confusing circumstances for people once they find themselves needing to draw on adult social care:

*“Needing social care at the moment is a bit like being in a shop with no prices. You know how much the care for your partner or parent will cost per week or month, but you have no idea how many weeks or months their need will go on, so you simply do not know what the bill is.”<sup>37</sup>*

### The scale of the challenge: a service in fast decline

18. That uncertainty has become worse and more oppressive in recent years. The cap on care costs, promised by the Government in 2021, was originally anticipated in October 2023.<sup>38</sup> It has now been delayed to October 2025.<sup>39</sup> There is a climate of uncertainty, therefore, surrounding promised reforms for disabled adults and older people. There is no improvement on the horizon for unpaid carers either. In fact, prospects are getting worse, as pressures increase and access to paid support becomes more restricted.
19. In 2020/21, there were 841,000 people receiving state-funded long-term care, and the need for social care services is set to increase as life expectancy grows and people live longer with complex conditions.<sup>40</sup>
20. Local government funding for adult social care, however, is not keeping pace with demographic pressures, and increasingly, access to care and support is rationed, driven by a 29% real-terms reduction in local government spending power between 2010/11 and 2019/20.<sup>41</sup> Estimates show that this has caused a drop of around 12% in spending per person on adult social care services between 2010/11 and 2018/19.<sup>42</sup> The quality and consistency of services has suffered acutely as local authorities have raised the threshold to receive support. They have felt the need to outsource the majority of care provision to independent sector home care and residential care providers, often on the basis of reducing costs as much as possible, rather than on

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36 Q 47 (Kirsty Woodard)

37 Q 183 (Sir Andrew Dilnot)

38 HM Government, *Build Back Better: Our plan for health and social care*, CP 506, September 2021, p 16: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1015736/Build\\_Back\\_Better-Our\\_Plan\\_for\\_Health\\_and\\_Social\\_Care.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1015736/Build_Back_Better-Our_Plan_for_Health_and_Social_Care.pdf) [accessed 17 October 2022]

39 HM Treasury, *Autumn Statement 2022*, CP 751, November 2022, p 56: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1118417/CCS1022065440-001\\_SECURE\\_HMT\\_Autumn\\_Statement\\_November\\_2022\\_Web\\_accessible\\_1.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1.pdf) [accessed 21 November 2022]

40 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

41 National Audit Office, *The adult social care market in England* (March 2021) p 6: <https://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf> [accessed 30 September 2022]

42 Health and Social Care Committee, *Social care: funding and workforce* (Third Report, Session 2019–21, HC 206), p 8

the basis of quality. As we explain in Chapter 4, we do not believe that the latest funding commitments made by the Government will be sufficient to compensate for these shortcomings.

21. The social care workforce is also facing significant pressures with large numbers of care workers leaving the sector for better pay and conditions elsewhere, as well as constraining immigration rules that make it difficult to recruit staff internationally.<sup>43</sup> As of October 2022, there were a record 165,000 vacancies in adult social care.<sup>44</sup>
22. At the same time, the market in social care has proliferated with an estimated 17,900 organisations involved in providing or organising adult social care in England as of 2021/22.<sup>45</sup> The quality of care is therefore highly dependent on the culture, strategic leadership and financial resources in each locality, leading to vast regional inequalities. For example, as of November 2021, several localities have 100% of social care services rated “Good” or “Outstanding” by the Care Quality Commission (CQC), while some have around 65%.<sup>46</sup> This fragmentation also makes it more challenging to transform the sector through direct or universal intervention.
23. The COVID-19 pandemic aggravated all these challenges, creating additional financial and service pressures for local authorities, and exacerbating inequalities. The pandemic also impacted the care workforce, with higher levels of staff sickness and burnout, which led to an estimated turnover rate of 34.8%.<sup>47</sup>
24. All this has major impacts on people’s lives. The LGA quoted research showing that just over half a million people are currently awaiting a care needs assessment, a care package, a direct payment or a review of an existing care plan.<sup>48</sup> Focusing specifically on people in midlife and older people, Age UK’s latest estimates show that in 2022, 12% of over-50s were living with some form of unmet need. This represents 2.6 million people, who might require assistance with activities of daily living like washing and eating.<sup>49</sup>
25. The choice for people is stark in the extreme: go without or self-fund, or more commonly, when it is a possibility, rely on family or friends. Pressure

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43 Migration Advisory Committee, *Adult Social Care and Immigration*, CP 665, April 2022, p 74: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1071678/E02726219\\_CP\\_665\\_Adult\\_Social\\_Care\\_Report\\_Web\\_Accessible.pdf#page=54&zoom=100,44,48](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1071678/E02726219_CP_665_Adult_Social_Care_Report_Web_Accessible.pdf#page=54&zoom=100,44,48) [accessed 2 November 2022]

44 Skills for Care, *The state of the adult social care sector and workforce in England* (October 2022) p 11: <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2022.pdf> [accessed 11 October 2022]

45 Skills for Care, ‘The size and structure of the adult social care sector and workforce in England’: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx> [accessed 8 September 2022]

46 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 26: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

47 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 87: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

48 *Q 65* (David Fothergill)

49 ‘New analysis finds 2.6m people over 50 have unmet care needs’, *Social Care Today* (7 September 2022): <https://socialcare.today/2022/09/07/new-analysis-finds-2-6m-people-over-50-have-unmet-care-needs/> [accessed 24 November 2022]

is growing inexorably on unpaid carers to ‘step up’ and provide the care and support that no one else will. And while friends and families are often prepared to provide support out of love, they often find that they must do so out of inevitable necessity and with insufficient support. The huge weight of evidence we have received shows that people are stripped of all choice and control when it comes to determining the terms of their most intimate relationships.

26. As Belinda Schwehr, CEO, Centre for Adults’ Social Care—Advice, Information and Dispute Resolution, described it, the main problem for unpaid carers is that among councils and government there is a doctrine of “natural or family support”, possibly perpetuated to deter people from pushing for larger care packages.<sup>50</sup> This in turn puts unpaid carers under high moral and practical pressure to provide care and support—a view contested by Ms Dyson, Director-General of Adult Social Care at the Department of Health and Social Care, who argued that the Government did not assume “that families will pick up the slack”, and that the funding model did take the severity of social care needs into account.<sup>51</sup> This, however, is at odds with the reality on the ground. Cutbacks in funded care and the low quality of some services have led to many people with little choice about whether to rely on, or provide unpaid care, simply because there is nothing else.<sup>52</sup> The result is a dehumanising system in which people feel that they have no control over their own lives and their relationships with others.
27. While some people who draw on care would choose otherwise, others prefer to draw on support from those close to them in the family—whether that is a spouse, child, parent, friend or neighbour. Reciprocally, many people want to provide that care to a person who is close to them. However, this can have a negative impact if it is not a positive choice for everyone involved, or if there is insufficient support.
28. Our evidence shows that unpaid carers, in many cases, face physical, financial and emotional distress. The more care someone provides, the greater the impact on their wellbeing in every respect.<sup>53</sup> In a survey, half of carers said that missing out on support had an impact on their physical health, while 78% suffered from stress and anxiety as a result of missing out on support, and 61% said missing out on support put a strain on their relationships with friends and family.<sup>54</sup> Carers who provide more than 50 hours of care per week are three times more likely to report that their health was ‘not good’ when compared with non-carers.<sup>55</sup>
29. One significant problem which we heard many times is that there is little support for carers to navigate the system, which means that they often find themselves endlessly searching for advice and information, despite the very little time that they have to do so. We were told that this can be particularly

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50 [Q 123](#) (Belinda Schwehr)

51 [Q 3](#) (Michelle Dyson)

52 [Q 20](#) (Dr Anna Dixon)

53 Emma Carduff *et al.*, ‘Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources’, *BMC Family Practice*, issue 15, no. 48, (2014), p 2: <https://bmcprimcare.biomedcentral.com/track/pdf/10.1186/1471-2296-15-48.pdf> [accessed 22 November 2022]

54 Carers UK, *Missing out: The identification challenge* (November 2016) p 4: <https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-the-identification-challenge> [accessed 30 September 2022]

55 *Ibid.*

challenging at times of transition, for example when a child starts accessing adult social care, or when an adult suddenly finds themselves in hospital. In many cases, neither carers nor the individuals themselves are signposted to information, which makes navigating the social care system especially difficult in a time of crisis.

30. Moreover, as service and workforce pressures increase, it seems certain that pressures on unpaid carers to provide care, whether they want to or not, will also increase. It is therefore essential that further steps are taken to ensure the well-being of people drawing on care and support and of unpaid carers. Tested solutions exist and our report outlines many of them. The issue is one of ability and willingness to implement them.

### A new approach to adult social care

31. It has become clear that nothing radical can change in the adult social care system, including in the role that unpaid carers undertake, until there is a fundamental reset in the attitude to and prospects for the people to whom they provide care and support. That is why our report explores how the entire adult social care system bears equally on the lives of disabled adults and older people, as well as on the unpaid family members or friends that step in. There is above all, therefore, an imperative to revalue what makes adult social care work at its best: the quality of trusted and reliable relationships. This in turn requires a move away from what was described as a transactional system—in which care services are clearly defined and time-limited, carried out to support someone once they meet the right eligibility criteria—towards one that values and rewards those long-term and constantly evolving relationships, whether they involve unpaid family members, personal assistants or care workers in directly provided or commissioned services.
32. That shift in vision requires replacing top-down and paternalistic approaches with one which values the partnership between disabled people and older adults, and the wider web of relationships that they exist within, which includes unpaid carers if this is their choice. This would offer a service based on ‘co-production’, where the choice of who cares and what is provided rests with the person whose life is at the centre of the decision, and the people they wish to include. This enables people whose lives are currently constrained and limited by a lack of suitable support to live a life that is more in line with the ambitions set out by Social Care Future, outlined earlier in this chapter. This extends the concept of social care beyond the provision of formal services into the wider community, ensuring that everyday provision—shops, libraries, buses and so on—is welcoming and accessible to all.
33. This is work in progress. Some local authorities have led the way in implementing this vision. They told us that it meant valuing and treating disabled people and older adults as equals, and seeing them as individuals who could be enabled to live the best life they can—not as problems to be solved. This approach proved to be more effective because it offered people solutions based on what they had expressed themselves as a need, ambition or desire. In other words, residents were given the means to live a better life “based on what they like doing rather than what we think they like doing.”<sup>56</sup> We discuss this specific example of best practice further in Chapter 5.



34. Many of the changes we suggest, therefore, are not new. They bear repetition because, even if they are in place in theory, principally in the Care Act 2014, they are not systematically implemented across the country—or implemented with a degree of lip service, rather than accompanied by the deeper cultural change needed to bring about a more fundamental transformation. This is largely due to the failure to prioritise realistic funding of adult social care, which will also help to raise the living standards, skills and status of key care workers, and stem the exodus from the service. We frequently heard that the success of almost any concrete solution is dependent on remedying the long-standing lack of resources. Although we decided not to focus exclusively on funding, given the degree of scrutiny that already exists around this topic, the recurrence with which it was brought to our attention led us to explore it further in Chapter 4.
35. This report is structured in a way that sets out the long-term changes needed to ensure that best practice becomes the norm, and to create a sustainable adult social care service. Many of these changes are challenging; some are already technically in place but largely dormant in practice; some exist on paper, but have not led to genuine transformation. They will bring greater voice and visibility to the service as a whole and open up new possibilities for disabled adults and older people.
36. We start in Chapter 2 by diagnosing the invisibility of the adult social care sector and ask ourselves why, as a society, we fail to acknowledge and value services that we are all likely to draw on at some point in our lives. Chapter 3 looks at the tangible consequences that this invisibility bears on the everyday lives of disabled adults and older people, as well as unpaid carers. Through the evidence of people who have lived experience, we draw the picture of the human reality of adult social care today—a reality often marked by despair and frustration, at odds with the vision of equal and fulfilling lives that social care is meant to facilitate.
37. In Chapter 4 of this report, we set out how to enact the changes that are needed so that people who draw on social care—no matter what their age or condition—and unpaid carers can thrive. At the heart of this has to be a fairer and more comprehensive funding settlement, and one that is extended for a period of at least three years, so that planned and essential changes can be made, particularly in terms of retaining the paid workforce. The human case is set out in the words of the experts by experience—people who have recent personal experience using or providing care for someone who uses social care services—we heard from for this report. The economic case is beyond question if more people are not to remain in hospital beds or living in institutional settings. But we also challenge the invisibility that shrouds adult social care at all levels, calling for a new national focus and new roles to champion the sector. In this context, we also focus on the transformative potential of Integrated Care Systems (ICSs), which open up an opportunity to put things right; an opportunity that should not be missed.
38. In Chapter 5, we discuss how the practice of adult social care needs to move from an exchange of time and task-driven services, to one where decisions are taken together by the person who draws on care and support, the unpaid carer and the social care professional in a ‘co-produced’ approach. We examine how this change of approach can transform the lives of individuals and the provision of services, listening to and responding to the ambitions as well as the needs of the individual, and thus enabling independent living rather than



creating dependence. We look at what needs to change to bring this about. We also look at how the whole system can benefit from co-production when those who draw on care and support or are unpaid carers are full partners in the design and delivery of care, both at the individual level and at the local or national policy level. This chapter also looks at the lessons that can be learnt from local authorities that are leading the way in their implementation of co-produced care and support.

39. At the heart of the adult social care system should be the objective of enabling independent living. This means that disabled adults and older people have the same choice and control over their lives as non-disabled people. We explore this in Chapter 6, as we examine how to further promote the transformative power of direct payments, and how the solutions offered by accessible and inclusive housing, including with the promise of digital technologies, need to be scaled up. Achieving this transformative change requires a broader, more inclusive view of social care, going beyond the provision of formal services.
40. Our final chapter focuses on what unpaid carers themselves need urgently as a matter of fairness. The message we consistently heard from unpaid carers was loud and clear: while most movingly described the joy and pride they find in providing care and support, they are exhausted—physically, emotionally and financially. We heard from unpaid carers who had not had a single break in years<sup>57</sup> and who described themselves as being “at breaking point.”<sup>58</sup> We listened as they told us that they had had to leave well-paid full-time jobs to care, sometimes for several different people at the same time, often ending up in extremely precarious situations.<sup>59</sup> Unpaid carers repeatedly expressed how abandoned and hopeless they felt. As Carers UK told us, “without an increase in the practical support carers are receiving, many more are likely to reach breaking point.”<sup>60</sup>
41. We need to know who is caring so that that they can get the support to which they are entitled, and we look in this chapter at the key role that health and social care professionals can play to make a significant difference to carers’ health and wellbeing. We emphasise that the poverty of unpaid carers, driven by exceptionally low social security benefits and difficulties in retaining work, must be addressed immediately with improvements to Carer’s Allowance, as well as more flexible support for carers who work, such as Carer’s Leave. The cost of living crisis will otherwise bear down cruelly on these families who may need to provide heat and food above and beyond the norm. We also look, in this chapter, at the importance of short breaks to protect carers’ physical and emotional wellbeing.
42. There are some reasons to be optimistic, but they are not sufficient and not at a scale to make the changes we want to see happen. Good things have been promised, but little has been delivered in recent years.
43. The Government’s recent *People at the Heart of Care* White Paper, with its 10-year vision and funding for housing and innovation, is a welcome recognition of the change needed, but it is not a fully formulated or resourced strategy

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57 [Q 35](#) (Katy Styles)

58 [Q 36](#) (Helen Spalding)

59 [Q 55](#) (Nadia Taylor)

60 Written evidence from Carers UK ([ASC0122](#))

for adult social care.<sup>61</sup> The Health and Social Care Act 2022 has brought forward ICSs, which bring adult social care services into new arrangements alongside NHS partners.<sup>62</sup> While this could be a major opportunity to redress traditional power imbalances between health and social care, these changes could also prove a distraction from the urgent attention which adult social care needs now and in its own right.

44. Creating a sustainable adult social care system will come with significant benefits, including to reducing pressure on the NHS; but we argue that reforming social care should happen first and foremost to enable both individuals who draw on care and support and unpaid carers to thrive, and to promote greater humanity, equality and independence. Our report sets out what we think needs to change to make this possible; to enable every citizen to live a “gloriously ordinary life”, regardless of their age or disability.<sup>63</sup> We have arrived at these conclusions not in the abstract but by involving and listening to witnesses and Specialist Advisers who are experts by experience. We have tested our analysis and conclusions with people who know whether they are necessary and will work. It has been a privilege to do so.

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61 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

62 Health and Care Act 2022, [sections 18-32](#)

63 [Q 23](#) (Tricia Nicoll)

## CHAPTER 2: “ENTRENCHED” INVISIBILITY: WHY DOES IT MATTER?

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45. In this chapter we look at the roots of the challenge set by the present status and prospects of adult social care. We explore the paradox as to why adult social care has been seen as largely ‘invisible’ in terms of the essential and increasing role that it plays in sustaining both society and the economy; and, until very recently, in terms of politics. When social care has come to national attention in recent years, the focus has been on the cost of care homes and paying for care for those who need it, as well as rising shortages in the paid care workforce. The intrinsic value of enabling good lives is not mentioned. It is therefore hardly surprising that when so much of adult social care is below the radar, the contribution of the unpaid carer is particularly invisible, and their voice goes unheard.
46. Despite the increase in people needing care and support, we heard from people who draw on care and support, charities and academics that adult social care is invisible. We even heard this from a previous Secretary of State for Health and Social Care. The Rt Hon Jeremy Hunt MP, Chancellor of the Exchequer and previously Secretary of State for Health and Social Care (2012–2018), noted that invisibility is “deeply entrenched”.<sup>64</sup> Similarly, we heard that there is “very little understanding of the contribution of adult social care or about the workforce, unpaid carers and the people who receive care and support”.<sup>65</sup> This invisibility can lead to those who draw on care feeling “that they do not matter.”<sup>66</sup>
47. A Carers Trust survey found that 91% of unpaid family carers felt ignored by the Government.<sup>67</sup> Many told us how they also felt dismissed and alienated by the services themselves. We heard that “the invisibility of social care perpetuates the despair and does little to promote dignity, choice and fulfilment of life.”<sup>68</sup> There are risks of increased loneliness, isolation, anxiety and depression due to chronic feelings of being undervalued.<sup>69</sup> One unpaid carer said: “Most of us are desperate. Most of us are drained. Most of us are in a state of grief. We need support, we need recognition.”<sup>70</sup> As well as having health implications for the individual carers, this increases the risk that care responsibilities are passed on to local authorities.<sup>71</sup>
48. Many stakeholders argued that the adult social care sector is more than invisible: it is also the subject of misconceptions among the general public, who often do not realise the diverse, versatile and positive role that the sector plays in society. Lucy Campbell, from Rights at Home UK, described the dominance of care homes in the media and political discourse, which does not reflect the variety of circumstances that exist within social care.<sup>72</sup> The Bureau of Investigative Journalism similarly argued that while there

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64 Q 15 (Jeremy Hunt MP)

65 Q 15 (Vic Rayner)

66 Q 15 (Dr Anna Dixon)

67 Carers Trust, ‘Over 90% of adult unpaid carers feel ignored by the Government’ (9 February 2022): <https://carers.org/news-and-media/news/post/169-over-90-of-adult-unpaid-carers-feel-ignored-by-the-government> [accessed 22 November 2022]

68 Written evidence from Reclaim Social Care Greater Manchester (ASC0121)

69 Written evidence from Bristol City Council (ASC0076)

70 Written evidence from PJ Woolfall (ASC0103)

71 Written evidence from Bristol City Council (ASC0076)

72 Written evidence from Lucy Campbell (ASC0075)

was extensive news and political coverage of the impact of the COVID-19 pandemic on residents and staff in residential care homes, “a fraction” of the same coverage was being given to those receiving care at home.<sup>73</sup>

49. These views reflect the overwhelming majority of evidence that we heard. However, Ministers and civil servants challenged the idea that social care was ‘invisible’. Michelle Dyson, Director-General of Adult Social Care, Department of Health and Social Care, argued that the situation has improved in the last three years. She accepted that this was not all for a good reason—the COVID-19 pandemic has certainly placed the spotlight on the huge difficulties faced by the sector—but argued that there were reasons for being more positive. For instance, care workers have recently appeared on Ipsos MORI’s trust index of most trusted professions. Mr Hunt also thought that while the sector was in many respects still largely invisible, the situation is better than it was 10 years ago. He credited part of this to Theresa May’s Government changing the name of the Department of Health to the Department of Health and Social Care, resulting in Secretaries of State for Health having to pay “lip service to social care in a way that they did not before.” Mr Hunt added that “there is still a very long way to go”.<sup>74</sup>

### *Reasons for invisibility*

50. There are a variety of reasons why adult social care is invisible, while also in plain sight. Many are complex cultural reasons, while others have a more obvious link to Government policy.

### *Public understanding and personal experience*

51. First, the need for, and access to, social care is often viewed as something affecting other people—‘them’, not ‘us’—and not a common cause for national debate or widely understood in all its complexity. This is because most people’s experience of social care is formed out of a crisis, when they are not best placed to think strategically. We were told that “many people only begin looking for information about services once they have reached a crisis,” with detrimental consequences for their own health and wellbeing.<sup>75</sup> In other words, people who need to access social care are often on the backfoot from the start.
52. Consequently, experience of social care is partial, unpredictable and associated, usually, with growing older and more dependent. The universal significance of social care as underpinning so much of our ability as a community and an economy to function, and the essential nature of it when it is needed is often missed and is seen as less of a priority.
53. It is also out of sight for the obvious reason that it is seen as a ‘private’ undertaking. Social care happens behind ‘closed doors’ and those who draw on it or provide it are not routinely present in the public space. Some have therefore described it as a “Cinderella service”: it is down to families to pick up the work not undertaken by adult social care professionals.<sup>76</sup> There is also an assumption from policy makers and professionals that families, especially women, will provide care and support, and that it is therefore an extension

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73 Written evidence from Bureau of Investigative Journalism ([ASC0096](#))

74 [Q 15](#) (Jeremy Hunt MP)

75 Supplementary written evidence from HealthWatch England ([ASC0134](#))

76 Written evidence from Reclaim Social Care Greater Manchester ([ASC0121](#))

of the traditional female caring role; alongside this is the implicit assumption that it is not a skilled activity.<sup>77</sup>

54. To an extent, this is an understandable and human reaction. Just as there is a natural aversion to thinking about or preparing for old age, there is a general reluctance as a whole in the community to think about when and how social care might be needed. The Centre for Care at the University of Sheffield argued that “there is a lack of public awareness about adult social care” that is born of several factors such as an unwillingness to think about a time where social care is necessary, fear based on negative news stories and stigma related to being in receipt of care.<sup>78</sup> The Local Government Association (LGA) pointed to the fact that many people do not know what adult social care is and how it operates; many people do not give much thought to their possible future social care needs; and people deliberately avoid thinking about potentially difficult future circumstances, which is also attributed to the way social care is portrayed by the national media.<sup>79</sup> One expert by experience went further, arguing that “it is more dangerous than invisibility, I am afraid. I think it is that people think that they know what it is but that it happens to other people.”<sup>80</sup>
55. People also avoid thinking about future circumstances because there are currently no concrete or quantifiable solutions, and they have no certainty when it comes to the scope or cost of their future needs. There is therefore a widespread misunderstanding about how social care works, who pays for it and how, how it is provided and how to access it. A study by the Health Foundation found that most participants had not thought about their future social care needs and how they might be paid for, explained in part by a lack of awareness and public discussion about social care planning. People often assumed that they had been paying towards their future social care through taxation<sup>81</sup> and over a third (38%) incorrectly think that social care services are generally free at the point of need. Moreover, only 5% of people are preparing financially for their future care costs to any great extent.<sup>82</sup> Significantly, once participants were given more information about social care, they were clear that the funding model should change.<sup>83</sup>

### *The need to know more*

56. One recurrent and fundamental cause of invisibility is the consistent lack of data across the whole field of adult social care policy and practice, which inhibits everything from effective intervention to basic understanding of the scale and scope of the service. The Office for Statistics Regulation (OSR) explains this in part by a failure to invest in data and analysis by making it harder for individuals and organisations to make informed decisions.<sup>84</sup> Crucially, it also makes introducing evidence-based policy and judging

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77 Written evidence from the Homecare Association ([ASC0074](#))

78 Written evidence from the Centre for Care ([ASC0058](#))

79 Written evidence from the Local Government Association ([ASC0042](#))

80 [Q 24](#) (Tricia Nicoll)

81 Written evidence from the Health Foundation ([ASC0020](#))

82 The Health Foundation, *Public perceptions of health and social care: what the new government should know* (September 2022), pp 19, 23: <https://www.health.org.uk/publications/reports/public-perceptions-of-health-and-social-care-what-government-should-know> [accessed 25 November 2022]

83 Written evidence from the Health Foundation ([ASC0020](#))

84 Office for Statistics Regulation, *Adult Social Care Statistics in England* (January 2020) p 3: [https://osr.statisticsauthority.gov.uk/wp-content/uploads/2020/01/19\\_11\\_15\\_SocialCare\\_SRv3.pdf](https://osr.statisticsauthority.gov.uk/wp-content/uploads/2020/01/19_11_15_SocialCare_SRv3.pdf) [accessed 29 September 2022]



appropriate funding for the sector difficult. We heard from Sir Andrew Dilnot that “collecting data is not a terribly expensive thing to do, but it is a prerequisite of careful understanding and analysis of how we are intervening, what the needs are, and what is working.”<sup>85</sup> However, only 40% of social care providers are fully digitised, with the remainder using paper records which frustrates public and political understanding.<sup>86</sup> The OSR identified the following gaps in what adult social care data currently measures:

- Delivery of social care outside statutory control. Statistics on social care activity are primarily sourced from data provided by Councils with Adult Social Services Responsibilities (CASSRs). The established assessment criteria mean that many individuals privately funding care or receiving unpaid care from family and friends have little or no contact with a local authority.
- Funding outside statutory control. There are gaps in understanding of the scale of household expenditure on privately funded care and the value of unpaid care. There is no official estimate of the value of unpaid care provided by family and friends, but unofficial estimates that do exist vary between £100 billion and £132 billion per year, far exceeding HM Treasury spending.
- Individual experiences and quality of care. There is little information on pathways and transitions between healthcare and social care. There is also little information on the outcomes for those who experience social care.<sup>87</sup>

57. An independent report led by Baroness Cavendish of Little Venice also identifies a series of factors that explain the lack of data about adult social care. They include the fact that collecting data is a burden for most stakeholders and there is a lot of duplication; data quality is poor; there are gaps in the data, especially regarding funding flows and outcomes of investment; there is limited information about supply, demand and fees in the social care market; commercial and regulatory concerns mean there is little transparency; data is not shared in a timely way, which limits analysis; and outcomes of social care are hard to measure.<sup>88</sup>

58. The Health Foundation and Future Care Capital have tried to address this by holding workshops on social care data with people using and providing care across the UK. Participants agreed that the system does not currently collect data about what matters to people who need care. People who draw on care and support and their carers said that data is currently used to restrict their access to care, rather than empower them, and they often could not access data about themselves.<sup>89</sup>

59. The Government recognises the problem—not least when it comes to making effective and consistent policy—and has sought to address the lack of data

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85 [Q 186](#) (Sir Andrew Dilnot)

86 Office for Statistics Regulation, *Adult Social Care Statistics in England* (January 2020) p 3: [https://osr.statisticsauthority.gov.uk/wp-content/uploads/2020/01/19\\_11\\_15\\_SocialCare\\_SRv3.pdf](https://osr.statisticsauthority.gov.uk/wp-content/uploads/2020/01/19_11_15_SocialCare_SRv3.pdf) [accessed 29 September 2022]

87 *Ibid.*, pp 3–4

88 Baroness Cavendish of Little Venice, *Social care: Independent report by Baroness Cavendish* (February 2022) p 64: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf) [accessed 22 November 2022]

89 Written evidence from the Health Foundation ([ASC0020](#))



in its adult social care White Paper, which sets out proposals for improving data collection and the sharing of data to help better identify unpaid carers.<sup>90</sup>

*Lack of political imperative*

60. A result—as well as a cause—of this relatively low profile is that adult social care does not command political attention in the way that the health service does. It is not a national service. It is a mixed economy in terms of provision, dependent on the local authority but often outsourced at local level, market driven, fragmented and diverse in terms of provision. The contrasts with the NHS are stark and the consequences are graphic.
61. First, social care has no powerful national identity.<sup>91</sup> The Scottish Government is seeking to remedy this through the National Care Service (Scotland) Bill, which is currently going through the Scottish Parliament. This would establish a National Care Service, to which Scottish Ministers could transfer social care responsibility from local authorities.<sup>92</sup> Without commenting on the merits or otherwise of a National Care Service to solve these issues, it is an example of an attempt to create a more visible identity for adult social care. The Scottish National Care Service is further discussed in Chapter 4.
62. This lack of visibility is partly the reason why there is a lack of parity of esteem between adult social care and healthcare. For instance, the Homecare Association noted how in one care home, workers had been allowed to add the NHS logo alongside the care logo on their uniforms. This made a substantial difference to the respect they gained from other professionals and service users.<sup>93</sup> Meanwhile, Ministers tend to be more preoccupied with healthcare as the NHS has a higher resonance with the public. As a result, social care is often perceived to be “in the shadow” of the NHS and as an “enabler for a more streamlined healthcare service”.<sup>94</sup> The Future Social Care Coalition argued that there was:
- “A huge difference between on the one hand the immense national recognition of, and pride in, the NHS—often seen as the single greatest achievement of post war Britain—and the care sector, which is similar in size and is equally important to the wellbeing of the nation, but has none of that sense of being a national treasure.”<sup>95</sup>
63. Second, the Department of Health and Social Care has no direct influence over the way in which social care budgets are spent, leading to large differences in the provision of social care between local authorities. The NHS and Community Care Act 1990, which followed the ‘Community Care Review’ led by Sir Roy Griffiths in the late 1980s, transferred the responsibility for funding, planning and means testing of community care services from the Department of Social Security to local authorities. The result was the

90 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 61: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

91 Written evidence from Care England (ASC0034)

92 The Scottish Parliament, *National Care Service (Scotland) Bill* (20 June 2022): <https://www.parliament.scot/-/media/files/legislation/bills/s6-bills/national-care-service-scotland-bill/introduced/bill-as-introduced.pdf> [accessed 30 September 2022]

93 Written evidence from the Homecare Association (ASC0074)

94 Written evidence from Mencap (ASC0046)

95 Written evidence from the Future Social Care Coalition (ASC0123)

emergence of a market in social care, accelerating as out-sourcing services increased. Funding has traditionally come from central government funding to local authorities, specific grants, business rates, Council Tax and user charges. This has made adult social care extremely exposed in recent years.

64. Reductions in local government spending power since 2010 have led to social care becoming an unsustainable funding burden on local authorities. The Association of Directors of Adult Social Services found that in 2022/23 adult social care accounted for 37.2% of the total local authority budget.<sup>96</sup> In 2022/23, the total budget for adult social care is £17.1 billion.<sup>97</sup> As a result, local authorities seek to cut spending on it each year or subsume it into their spending on other services such as libraries and education. The assumption that local authorities will supplement funding gaps with local taxes such as by raising council tax, the social care precept, and retention of business rates serves to widen existing regional disadvantages given variations in tax bases, notwithstanding the reluctance of local areas to increase council taxes. Funding challenges will be discussed further in Chapter 4.
65. Adult social care is also provided by an unstable market. Most social care services are delivered by independent sector home care and residential care providers, which are mainly for-profit companies but also include some voluntary sector organisations. It is the responsibility of local authorities to commission care from those providers, and therefore to ensure that the local care market is healthy and diverse. In 2021/22 around 17,900 organisations were involved in providing or organising adult social care in England, delivered in an estimated 39,000 establishments.<sup>98</sup> In addition, around 70,000 direct payment recipients are estimated to be employing their own staff.<sup>99</sup>
66. This fragmentation creates massive confusion at every level of the service. As the National Care Forum said: invisibility is “largely caused by how confusing and complicated the system is for everyone involved.”<sup>100</sup> This was also highlighted by the National Care, Support and Independent Living Service (NaCSILS), which argued that the fragmentation of the sector means that there is no one central visible entity that addresses most social care concerns.<sup>101</sup> Inclusion London said:

“The legal framework is set out by national government, but the support is delivered and funded by local authorities, who make all decisions in individual cases and about the support services in their area. This leads to variations in the individual’s experiences and a very low national profile for social care as opposed to the NHS—a centrally funded system.”<sup>102</sup>

96 Association of Directors of Adult Social Services, *Spring Budget Survey 2022* (19 July 2022) p 9: <https://www.adass.org.uk/media/9390/adass-spring-budget-survey-2022-pdf-final-no-embargo.pdf> [accessed 29 September 2022]

97 *Ibid.*

98 Skills for Care, ‘The size and structure of the adult social care sector and workforce in England’: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx> [accessed 8 September 2022]

99 Skills for Care, *Individual employers and the personal assistant workforce* (March 2022): <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/Individual-employers-and-the-PA-workforce/Individual-employers-and-the-PA-workforce.pdf> [accessed 29 September 2022]

100 Written evidence from the National Care Forum (ASC0060)

101 Written evidence from the National Care, Support and Independent Living Service (ASC0114)

102 Written evidence from Inclusion London (ASC0108)

67. Third, the social care workforce is individualised, unidentified and wrongly judged to be unskilled. The LGA described how the care workforce is often “framed in negative terms, for example, ‘unskilled’, ‘poorly paid’ and ‘suffering from burn out’.”<sup>103</sup> Witnesses also said that the social care sector is often portrayed as a sector in crisis, reinforcing demoralisation, with attention given to ‘when things go wrong’ and negative topics such as staffing issues or low pay. While both staffing and pay are indeed dominant issues, made worse during the COVID-19 pandemic, the huge and positive contributions that the sector makes to the community, the economy and to the everyday survival and wellbeing of so many people, are overlooked. Charity United Response said, for example:

“Public perception of the system does not always reflect the positive impact that adult social care can have on young and working aged disabled people, for whom the purpose of social care is to expand their lives so they can have as independent a life as possible.”<sup>104</sup>

68. Changing the narrative and emphasising the positive, transformational nature of good adult social care, and the flourishing relationships which mark best practice, would make adult social care more visibly appreciated. The narrative around social care needs to be shifted in order to increase its visibility.<sup>105</sup> This approach moves beyond formal services, to include the wider network of support that enables overall wellbeing. It is through engagement with these wider support networks that a better vision of social care can be achieved.

### *COVID-19*

69. The COVID-19 pandemic, ironically, while raising the profile and public concern about care home residents who were confined, isolated and vulnerable, and about the difficulties staff faced, compounded the invisibility of the rest of the adult social care sector. One registered provider of social care described this as “a perfect storm and for some there is no way back to safe harbour.”<sup>106</sup> However, the pandemic did bring the “chronic underfunding and lack of investment from central government into sharp focus” and “highlighted that there is no parity with the NHS in terms of investment or in the terms and conditions that can be provided to staff.”<sup>107</sup> All these factors caused recruitment and cash-flow issues for many care providers.
70. However, if attention was focused on the struggle of care homes to take care of their inhabitants, the pandemic intensified the visibility gap between care home and care at home: while there was extensive news and political coverage of the impact of the pandemic on residents and staff in care homes, there was little on what was happening to those receiving care at home, who lost access to many of the support services and opportunities in the community on which they and their carers relied so heavily.<sup>108</sup> The anxieties felt by people having paid carers coming into their homes, and staff potentially going into multiple vulnerable people’s homes, were equally widely not understood or shared with the public.

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103 Written evidence from the Local Government Association ([ASC0042](#))

104 Written evidence from United Response ([ASC0045](#))

105 Written evidence from the Local Government Association ([ASC0042](#))

106 Written evidence from Sandra Joyce ([ASC0007](#))

107 *Ibid.*

108 Written evidence from the Bureau of Investigative Journalism ([ASC0096](#))

### How invisibility diminishes the service

71. As we discuss in Chapter 3, there are misconceptions and stereotyping surrounding individuals with care needs that directly impact the quality and outcomes of social care services, because they condition the way that social care services are designed. Services are effectively considered sufficient if they meet individuals’ basic needs. There is little thought given to exploring, acknowledging or meeting a person’s ambitions and desires, let alone to helping them find the means to accomplish their goals. This is far removed from the vision of adult social care as a system that enables people to live full, equal, contributory and ultimately ordinary lives. This reflects not just the pressures on the system driven by years of underfunding and the local variations which are so evident; it also means that no matter what age or condition, disabled adults and older people have very few choices and face significant hardships with a fear of what the future might bring. Relationships and trust suffer when everything becomes a costed transaction; when policy deliberately designed as an expansive and innovative future for adult social care, such as the Care Act 2014, is not put into practice; and a shrinking workforce is under significant and increasing strain.
72. There is no doubt that underfunding has led to the rationing of care, restricted choice and a loss of quality of life.
73. Unpaid carers are on the front line in every respect. Every cut in funding affects them directly. As we have already made clear, they inhabit a world in which the social and economic contribution of unpaid carers is taken for granted, regardless of carers’ individual challenges or the choices that people who draw on care might make about who they would like to support them. The great difficulties that affect so many unpaid carers so directly—financial distress, loss of work, lack of recognition, mental and physical exhaustion—are further discussed in Chapters 3 and 7.
74. Second, the quality of care provided is very variable, especially from one locality to the other. The CQC data from October 2021 showed that there was significant regional variation in care quality. For example, several local authorities had 100% of social care services rated ‘Good’ or ‘Outstanding’, while the worst had around 65%.<sup>109</sup> We heard that the culture of local authorities and the services on offer differ widely. For instance, Tricia Nicoll, an expert by experience, noted that at one local authority “the director absolutely got it”, whereas in another they had the opposite experience.<sup>110</sup> Likewise, another expert by experience, Andy McCabe, expressed anxiety about moving local authorities because he might have to “fight to get the same amount of funding as I get now”, despite having the same needs.<sup>111</sup>
75. Third, the fact that so much happens and is provided out of sight means that the trust that exists between the public and the NHS is not replicated in terms of social care. This is reflected in the fact that so many experts by experience, both individuals with care needs and unpaid carers, feel that they are ‘battling’ and ‘fighting’ the system at all times. Some described living in constant fear that support might be taken away from them. One expert by experience said that “social workers have a lack of understanding

109 Department of Health and Social Care, *Evidence review for Adult Social Care Reform* (1 December 2021) p 20: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1037884/evidence-review-for-adult-social-care-reform.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037884/evidence-review-for-adult-social-care-reform.pdf) [accessed 29 September 2022]

110 Q 31 (Tricia Nicoll)

111 Q 23 (Andy McCabe)

of how the system works” and “don’t understand the hardships we face as unpaid carers or the stress and difficulty of being a parent carer.”<sup>112</sup>

76. Fourth, attempts to resolve some of the challenges faced by adult social care, such as the Care Act 2014, have not been properly implemented. One expert by experience noted:

“There is a systematic problem with the functioning of the Care Act 2014. There is an invisible world that is only seen by service users... I believe the core problem is that local authorities do not believe in the Care Act 2014, they don’t believe that disabled people can live a fulfilling, independent life and their interpretation and application of the Care Act 2014 is cynical and adversarial.”<sup>113</sup>

77. Laura Gaudion, Interim Director of Adult Social Care and Housing Needs, Isle of Wight Council, said that the reasons are more complicated. She argued that councils lack “the basic steps that help us to empower that person in the way the legislation intends”, pointing to lack of funding and a skilled workforce “to be able to support people to take control in the way that the Act envisages”, as well as a culture of a “time and task-based care offer” rather than an offer based on individual wellbeing.<sup>114</sup> The Care Act 2014 is discussed further in chapter 4.
78. Finally, workforce challenges have never been addressed holistically or in terms of status, pay, qualification, career progression and parity of esteem. A national plan for the adult social care workforce has never been a political priority. The social care workforce is discussed further in Chapter 4.
79. And, while there is so much skill, good practice, compassion and empathy throughout the service, from the top leadership to the paid carer working daily against the clock to engage with and support people drawing on care in the community, this can be lost in the experience of so many people whose daily lives are a constant struggle.
80. **Adult social care, with the exception of recent proposals for funding reforms, has been historically relatively invisible in terms of national policy and politics. This is now increasingly damaging to both those who draw on and who provide unpaid care at a time of growing need, rising costs and a shrinking workforce.**
81. The consequences are explored in the next few chapters.

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112 Written evidence from Helen Spalding ([ASC0003](#))

113 Written evidence from Daniel Reed ([ASC0050](#))

114 [Q 171](#) (Laura Gaudion)



### CHAPTER 3: “THE HOPE THAT THINGS ARE GOING TO GET BETTER”: THE REALITY OF ADULT SOCIAL CARE TODAY

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#### What does it feel like to be drawing on adult social care today?

82. This chapter looks at the daily lives and realities of disabled people and older people who draw on social care, as well as of unpaid carers. The aspirations that disabled people and older adults have for independent living, choice and control stand in sharp contrast with their daily reality and this impacts deeply upon the lives of unpaid carers. We explore how the services provided in adult social care are not only influenced by limited resources, but also by deeper cultural habits—a fear of ageing and what it might bring, as well as negative images that are held of disabled people and older adults. This has led, in policy and in practice, to misleading assumptions that are made about what individuals with care needs want and what they can do, and has directly inhibited what social care policy should aim to provide. Much of the evidence we received reflects a failure to match even the basic expectations of today, as well as a failure to anticipate or to plan for the future, particularly for the growing number of people without children.
83. These assumptions and the risks inherent in them for the future directly impact on all aspects of the lives of unpaid carers. We look closely at the reality of their lives as they strive to find the right support for their families and friends, as well as for themselves; and the toll that this takes on their health and wellbeing at a profound level.

#### *Stigma and discrimination against older adults and disabled people*

84. The relative invisibility of the adult social care sector takes many forms but it also reflects the lack of empathy that many disabled people and older people experience in their daily lives. People who draw on care are seen, too often, as set apart, different from and essentially not equal to other citizens.
85. While the Equality Act 2010 protects people from discrimination or unfair treatment on the basis of certain personal characteristics, which include age and disability,<sup>115</sup> it does not always hold in practice. Disability Rights UK pointed to antiquated notions by which disabled people were “people who had something wrong with them” and stressed that this stigma still underpins much of modern society’s views on disability: “Coming to disabled people, we look back and our lives might not be valued equally. We still find this today.”<sup>116</sup> We come back to the Equality Act in Chapter 6.
86. Disability is frequently associated with false assumptions made about the amount of care disabled people need and how productive they are. This contributes to an overarching narrative that portrays disability as a problem. A study carried out by disability charity Scope in 2018, for example, found that up to 75% of respondents thought that disabled people need to be cared for some or most of the time.<sup>117</sup> Around one in three (32%) people said that they thought disabled people are not as productive as non-disabled people at least some of the time.<sup>118</sup> The survey also found that the public’s understanding of

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115 Equality Act 2010, [section 4](#)

116 [Q 82](#) (Fazilet Hadi)

117 Scope, *The Disability Perception Gap* (May 2018) p 10: <https://www.scope.org.uk/scope/media/files/campaigns/disability-perception-gap-report.pdf> [accessed 12 September 2022]

118 *Ibid.*, p 11



the prevalence of disability is inaccurate. The proportion of disabled people in the general population is 22%;<sup>119</sup> yet six in 10 respondents thought it was 20% or less, and four in 10 respondents thought it was 10% or less.<sup>120</sup>

87. Witnesses shared anecdotes with us to reflect how stigma and discrimination against disabled people can occur on a day-to-day basis. One expert by experience from Disability Rights UK said:
- “Often, it is not the disabled person who is talked to. It is our families, our carers and the people around us. Quite shockingly sometimes, in a shop, someone will talk to the person with me, even though I have the credit card. I find that extremely annoying. Again, these things are so embedded in our society. It is the notion of what is valuable.”<sup>121</sup>
88. ‘Ageism’ is also alive and well.<sup>122</sup> One witness told us that “we place a really low value on older people generally”.<sup>123</sup> Older people are frequently seen as passive, frail, vulnerable and dependent. As a society, we see them as a “burden” and a “problem to fix”.<sup>124</sup>
89. The Centre for Ageing Better told us that their own research has found that ageing is framed as a process of inevitable decline towards death.<sup>125</sup> In advertising, ageing is often shown as something that needs to be fought and resisted, for example with anti-ageing products.<sup>126</sup> The advertising sector also tends to caricature older age, with older adults often portrayed as inactive and powerless to act.<sup>127</sup>
90. In the media, it was found that older people are often framed as inherently vulnerable, for example in the context of scams, which contributes to the idea that older people do not have any agency and have no control over their lives.<sup>128</sup>
91. Political discourse is also problematic. The study carried out by the Centre for Ageing Better established that older people are usually associated with heightened pressure on public services, which contributes to portraying them as a burden and a drain on resources. We were also told that political discourse often perpetuates intergenerational conflict by pitting younger generations against older generations in a fight for resources.<sup>129</sup>

### *The forgotten purpose of adult social care*

92. The stigma and prejudice directed against disabled adults and older people has tangible repercussions in the way that key services in society are designed to meet their needs and ambitions. The underlying narrative and the lower value that is placed on certain individuals, which originates in the

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119 Department for Work and Pensions, *Family Resources Survey: financial year 2020 to 2021* (31 March 2022): <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021> [accessed 12 October 2022]

120 Scope, *The Disability Perception Gap* (May 2018) p 7: <https://www.scope.org.uk/scope/media/files/campaigns/disability-perception-gap-report.pdf> [accessed 12 September 2022]

121 [Q 82](#) (Fazilet Hadi)

122 [Q 79](#) (Luke Price)

123 *Ibid.*

124 [Q 80](#) (Luke Price)

125 [Q 79](#) (Luke Price)

126 *Ibid.*

127 *Ibid.*

128 *Ibid.*

129 *Ibid.*

assumption that they are a ‘burden’ on society, entails an assumption that a more restricted kind of life is appropriate for older adults and disabled people, with the expectation that they will accept a different and reduced quality of life compared to the rest of the population.

93. One of the most visible illustrations of this is the neglect of the needs of disabled people and older adults in the built environment. The Government’s National Disability Strategy, published in 2021, stated that only one in 10 homes in England have at least one adaptation for disabled people;<sup>130</sup> only a quarter of train stations have step-free access between all platforms;<sup>131</sup> and of the 10 most populated English county councils’ websites, nine did not meet accessibility standards.<sup>132</sup> These all reflect society’s failure to recognise or respect what it means to be a disabled or older citizen, and to provide the basic requirements enjoyed by everyone else.
94. Ian Loynes, an expert by experience who is also the CEO of SPECTRUM Centre for Independent Living, told us:

“There is a notion that, once you become disabled, you are automatically dependent and you need somebody else; you are just looked after and you are wasting your life until you die. That is not the reality for any age or for any disabled people.”<sup>133</sup>

95. The dramatic consequences of stigma and discrimination on social care services was felt particularly acutely during the COVID-19 pandemic. One witness told us that the crisis “really did show us that we had not made the gains that we thought we had made,” as disabled people and older adults felt that they were treated differently from other citizens.<sup>134</sup> One unpaid carer to her mother, who has dementia and lives in a care home, told us that during the pandemic, she felt as though her mother was “in prison” because her “human rights had been completely stripped away” as she was left on her own with no one to advocate for her.<sup>135</sup>
96. The purpose of adult social care should be to challenge these perceptions and to enable older adults and disabled people to live a life of their choice. One expert by experience told us:

“I just want to get on and live my life like other people, and I need the assistance to be able to do that. That is what social care should be about. It is about enabling us all to fulfil our ambitions and what we want to do in everyday life, as people who do not need to use assistance services would just take for granted.”<sup>136</sup>

This understanding of the purpose and outcomes of adult social care is aligned with that of many other stakeholders.<sup>137</sup>

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130 HM Government, *National Disability Strategy*, CP 512, July 2021, p 18: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1006098/National-Disability-Strategy\\_web-accessible-pdf.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006098/National-Disability-Strategy_web-accessible-pdf.pdf) [accessed 12 September 2022]

131 *Ibid.*

132 *Ibid.*

133 [Q 53](#) (Ian Loynes)

134 [Q 83](#) (Fazilet Hadi)

135 Written evidence from J Hine ([ASC0049](#))

136 [Q 23](#) (Sue Bott)

137 Written evidence from the National Care Forum ([ASC0060](#)), Reclaim Social Care Greater Manchester ([ASC0121](#)) and Diana Pargeter ([ASC0038](#))

97. These definitions of the purpose and outcomes of adult social care are far removed, however, from the reality of adult social care for most people. One expert by experience wrote to us that in reality, “it is as if adults in social care don’t matter that much.”<sup>138</sup>
98. We heard instead that social care services focus on providing older adults and disabled people with the minimal care and support that is necessary to meet their most basic needs. The Wiltshire Centre for Independent Living said: “When being assessed for care services people are told what they need to live a basic existence in terms of personal care.”<sup>139</sup> Inclusion London added that social care support is largely regarded as support to meet basic personal care needs as opposed to support to ensure people can live a normal life with equal choices and rights.<sup>140</sup>
99. Disability charity Leonard Cheshire, for example, pointed to research finding that the lives of working age disabled people have been curtailed due to inadequate social care and support over the last 12 months. This has meant that 41% have not been able to visit family and friends; 36% have been unable to leave their house, shop for food or clean their home; 33% have been unable to partake in their hobbies; and 28% have not been able to prepare a meal.<sup>141</sup>
100. During our visit to a disabled people’s organisation in London, one participant also linked the shortcomings of care services to the discriminatory view that older adults and disabled people cannot or should not live equal lives. The participant said disabled people were not seen as productive human beings, and instead were made to feel that they should be grateful for the “tiny” amount of support they receive to cover their most basic and urgent needs. They argued that support barely existed beyond this or was too difficult to access.<sup>142</sup>
101. We heard that as a result, social care assessments are too often a “tick-box”<sup>143</sup> exercise: services are provided to cover essential needs once a person meets the right eligibility criteria, or ticks the right box, making for a highly impersonal system that leaves no room for a person to express how they could be empowered to live a meaningful life beyond basic personal care. This is aggravated by local authorities facing reduced budgets: they are more likely to act as ‘gatekeepers’ to keep people out of the system. This is missing the ‘social’ aspect of care, and instead makes for what one expert by experience described as a “medicalised” model of care:

“The thing about the NHS is that it is very transactional. Even if it is positive like having a baby, it is still transactional. You want some support, you want this, you want that; it is an exchange, and you get a result. We try to apply the same principle to social care ... but nobody has the conversation about what would really enable you to keep living the life you want to live.”<sup>144</sup>

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138 Written evidence from Ann Holden ([ASC0016](#))

139 Written evidence from the Wiltshire Centre for Independent Living ([ASC0010](#))

140 Written evidence from Inclusion London ([ASC0108](#))

141 Written evidence from Leonard Cheshire Disability ([ASC0079](#))

142 Summary of Adult Social Care Committee visit to Real, 6 September 2022: Appendix 4

143 [Q 23](#) (Sue Bott)

144 [Q 23](#) (Tricia Nicoll)

102. In spite of policy rhetoric and genuine attempts to embed new approaches, social care is an inflexible system. There is very little scope to personalise care packages to each person’s ambitions and aspirations. Instead, people are expected to adapt to the narrow range of services that are on offer. One expert by experience told us an anecdote concerning their friend who has some social care support, and who used their funding to pay for a season ticket for an assistant to accompany them to see the football on weekends. This enhanced the person’s life while giving a break to their wife every week; it was cheaper than traditional services, achieved a good outcome and was socially inclusive; and yet it was faced with fierce criticism in the media and from the general public. “Somehow we have to get over that,” we were told. “I suppose we have to ask the general public: ‘If something happened to you, what would you want in your everyday life?’”<sup>145</sup> In most cases, it is not a question that is asked to older adults and disabled people when they are assessed for social care services; and their response to it is not seen as relevant.
103. Social care services, therefore, find it difficult to listen to what people who are in receipt of care have to say about their personal needs, ambitions and desires.<sup>146</sup> We were told that conversations rarely happen which would help social workers to genuinely understand what it takes for a person to live the life that they want, continue to go to work, practice a hobby or look after their children. Instead, services are provided in a top-down manner, and people are expected to adapt their lives to the generic offer they are presented with.
104. This often happens despite the best efforts of social workers. Many witnesses described to us the valuable work carried out by some social workers and local authorities, who support the vision of adult social care as an enabler for people to live an equal life, but eventually find themselves unable to achieve this vision in the current system. One expert by experience told us that many social workers who have “a creative thrust and social justice” are met with a system that requires them to become “checklist completers and box-tickers.” The same witness concluded: “They want to be able to use their skills, and support people in a progressive and empowering way. I think the system is failing them as well.”<sup>147</sup>

*Trust and power: local authorities as gatekeepers*

105. In this system, access to appropriate social care services was described to us as extremely difficult to achieve. Because local authorities carry out assessments of needs based on narrow eligibility criteria, people are pushed out of the system until their needs become extreme and urgent. One expert by experience described to us why she is not eligible for support: “I have the misfortune of being able mostly to hold down a job, or work.” If her life was “in a really bad place,” she anticipated, then she might qualify for support.<sup>148</sup>
106. This is due, to a large extent, to a lack of resources. As the last chapter outlined, cuts in services have meant that many local authorities have felt that they have had no choice but to increase thresholds for eligibility for services to try to reduce demand, which leads to higher levels of unmet need. The LGA quoted research showing that just over half a million people are

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145 Q 24 (Sue Bott)

146 Q 25 (Tricia Nicoll)

147 Q 24 (Andy McCabe)

148 Q 23 (Tricia Nicoll)

currently awaiting a care needs assessment, a care package, a direct payment or a review of an existing care plan.<sup>149</sup> The CQC’s latest data shows that in January and March 2022, 61% of councils said they were having to prioritise assessments and were only able to respond to people with specific circumstances.<sup>150</sup> Laura Gaudion, the Interim Director of Adult Social Care and Housing needs at the Isle of Wight Council, told us: “We do the very best we can with the resources we have available. There are things we cannot subsidise. There are challenges we cannot resolve.”<sup>151</sup> Despite trying to find concrete solutions in current circumstances, therefore, the lack of resources was frequently depicted as the main hurdle to effective change and transformation.

107. Local authorities and social workers face significant challenges in the provision of social care, therefore, but the difficulty of accessing care and support is such that they are often seen as rationing services for older adults and disabled people. The need to stretch inadequate budgets across as many people as possible can lead to the codifying of a penny-pinching approach to assessment, which is at odds with the purpose of adult social care. During our visit to a disabled people’s organisation, one participant explained that social workers had repeatedly re-assessed her needs in the past years in order to reduce the amount of care she was provided, trying every time to make her agree to care packages that she found inappropriate; for example, to provide her with night pads instead of care throughout the night. We were told that the approach taken to assessments by some social workers is “offensive”, and people frequently described to us as having to relentlessly “fight” against their local authority in order to access any form of care or support.<sup>152</sup> Such a situation where trust has broken down is extremely challenging both for the person and for the social worker. There is a widespread view that the concept and practice of assessments are unfit for purpose and outdated, and currently act as an obstacle to a social care system that enables people to live fulfilling lives.
108. Those who are assessed for their needs do not feel able to challenge the outcome of their assessment, even if the support they will get as a result is not sufficient to meet their needs. Another participant to our visit to a disabled people’s organisation told us that people are “scared to fight” and have to be “appreciative of the tiny bit of care they get.”<sup>153</sup> The participant recalled how, after they had tried to challenge the outcome of an assessment that provided their grandmother with only 15 minutes of support a day, they were told to lock their grandmother up at home if they needed to leave her to go food shopping.<sup>154</sup> Belinda Schwehr, the chief executive of specialist advice charity CASCAIDr, who has previously practiced as a barrister, described at length the difficulty of challenging the decisions made by local authorities. For the majority of people who have no legal training, therefore, it is seen as practically impossible to challenge the outcome of an assessment, which

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149 [Q 65](#) (David Fothergill)

150 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 35: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

151 [Q 175](#) (Laura Gaudion)

152 Summary of Adult Social Care Committee visit to Real, 6 September 2022: Appendix 4

153 *Ibid.*

154 *Ibid.*



results in them usually taking “what they are given” and being “expected to be grateful.”<sup>155</sup>

109. Often, as a result, people feel powerless in the face of their local authority and some live in constant anxiety that services will be reduced or altogether removed from them. One expert by experience described to us that whenever they contact social care for a review, advice or a support, they fear their budget will be cut: “Just by contacting them and them getting more involved in my life, suddenly things might start getting pulled away.”<sup>156</sup>

*The role of friends and families*

110. This lack of choice and control extends to people’s relationships with their friends and families. Against a background where there are 165,000 vacancies in the social care workforce, we were told that there is an expectation from local authorities that families will provide most of the support for their person they care for, and that this support can be relied upon and used as a way of cutting budgets or minimising expenditure.<sup>157</sup> One expert by experience recalled how, when he turned 18 years old, his local authority asked his father to provide more support, requiring him to cut his working hours to three days a week. Now 15 years later, the same witness described his fear that the local authority will cut his social care budget because he is moving near his father again, who although he is past his mid-70s, might still be expected to provide care and support for his working age son.<sup>158</sup>
111. There is, therefore, an embedded narrative by which care and support should come from families first, leaving no room for individuals with care needs or unpaid carers to exercise any choice over their relationship with each other. “Carers feel that they must do whatever the local authority says the local authority will not do, or else that they risk their loved one being taken away and being stuck in a care home,” said Ms Schwehr.<sup>159</sup>
112. While many older adults and disabled people would continue to choose to draw on care and support from their friends and families, or unpaid carers, there are also many who do not wish to choose this arrangement. Unpaid carers can also feel obliged to step into the caring role and fear they will be judged if they do not or cannot provide care. One expert by experience told us: “You want to have an ordinary relationship with your friends and the people in your network. You do not want a relationship where there is an expectation that they will come along and help you do things.”<sup>160</sup>
113. The social care system, however, is not built to account for the fact that some people may not wish to rely on friends and relatives to lead a fulfilling life; even though, in the case of a disabled child, for instance, this might mean living an adult life aligned with the expectations of their parents or siblings, rather than their own.<sup>161</sup>
114. Given that there is relatively little help or guidance to enable independent living, such as direct payments and personal assistance, finding alternative

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155 [Q 123](#) (Belinda Schwehr)

156 [Q 23](#) (Andy McCabe)

157 [Q 28](#) (Andy McCabe)

158 *Ibid.*

159 [Q 123](#) (Belinda Schwehr)

160 [Q 27](#) (Sue Bott)

161 [Q 46](#) (Ian Loynes)



forms of care was described to us as an “uphill battle”.<sup>162</sup> One witness told us that the current system “simply does not work” for those who do not wish to receive care from family or friends, and that there is “a lot of bureaucracy if people wish to take control.”<sup>163</sup>

*Ageing without children: failing the future*

115. Adult children are the most common providers of unpaid care to their parents when they reach older age and their care needs are greatest.<sup>164</sup> The assumption that older adults and disabled people have families and friends that will provide care and support for them therefore has tangible implications for the fast-growing group of people who, for whatever reason, are ageing without children. They might have not had children through choice, infertility or other circumstance; for example, they or their partner are unable to have children, or they did not meet someone with whom they wished to have children. It might also be that they have children, but those children have predeceased them, have care needs of their own, or are unable to provide care and support because they do not live close, or are unwilling to.
116. The Office for National Statistics (ONS) says that while one in 10 women born in the cohort that followed World War Two did not have children, this increased to one in five women born in the 1960s cohort. In addition, women born in the 1960s cohort will have longer lives, meaning that they will reach older age without children to provide unpaid care and support.<sup>165</sup>
117. As discussed above, many other groups who might find themselves ageing without children for different reasons. Changes in social attitudes, values and behaviour are also contributing to the increasing number of people ageing without children, with many individuals unable to rely on support from their children, who might have moved away from their families because of work commitments. Ageing Well Without Children estimates, therefore, that there are currently around 1.2 million people over the age of 65 ageing without children, which is set to rise to 2 million by 2030.<sup>166</sup> Research commissioned by the charity Independent Age concluded with a similar estimate: it found that 15% of older people are without children, which represents about 1.5 million people.<sup>167</sup> This number was estimated to reach 4 million by 2040.<sup>168</sup> For them, we were told that the prospect of ageing causes great fear, as the current system is ill-prepared to respond to their needs. This fear is not just

162 [Q 145](#) (Andy McCabe)

163 [Q 15](#) (Dr Anna Dixon)

164 Office for National Statistics, ‘Living longer: implications of childlessness among tomorrow’s older population’ (August 2020): <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglonger/implicationsofchildlessnessamongtomorrowsolderpopulation#what-are-the-informal-care-implications-of-high-levels-of-childlessness-for-future-older-populations> [accessed 15 September 2022]

165 In 2019, there were an estimated 23,000 women aged 80 years in England and Wales who did not have children; by 2045, this number is projected by the ONS to triple to 66,000 as the 1960s cohort of women reaches 80 years old. These statistics do not account for the numbers of men who do not have children—a group on which no data is officially collected. See Office for National Statistics, ‘Living Longer: implications of childlessness among tomorrow’s older population’ (August 2020): <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglonger/implicationsofchildlessnessamongtomorrowsolderpopulation> [accessed 5 October 2022]

166 [Q 47](#) (Kirsty Woodard)

167 Independent Age, *In Focus: Experiences of older people without children* (April 2020) p 1: [https://www.independentage.org/sites/default/files/2022-04/IA-PI-377\\_Without\\_children\\_snapshot\\_v4.pdf](https://www.independentage.org/sites/default/files/2022-04/IA-PI-377_Without_children_snapshot_v4.pdf) [accessed 14 November 2022]

168 Independent Age, *In Focus: Experiences of older age in England* (April 2020) p 33: [https://www.independentage.org/sites/default/files/2020-03/Report\\_vF\\_0.pdf](https://www.independentage.org/sites/default/files/2020-03/Report_vF_0.pdf) [accessed 14 November 2022]

of loneliness—ageing without children brings tangible challenges, such as in undertaking low-level support tasks, personal tasks and navigating the complex social care system.

118. There is real difficulty in estimating the exact number of people ageing without children, which reflects the fact that there is a “complete and utter lack of data”.<sup>169</sup> Data is only recorded on the number of women who do not give birth; no data exists about men ageing without children. This data also does not include the numbers of people estranged from their children, those whose children have predeceased them or those who live far from their children. Any estimate for the cost and provision of social care for this population, therefore, cannot be reliable. This reflects the fact that planning for their needs is not a policy priority.<sup>170</sup>
119. What we do know, however, is that the system is not designed or prepared to respond to the needs of this group. People ageing without children, as a result, often fall into the formal care system earlier. The organisation Ageing Well Without Children said that people ageing without children are significantly more likely to move into a care home, at a younger age and a lower level of need, “simply because there are no other options out there.”<sup>171</sup> This is symptomatic of a system that leaves little choice or control to those who do not wish to, or cannot, rely on the care and support of unpaid carers.
120. The future looks extremely hazardous for people ageing without children, and yet they are a fast-growing group.
121. *The Government should implement mechanisms to collect more accurate data on the number of people ageing without children, including men who do not have children, people who are estranged from their children, or people whose children have pre-deceased them.*
122. *Further research is required to understand the prospects of people ageing without children. The Government should work with charities, civil society and academics to understand how their needs can better be met.*

### What does it feel like to be an unpaid carer today?

#### *What do we owe the unpaid carer?*

123. Throughout our inquiry, we were reminded of the huge value of the contributions unpaid carers make, including in basic economic terms. Unpaid carers effectively provide a significant portion of the caring that individuals who draw on social care services need. They are therefore a fundamental pillar of the adult social care system, despite many not actively choosing to become an unpaid carer. One unpaid carer told us: “The system should treat us as the bedrock of healthcare and social care, because that is what we are. Without us, the whole thing falls into a hole.”<sup>172</sup>
124. Putting an exact figure on the economic value of unpaid care is difficult and estimates vary. The ONS estimates that the gross added value of unpaid care

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169 [Q 46](#) (Kirsty Woodard)

170 Written evidence from Dr Robin Hadley ([ASC0002](#))

171 [Q 46](#) (Kirsty Woodard)

172 [Q 39](#) (Norman Phillips)

in the UK was £59.5 billion in 2016.<sup>173</sup> The Nuffield Trust wrote that unpaid carers provided care worth £193 billion per year during the pandemic.<sup>174</sup> Professor Sue Yeandle, the Director of the Centre for International Research on Care, Labour and Equalities (CIRCLE) pointed to a figure of £132 billion per year, which she argued was the product of a methodology that was considered the best method for the purpose.<sup>175</sup>

125. What is certain is that these figures are significant, and that the state could not afford to replace the work of unpaid carers with formal care services. Dr Valentina Zigante, from the London School of Economics, told us: “We know very well that carer breakdown is what causes people to need to go into residential care. It is massively costly in economic value to society.”<sup>176</sup> In other words, without the work they carry out, the strain on formal social care services would be immense. Yet it is clear that many unpaid carers are effectively at risk of breakdown. A survey carried out among councils in spring 2022 showed that 73% reported rising numbers of breakdowns of unpaid carer arrangements.<sup>177</sup> We were told by unpaid carers themselves: “It’s not possible to pour from an empty cup, so if there is no support for carers to rest and to have a tiny modicum of a life, they will continue to burn out and then two people will need state support.”<sup>178</sup>
126. One witness pointed out that was not only a moral imperative, but that it also made economic sense, given the significance of their economic contribution.<sup>179</sup> One expert by experience put it simply: “Someone—the state or whoever—has to say to people, ‘Please look after your family and we will help you to do that’.”<sup>180</sup>
127. We heard the stories of husbands, wives, mothers, fathers, daughters-in-law, brothers, sisters, friends, neighbours and many others who were providing unpaid care and support. They told us, most often, of the joy and fulfilment it brought them. One unpaid carer described to us how much she and her family have learnt and grown from providing care to her 23-year-old daughter with severe learning disabilities.<sup>181</sup> Another unpaid carer to her daughter portrayed her experience in the following terms:

“Maddie is a really beautiful person inside and out and is incredibly tolerant of us. She has taught us all a huge amount. I would describe my beautiful daughter as the beating heart of our family. I would say that we are all better people for having her in our lives.”<sup>182</sup>

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173 Office for National Statistics, ‘Unpaid carers provide social care worth £57 billion’ (10 July 2017): <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10> [accessed 14 September 2022]

174 Written evidence from the Nuffield Trust (ASC0104)

175 Supplementary written evidence from Professor Sue Yeandle (ASC0153)

176 Q 55 (Dr Valentina Zigante)

177 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 45: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

178 Written evidence from Connected Project, Service User and Carer Advisory Group, University of Bristol (ASC0027)

179 Q 69 (Fatima Khan-Shah)

180 Q 140 (Norman Phillips)

181 Q 36 (Helen Spalding)

182 Q 85 (Kate Sibthorp)

When it is the result of a genuine choice made by the person and by the unpaid carer, and with the right support, therefore, caring can be a life affirming experience.

128. But many unpaid carers face an alternative future. The expectation that friends and families should provide unpaid care not only takes away any choice or control from older adults and disabled people, but it also denies a fundamental choice to unpaid carers themselves, who often find that they have little or no say in the amount of support they are expected to deliver. One unpaid carer told us: “I do not think I have any choice. There is no choice for me in the hours that I provide in care, the shifts I do or the holiday I take.”<sup>183</sup>
129. The pressure to provide unpaid care does not affect everyone equally. Overwhelmingly, it is still seen as a female role. One witness described it as “a culture in which carers, and that means mainly women, simply step up.”<sup>184</sup> Up to 58% of unpaid carers in the UK are women.<sup>185</sup> Similarly, different cultural expectations prevailing in some Black, Asian and Minority Ethnic (BAME) communities mean that people from BAME backgrounds are more likely to be carers, as well as to provide longer hours of care, compared to white carers.<sup>186</sup> This in turn means that the detrimental impacts that unpaid care can have on financial, physical and mental well-being are likely to be felt more acutely by these groups.

*Financial, physical and emotional strain*

130. Unpaid care comes with significant challenges, and many carers told us that it involves varying degrees of sacrifice. “You need to change your mindset to be able to survive,” said one unpaid carer;<sup>187</sup> another told us: “It is not what you want, it is what you need. If you reduce your life to what you need, you can cope.”<sup>188</sup>
131. One key challenge is financial. Unpaid carers who provide many hours of support every week are more likely to be unable to remain in employment, meaning that they cannot rely on a regular income. One unpaid carer described to us how he went from working 60 hours a week as a senior manager in an IT company, to leaving his job to provide full-time care and support to his wife, who has multiple sclerosis, and having to sell his house as a result.<sup>189</sup> We heard from another unpaid carer who at 46 years old had been a university graduate with a background in international relations and experience in licensing law, but who had had to give up work and become a full-time carer for her parents, husband and children.<sup>190</sup>
132. Where carers are eligible for benefits, they more often than not live precariously and in poverty. In England and Wales, those who care for someone at least 35 hours per week and earn less than a certain amount per week are eligible for Carer’s Allowance, which since April 2022 provides

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183 [Q 37](#) (Katy Styles)

184 [Q 123](#) (Belinda Schwehr)

185 Written evidence from the Trades Union Congress ([ASC0040](#))

186 Written evidence from the Joseph Rowntree Foundation and London Unemployed Strategies ([ASC0116](#))

187 [Q 37](#) (Katy Styles)

188 [Q 36](#) (Norman Phillips)

189 [Q 44](#) (Norman Phillips)

190 [Q 55](#) (Nadia Taylor)

£69.70 per week. This represents just under £2 per hour; in contrast to the National Living Wage, which stands at £9.50 per hour for individuals over the age of 23.<sup>191</sup> We heard from an unpaid carer in this position, for whom it means an annual income of £3,624.40, which she described as “outrageously low”. It has meant using up all her savings and still not being able to afford basic necessities like prescriptions or transport.<sup>192</sup>

### Box 2: Carer’s Allowance

Carer’s Allowance is the chief benefit for carers. Carers either have to live with, or be related to, the person they are caring for. As of 2022/23, this benefit is worth £69.70p per week per week for those claiming it.

Carer’s Allowance is not based on the carer’s income and capital nor that of their partner, so the benefit is not means tested. However, Carer’s Allowance cannot be paid if the carer’s earnings from work are over a cap of £132 per week.<sup>193</sup>

Due to ‘overlapping benefits’ rules, Carer’s Allowance cannot typically be paid to a carer if they receive one or more of the following benefits: state pension; contributory Employment and Support Allowance; Incapacity Benefit; Maternity Allowance; Bereavement or widow’s benefits; Severe Disablement Allowance; or Contribution-based Jobseeker’s Allowance.

The carer, however, can be paid a small amount of Carer’s Allowance to supplement the other benefits they receive, if any of the above benefits are under the amount of the Carer’s Allowance.<sup>194</sup>

Carer’s Allowance eligibility is determined by three sets of criteria concerning the carer, the person drawing on care and the type of care provision.

The carer must meet all the following criteria: aged 16 or over; caring for at least 35 hours per week; resided in England, Scotland or Wales for at least two of the last three years; normally live in England, Scotland or Wales, or lives abroad as a member of the armed forces; not subject to immigration control; earns £132 per week or less after tax, National Insurance and expenses are deducted; not in full-time education; and studying less than 21 hours per week.<sup>195</sup>

The person who draws on care must already receive one of the following benefits: the daily living component of Personal Independence Payment (PIP); the middle or highest care rate of the Disability Living Allowance; Attendance Allowance; Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit; the basic (full day) rate of Constant Attendance Allowance with a War Disablement Pension; Armed Forces Independence Payment; the daily living component of Adult Disability Payment; or the middle or highest care rate of Child Disability Payment.<sup>196</sup>

133. While it is not always the case that unpaid carers have to give up work altogether, there is a wealth of evidence to show the impact caring has on the ability to work. The Social Research Institute CLOSER, University College

191 HM Government, ‘National Minimum Wage and National Living Wage rates’: <https://www.gov.uk/national-minimum-wage-rates> [accessed 16 September 2022]

192 Q 55 (Nadia Taylor)

193 HM Government, ‘Carer’s Allowance’: <https://www.gov.uk/carers-allowance> [accessed 10 October 2022]

194 Carers UK, ‘What is Carer’s Allowance?’: <https://www.carersuk.org/help-and-advice/financial-support/help-with-benefits/carers-allowance> [accessed 10 October 2022]

195 *Ibid.*

196 *Ibid.*



London, pointed to research showing that around one in seven working carers reduce their economic activity in midlife, and that even 10 hours provision of unpaid care a week by people in midlife has negative consequences for employment.<sup>197</sup>

134. The chances of not being able to work increase as more care is provided. Six in 10 of those who are caring for 35 hours or more a week are not in work, three times the rate of those caring for less than 20 hours a week. Those caring for 20 to 35 hours a week are also less likely to be employed, with around a third not in work or not able to work. Of those carers who are working, those with higher caring responsibilities (more than 35 hours or 20 to 34 hours) are more likely to work part-time than those providing lower levels of care (less than 20 hours): 43%, 32% and 29% respectively.<sup>198</sup>
135. Even for those in employment, caring can impact their ability to enjoy, perform or work full-time. A recent survey by Carers UK has shown that 75% of respondents worry about continuing to juggle work and care, while 65% had given up opportunities at work because of caring. The survey also found that 29% of respondents had already reduced their hours at work as a result of caring, and a further 11% felt they needed to, to help manage their caring responsibilities.<sup>199</sup>
136. The Joseph Rowntree Foundation shared statistics that clarify the link between unpaid care and poverty, particularly for unpaid carers who provide more hours of support: the organisation’s research found that in 2019/20, 44% of working age adults who were caring 35 hours or more a week were in poverty. This compares to 21% of non-carers.<sup>200</sup>
137. Unpaid carers are therefore particularly at risk of increasing poverty as the cost of living crisis bites week by week in the UK. A recent survey carried out by Carers UK paints a worrying picture of the next few months, with 75% of unpaid carers saying that they are stressed or anxious about their finances (compared to 52% in November 2021).<sup>201</sup> The survey found that three-quarters of unpaid carers worried they would have to cut back on heating, and that a third were worried they would have to use a foodbank.<sup>202</sup>
138. Many carers stressed that Carer’s Allowance is the lowest benefit of its kind, which is reflective of the value that is placed on unpaid care. In addition, the threshold to claim Carer’s Allowance was described by many stakeholders as too high. Carers’ Trust, for example, said that the system for claiming Carer’s Allowance is so restricted that more than half (51%) of unpaid carers responding to the organisation’s ‘Pushed to the Edge’ survey question on whether they were able to claim Carer’s Allowance said they were not.<sup>203</sup> The We Care Campaign wrote that the current benefits system has failed to keep up with societal changes in the job market, the cost of living and the fact that

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197 Written evidence from CLOSER, UCL Social Research Institute (ASC0069)

198 Written evidence from the Joseph Rowntree Foundation and London Unemployed Strategies (ASC0116)

199 Carers UK, *State of Caring 2022* (November 2022) p 44: [https://www.carersuk.org/images/Research/CUK\\_State\\_of\\_Caring\\_2022\\_report.pdf](https://www.carersuk.org/images/Research/CUK_State_of_Caring_2022_report.pdf) [accessed 8 November 2022]

200 Joseph Rowntree Foundation and London Unemployed Strategies (ASC0116)

201 Carers UK, *Under Pressure: Caring and the cost of living crisis* (March 2022) p 2: [https://www.carersuk.org/images/Carers\\_UK\\_research\\_briefing\\_-\\_Under\\_Pressure\\_-\\_Caring\\_and\\_the\\_cost\\_of\\_living\\_crisis.pdf](https://www.carersuk.org/images/Carers_UK_research_briefing_-_Under_Pressure_-_Caring_and_the_cost_of_living_crisis.pdf) [accessed 13 September 2022]

202 *Ibid.*, p 3

203 Written evidence from Carers Trust (ASC0097)



family carers are giving up their economic stability to provide support in the absence of any other care solution.<sup>204</sup>

139. We also heard that unpaid carers face significant health challenges, both physical and mental. They are more likely to be unwell, frail and at risk of vulnerability. One unpaid carer told us: “I can honestly say that I have been exhausted for 22 years. I have not slept for 22 years. I have not had a respite for 22 years.”<sup>205</sup> Research carried out by Carers UK based on unpaid carers’ responses to the 2021 GP Patient Survey confirm this: it found that 60% of carers report a long-term health condition or disability compared to 50% of non-carers.<sup>206</sup> Personal health is neglected as the focus is relentlessly on the daily need to provide care to a partner, friend or member of their family.<sup>207</sup> The Nuffield Trust also noted that the 1.3 million people who provided more than 50 hours a week of unpaid care during the pandemic face an impact on their health equivalent to the loss of 18 days in full health for every year spent caring.<sup>208</sup>
140. There are also impacts on mental health. CLOSER’s research noted that unpaid care is linked with lower levels of baseline and follow-up wellbeing measures.<sup>209</sup> A recent survey carried out by Carers UK found that 30% of carers said their mental health was bad or very bad; and 29% said they felt lonely often or always.<sup>210</sup> This is confirmed by unpaid carers who told us that they feel exhausted, isolated and emotionally unwell. One unpaid carer told us:

“I was helped by the psychiatrist, because they wrote to the system to say, “With the stresses and strains Mr Phillips is under, he is near-suicidal, so you either help him or he isn’t going to be around to help the person”. I literally was at my wits’ end. I did not know how to cope.”<sup>211</sup>

### *The inadequacy of support for unpaid carers*

141. Despite the importance of providing support to unpaid carers, and the scale of the financial, physical and emotional issues they face, there is little recognition or understanding of these challenges in wider society. Unpaid carers bear their own burden of invisibility: they described to us how they feel forgotten, alienated and left behind. One unpaid carer told us that they feel “pushed to the fringes of society” and “completely ignored”.<sup>212</sup> Unpaid carers, therefore, are at once taken for granted, and let down: there is an expectation that they will support the person they care for, but little recognition of the challenges they face, or their own expertise in caring. Ultimately, this was perceived by unpaid carers as a societal failure to value unpaid care, despite the significance of unpaid carers’ contribution. One unpaid carer challenged us by asking: “If we really deliver £132 billion to the economy through the

204 Written evidence from We Care Campaign ([ASC0032](#))

205 [Q 55](#) (Nadia Taylor)

206 Carers UK, *Carers’ health and experiences of primary care: Data from the 2021 GP Patient Survey* (February 2022) p 5: [https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy\\_file&id=7899](https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=7899) [accessed 13 September 2022]

207 Written evidence from the Richmond Group of Charities ([ASC0117](#))

208 Written evidence from Nuffield Trust ([ASC0104](#))

209 Written evidence from CLOSER, UCL Social Research Institute ([ASC0069](#))

210 Carers UK, *State of Caring 2022* (November 2022) p 33: [https://www.carersuk.org/images/Research/CUK\\_State\\_of\\_Caring\\_2022\\_report.pdf](https://www.carersuk.org/images/Research/CUK_State_of_Caring_2022_report.pdf) [accessed 8 November 2022]

211 [Q 40](#) (Norman Phillips)

212 [Q 56](#) (Nadia Taylor)

work we do, that saves every UK taxpayer about £900 a year in tax. Are you just going to abandon those people?”<sup>213</sup>

142. The physical and emotional challenges faced by unpaid carers can also be linked to the difficulty of accessing short breaks. Many witnesses told us that they have not been able to take a break from caring in many years, with one witness saying that she had not had a break or a day off in eight years.<sup>214</sup> Age UK highlighted that a very small proportion of carers are receiving breaks to help them cope. According to the organisation, only 1% of carers have needed and been able to access respite care or support (for 24 hours or more) in the three months up to March 2022.<sup>215</sup>
143. Evidence suggests that rather than getting more support, unpaid carers are now getting less. The Nuffield Trust identified what it calls an “erosion of support” in recent years: it found that the number of unpaid carers receiving direct support (payments, personal budgets, or support commissioned by councils) dropped by 13,000 between 2015 and 2021. Further analysis shows an 11% drop (19,000) in carers receiving respite care compared to five years ago.<sup>216</sup> For many unpaid carers, this shows that wider society is not interested in their hardships. We were asked: “When is the help coming? ... If you could deliver one thing for carers, it would be hope that things are going to get better and that the system is going to value us.”<sup>217</sup>

*Failing to connect with unpaid carers*

144. The isolation that marks the lives of unpaid carers and underpins invisibility is compounded by the fact that unpaid carers frequently appear to be out of sight or marginal to the health and care professionals also involved in providing support, who are often not aware of how much knowledge carers accrue in their caring roles. The unpaid carer is rarely considered an equal partner in care. At worst and in some cases, this can result in hostile relationships between unpaid carers and staff, with many unpaid carers saying that they are seen and treated as a problem. One unpaid carer wrote: “By professionals in the NHS we are not wanted at all. They see us as a nuisance... We know we are not listened to and not heard. We are kept out of ward rounds, meetings, denied paperwork, email addresses, phone calls.”<sup>218</sup> Another recounted that “An O.T. who visit you in your home, and dismisses the person who does the main caring and refers to them as the ‘the toenail cutter’ makes a carer feel small, undervalued”.<sup>219</sup>
145. Carers Trust described to us how unpaid carers are excluded at multiple points of the care pathway. They are not listened to or informed of important information that is required to support the person they provide care for.<sup>220</sup> This lack of consideration for unpaid carers can be tangible: one unpaid carer explained how, when their partner is in hospital, they felt as if they had “no rights”, with no dedicated spaces for them to sleep, eat, go to the toilet

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213 [Q 140](#) (Norman Phillips)

214 [Q 35](#) (Katy Styles)

215 Written evidence from Age UK ([ASC0119](#))

216 Written evidence from Nuffield Trust ([ASC0104](#))

217 [Q 141](#) (Norman Phillips)

218 Written evidence from PJ. Woolfall ([ASC0103](#))

219 Written evidence from Joy Ford ([ASC0017](#))

220 [Q 73](#) (Rohati Chapman)

or get a drink. “We are not seen as a true workforce, if you like, or partner providers for the NHS and social care,” they said.<sup>221</sup>

146. Discharge from hospital was frequently referred to as a key transitional point in which the failure of health and care staff to communicate and acknowledge the role of unpaid carers was particularly problematic, and often led to unsafe outcomes for the person coming out of hospital. One unpaid carer described how her older mother was once discharged and parked on the street in her wheelchair with the key dangling off the handle while she was away because staff were not insured to turn the key in the lock and enter the property. This was not information that was communicated to her prior to discharge. The witness said:

“Imagine a blind lady who is already very vulnerable and rather unwell for many other reasons, finding herself on the street with everybody coming and going past her, not really knowing where she is or why she is there, while I run after her, catching two buses... racing home to ensure that she is not left alone for too long after being dropped off.”<sup>222</sup>

*Navigating the social care system: a constant fight*

147. Whether it is trying to get support for themselves or for the person they provide care for, unpaid carers often find that they are left to their own devices when it comes to navigating the adult social care system. Explaining to us how she worked through possible options for financial or emotional support, one unpaid carer told us that “you have to mine that information yourself.”<sup>223</sup> Another witness noted that carers “burn up a lot of resource in the system asking questions.”<sup>224</sup> Dementia Carers Count pointed to the failure of services to signpost carers, saying that “all too familiar” experience shared by family carers is to find out support by chance, for example through a conversation with another family carer or a reference from someone at the dementia café.<sup>225</sup>
148. This is compounded by the fact that the social care system makes it very difficult for unpaid carers, both to identify support for themselves and to organise formal support for the person they care for. We were told that the social care system makes no sense, with one witness recounting that he was given 32 pamphlets in his local hospital after he introduced himself as a carer.<sup>226</sup> An unpaid carer described their frustration when trying to get more information about local adult social care services and finding that the process was left entirely up to her. “There must be many people who are overwhelmed by the *ad hoc* nature of adult social care and who find it almost impossible to navigate their way through the maze,” she wrote.<sup>227</sup>
149. In many cases, unpaid carers described the experience of accessing care and support for themselves and the person they provide care for as a constant fight. An unpaid carer to their daughter with learning disabilities wrote that, as the person dealing with all the relevant agencies since her daughter was born, she found that “at every stage to some extent there have been reels of

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221 [Q 136](#) (Katy Styles)

222 [Q 56](#) (Nadia Taylor)

223 [Q 37](#) (Katy Styles)

224 [Q 135](#) (Norman Phillips)

225 Written evidence from Dementia Carers Count ([ASC0095](#))

226 [Q 36](#) (Norman Phillips)

227 Written evidence from Nicola Pacult ([ASC0066](#))

red tape to negotiate, and authorities to battle with.”<sup>228</sup> One witness who has provided care to their daughter for 23 years described her relationship with social services as “battle after battle after battle”.<sup>229</sup> She explained that, instead of being able to rely on local authorities and social services providing her with the advice, information and support that she needs, it is up to her to do as much research as she can herself and build up her own knowledge so that she is prepared to confront services with requests for specific support.<sup>230</sup>

150. The relationship between unpaid carers and social services can be similar to the one described by older adults and disabled people: one in which trust has broken. Because of the difficulty of accessing care and support, social workers and local authorities are seen as gatekeepers, and there is very little trust in the system’s ability or willingness to provide any help. Some unpaid carers told us that they live in fear of assessments, which they see as a process that is designed to minimise their needs, so as to deny them any support. One witness recalled telling a social worker that she did not feel able to continue caring for her daughter without a break; the assessment came back describing her as “tired”.<sup>231</sup> The same witness described feeling undervalued and not listened to. “I always feel that I am lying. I always feel that they do not believe me, that I am making it up or that I am somehow exaggerating it.”<sup>232</sup>
151. Unpaid carers also share a fear of seeing services being taken away from them. One witness explained:

“At the moment, I am sitting on top of a funnel and I see all these other poor souls drowning, having their services taken away because the system cannot afford it. Every day, I live in fear that the water will come up to my feet, and then what will I do for my wife?”<sup>233</sup>

### **What happens if nothing changes? The risks of failing to reform**

152. From all sides we have heard how adult social care is failing the people that it serves, despite the hard work and best intentions of people working in the sector. At the same time, the political will to tackle the scale of the problem and to significantly transform the system seems to be missing. Yet the risks of failing to reform are great.
153. As outlined in Chapter 2, from a demographic perspective, demand for adult social care is only set to grow. There is a continuing trend towards more people living longer with multiple long-term conditions.<sup>234</sup> Current trends also point towards an increase in the prevalence of disability among working age adults. In 2020/21, 21% of working age adults reported a disability, compared to 15% in 2010/11.<sup>235</sup> Given the current pressures and shortcomings of the system, reform is therefore critical. As Professor Donna Hall, formerly CEO of Wigan Council, told us: “The biggest risk we face in

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228 Written evidence from Lyn Deakin ([ASC0036](#))

229 [Q 36](#) (Helen Spalding)

230 *Ibid.*

231 [Q 36](#) (Helen Spalding)

232 *Ibid.*

233 [Q 44](#) (Norman Phillips)

234 Written evidence from CLOSER, UCL Social Research Institute ([ASC0069](#))

235 Department for Works and Pensions, ‘Family Resources Survey: financial year 2020 to 2021’ (31 March 2022): <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021> [accessed 30 September 2022]

social care is not to change the way we do things, because the whole service will fall. Things will collapse.”<sup>236</sup>

154. Ensuring the sustainability of the sector is also critical to protect the NHS. Without a sustainable social care system to which patients can be safely discharged, NHS backlogs will only grow, and pressures on the overall system will intensify. Almost three-quarters (73%) of healthcare leaders say that a lack of adequate social care capacity has a significant impact on their ability to tackle the elective care backlog.<sup>237</sup> For example, the failure to find suitable community placements is one of the reasons that patients stay in hospital for years.<sup>238</sup> NHS statistics for July 2022 show that only four in 10 patients were able to leave hospital when they were ready to.<sup>239</sup> As Mr Hunt made clear: “The reforms everyone wants for the NHS will fall over unless we address the issues in social care”.<sup>240</sup>
155. **Creating a sustainable social care system in which people, their families and friends can thrive is a national imperative. Investment is cost effective both in economic and social terms, as a sustainable adult social care service is an indispensable partner to the health service.**

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236 [Q 87](#) (Professor Donna Hall)

237 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 21: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

238 *Ibid.*, p 65

239 *Ibid.*, p 21

240 [Q 16](#) (Jeremy Hunt MP)

## CHAPTER 4: “THE GREATEST RISK IS NOT TO CHANGE”: PRINCIPLES AND POSSIBILITIES

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156. Our inquiry focused on the invisibility of adult social care particularly as it relates to unpaid carers and those they provide care for. Having listened to our witnesses, we have come to the conclusion that without radical and long-term changes in the adult social care service as a whole, changes to the lives of unpaid carers can only be marginal, and the short-term and urgent changes that are needed to alleviate immediate pressures on them will be partial and unsustainable.
157. This chapter sets out the broader changes that we think are needed. We must rethink how we, as a society, appreciate the role of adult social care and of those who provide care today, and are expected to provide it tomorrow. We acknowledge the uniquely challenging funding landscape for adult social care, which has to be addressed; and we make clear that the proper resourcing of adult social care should be a national imperative, particularly to retain and enhance the status and skills of the paid care workforce.
158. In terms of immediate possibilities, however, we believe that while adult social care must be designed and delivered locally, action is long overdue to raise the national profile, infrastructure and accountability for the service. This should focus on advocacy as well as bringing challenge and status to adult social care, which will give greater voice as well as visibility to the sector.
159. We do not believe that new legislation is necessary. Existing laws must be enforced and must achieve their intent. Many solutions can be found in the Care Act 2014, which has not been appropriately implemented. The legislation should urgently be implemented, along with its guidance.
160. Finally, we look at the potential of more recent legislation, Integrated Care Systems (ICSs) and what must be done to ensure that adult social care optimises the new opportunities to raise its profile and move towards greater reengagement of those who draw on and provide care and support.

### Changing the lens

161. Without fundamentally changing our appreciation of the role of adult social care as a critical service for people and communities, and as a key investment in our society and economy, any attempt to reform the sector will falter.
162. The first challenge in achieving such a significant cultural shift is to reassert the full purpose of adult social care. We put this question to witnesses and respondents, who frequently pointed to the vision of social care that was developed by the social movement Social Care Future to make possible the rightful ambition of people who “all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”<sup>241</sup> We endorse this definition, which celebrates the potential role of adult social care and reflects the ambitions, the values and the contribution of people who use adult social care services. We believe that it should steer the basis of any reform.

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241 Social Care Future, ‘A vision for the future of social care’: <https://socialcarefuture.blog/2021/04/29/a-vision-for-the-future-of-social-care/> [accessed 15 September 2022]



163. To achieve this, the national discourse will have to change. As one witness put it: “We have to stop thinking about going to social care as a disaster. Social care is an enabler.”<sup>242</sup>
164. To create an enabling service means developing all the means available for people to have greater choice and control over their lives. In turn, that means deciding for themselves the kind of relationship they want to have with the people around them, whether that is family and friends, or a personal assistant to support them. While such choices do exist in principle, they are often not exercised in practice. In summary, we are looking for greater resources to enable a focus on the diverse needs of working age disabled people and older people. This will also be a first step towards developing the full range of support and opportunities for the unpaid carers now facing increasing pressure as the paid workforce declines.
165. Several changes are necessary if this is to happen. The Government must step up to the challenge of funding adult social care to attract more people into the sector and to promote their skills. Second, there is a need for more robust infrastructure, which will provide greater advocacy and agency for adult social care. The implementation—or lack of—of the Care Act 2014 must also be addressed.
166. **We endorse Social Care Future’s definition of the purpose of social care: to make possible the rightful ambition of people who “all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”**<sup>243</sup>

### **Facing reality: funding and workforce**

#### *An appropriate funding settlement for adult social care*

167. Adult social care and the budgets of local authorities for its delivery have been chronically under-funded for many years—both a cause and a consequence of the lack of attention paid to the sector. For example, while the total budget for publicly funded adult social care in 2022/23 is £17.1 billion,<sup>244</sup> the commissioning budget for the NHS for the same year is £153 billion.<sup>245</sup> This is despite the fact that the adult social care workforce is larger than that of the NHS.<sup>246</sup>
168. Mr Hunt told us: “The biggest gap at the moment is in local authority funding.”<sup>247</sup> The LGA in turn confirmed that the origins of the current challenges in the system can largely be traced to the pressures created by years of underfunding, together with significant increases in costs.<sup>248</sup> We have

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242 [Q 142](#) (Tricia Nicoll)

243 Social Care Future, ‘A vision for the future of social care’: <https://socialcarefuture.blog/2021/04/29/a-vision-for-the-future-of-social-care/> [accessed 15 September 2022]

244 Association of Directors of Adult Social Services, *Spring Budget Survey 2022* (19 July 2022), p 9: <https://www.adass.org.uk/media/9369/adass-spring-budget-survey-2022-pdf-final-no-embargo.pdf> [accessed 30 September 2022]

245 NHS England, *Our 2022/23 business plan* (July 2022) p 21: [https://www.england.nhs.uk/wp-content/uploads/2022/08/B1733\\_Our-2022-23-Business-Plan\\_July-2022.pdf](https://www.england.nhs.uk/wp-content/uploads/2022/08/B1733_Our-2022-23-Business-Plan_July-2022.pdf) [accessed 16 September 2022]

246 House of Commons Library, *Adult social care workforce in England*, [Research Briefing 9615](#), 5 September 2022

247 [Q 13](#) (Jeremy Hunt MP)

248 [Q 165](#) (David Fothergill)

already discussed in previous chapters the impact that this is having on the erosion of basic services, and in turn on fundamental human relationships.

169. It is difficult to estimate the scale of the funding gap, because there is no national government budget for adult social care in England. Services are instead financed through local government revenue. According to the National Audit Office, government funding for local authorities has fallen by 55% in 2019/20 compared to 2010/11, which resulted in a 29% real-terms reduction in local government spending power.<sup>249</sup> Given that spending on adult social care constitutes a significant proportion of local authority spending, this has had important implications for the delivery of services. Estimates show that spending per person on adult social care services has fallen in real terms by around 12% between 2010/11 and 2018/19 in England.<sup>250</sup>
170. At the same time, the cost of adult social care is increasing as demand for services grows, aggravated by inflation and pay pressures, which will contribute to increasing the cost of care services for local authorities in the next few years.<sup>251</sup> London Councils provided us with a picture of the challenges faced by local authorities in the capital, where the boroughs’ core spending power has fallen by almost a quarter in the decade since 2010, while the population grew by approximately 12% in the same period.<sup>252</sup>
171. The consequences of the funding gap in adult social care mean that there are increasing levels of unmet need. One expert by experience described to us the “excessive” amount of money he has had to contribute to his care costs, and how this pushes many disabled people into poverty. “It is causing a lot of mental anguish and mental health problems. Even if it was not, it would still be morally wrong,” he told us.<sup>253</sup> The Association of Directors of Adult Social Care told us that as of March 2022, toward the end of the most difficult winter most Directors of Adult Social Services had experienced, a third of councils (33%) were asking carers to provide more support to replace a reduction in commissioned support, for example by taking paid or unpaid time off work.<sup>254</sup>
172. Faced with limited resources, local authorities have no choice but to reduce access to services, or to ration what is available to basic eligibility and very basic needs. We heard of councils where cuts to budgets are causing immense challenges to the delivery of adult social care to those who most needed it. Up to 97% of directors of adult social services across England recently reported feeling “pessimistic” or “very pessimistic” about the financial state of the wider health and social care economy in their local areas over the next 12 months.<sup>255</sup> In that context, adopting an approach to social care that goes beyond statutory duties can be extremely challenging.<sup>256</sup> Additionally,

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249 National Audit Office, *The adult social care market in England* (March 2021) p 6: <https://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf> [accessed 16 September 2022]

250 Health and Social Care Committee, *Social care: funding and workforce* (Third Report, Session 2019–21, HC 206)

251 Written evidence from the Local Government Association (ASC0042)

252 Written evidence from London Councils (ASC0131)

253 Q 148 (Andy McCabe)

254 Written evidence from ADASS (Association of Directors of Adult Social Services) (ASC0135)

255 Association of Directors of Adult Social Services, *Autumn Survey Report 2022* (November 2022) p 14: [https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS\\_Autumn\\_Survey\\_Report\\_Publication\\_15\\_November\\_2022.pdf](https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS_Autumn_Survey_Report_Publication_15_November_2022.pdf) [accessed 17 November 2022]

256 Q 92 (Les Billingham)

cuts in other areas of local authority spend often mean that the wider web of support that people draw on is reduced, too, which increases the pressure on social care.

173. The extent of the crisis has been in part recognised by the Health and Social Care Levy Act 2021,<sup>257</sup> which is now repealed but was originally intended to introduce an additional £12 billion per year for health and social care on average over the next three years, amounting to an additional £36 billion by 2024/25. Of this, £5.4 billion would have been dedicated to the adult social care system over three years.<sup>258</sup> The majority (£3.6 billion) would have been spent on capping care costs to an £86,000 limit and extending means testing, and to help local authorities pay a fair cost for care, from October 2023. Another £1.7 billion was set aside for transforming adult social care services across England.<sup>259</sup> The breakdown of this £1.7 billion investment was outlined in the Government White Paper in December 2021.<sup>260</sup>

### Box 3: Government investment in adult social care

The £1.7 billion investment was broken down as follows:

- £500 million to enable the social care workforce to have the right training and qualifications, and feel more recognised and valued;
- £300 million to integrate housing into local health and care strategies;
- £150 million to drive greater adoption of technology and to digitise the social care sector;
- £25 million to provide better support to unpaid carers;
- £30 million to help local areas innovate around the support and care they provide in new and different ways;
- £5 million to pilot new ways to help people understand and access the care and support available; and
- £70 million to increase the support offer across social care to improve the delivery of care and support services.

While figures do not add up to £1.7 billion, we were informed by civil servants that this was deliberately designed to allow for some flexibility.

Source: Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

174. Most stakeholders agree that these funding reforms would have been insufficient, both to ensure the sustainability of the adult social care sector

257 [Health and Social Care Levy Act 2021](#)

258 HM Government, *Build Back Better: Our Plan for Health and Social Care*, CP 506, September 2021, p 16: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1015736/Build\\_Back\\_Better\\_-\\_Our\\_Plan\\_for\\_Health\\_and\\_Social\\_Care.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1015736/Build_Back_Better_-_Our_Plan_for_Health_and_Social_Care.pdf) [accessed 26 September 2022]

259 Department of Health and Social Care, ‘Health and Social Care Levy to raise billions for NHS and social care’ (April 2022): <https://www.gov.uk/government/news/health-and-social-care-levy-to-raise-billions-for-nhs-and-social-care> [accessed 30 September 2022]

260 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

and to successfully improve the quality of services. The Health Foundation, for example, told us that “significant additional investment and more fundamental reforms” are needed to provide care to everyone who needs it.<sup>261</sup> Similarly, we were told that the additional funding would be insufficient to carry out the transformative reforms that the Government laid out in the White Paper. The LGA wrote that although the Government’s ambitions to transform the outcomes of care should be supported, they were “increasingly concerned that the amount of funding Government has earmarked for them is insufficient.”<sup>262</sup> As one witness put it to us: “There is a mismatch coming down the line between the vision of what people should be able to do and the funding that sits alongside it.”<sup>263</sup>

175. Instead of increasing the funding settlement for adult social care, however, the Government has repealed the Health and Social Care Levy Act,<sup>264</sup> as well as some of its funding and reform pledges. The Chancellor, Mr Hunt, committed in the latest Autumn Statement to increasing the funding for healthcare and adult social care by only £8 billion in 2024/25.<sup>265</sup> This includes £4.7 billion dedicated to adult social care, which is to be funded by new grant funding, further flexibility for local authorities on council tax and crucially, delaying the rollout of adult social care charging reform, which would have implemented the £86,000 cap on care costs, to October 2025.<sup>266</sup>
176. There is limited information on the exact nature and objectives of the additional funding. The Government has said that:
- £1 billion will be distributed between now and 2024/25 through the Better Care Fund to facilitate discharge from hospital;
  - £1.9 billion will be distributed between now and 2024/25 to local authorities through the Social Care Grant for adult and children’s social care; and
  - £680 million will be distributed between now and 2024/25 through a grant ringfenced for adult social care, which will also support discharge.

No announcements were made concerning funding for the reforms set out in the 2021 White Paper.<sup>267</sup>

177. The lack of certainty that has surrounded future funding for adult social care in the past years is a significant impediment to any meaningful change. The Association of Directors of Adult Social Services wrote that recent political

261 Written evidence from the Health Foundation ([ASC0020](#))

262 Written evidence from the Local Government Association ([ASC0042](#))

263 [Q 15](#) (Vic Rayner)

264 [Health and Social Care Levy \(Repeal\) Act 2022](#)

265 HM Treasury, *Autumn Statement 2022*, CP 751, November 2022, p 26: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1118417/CCS1022065440-001\\_SECURE\\_HMT\\_Autumn\\_Statement\\_November\\_2022\\_Web\\_accessible\\_1.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1.pdf) [accessed 21 November 2022]

266 *Ibid.*

267 HM Treasury, *Autumn Statement 2022*, CP 751, November 2022, p 26: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1118417/CCS1022065440-001\\_SECURE\\_HMT\\_Autumn\\_Statement\\_November\\_2022\\_Web\\_accessible\\_1.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1118417/CCS1022065440-001_SECURE_HMT_Autumn_Statement_November_2022_Web_accessible_1.pdf) [accessed 21 November 2022]

and financial uncertainty has left people needing and working in adult social care “in limbo” and with “no plan” at a time of “intense challenges”.<sup>268</sup>

178. Even more importantly, we believe that the current share of Government investment that is dedicated to the sector falls short of what is required to tackle major challenges that are facing services, and in turn failing people and families. The King’s Fund wrote that while the additional funding indicates that the Government recognises the “perilous” state of the sector, “increases to the national living wage, hikes in energy prices and ongoing inflationary pressures will all add to social care providers costs.” This means that it is unclear where the proposals leave local authorities’ finances in real terms.<sup>269</sup>
179. In 2020, the House of Commons Health and Social Care Committee, then chaired by Mr Hunt, recommended as a starting point that social care funding must increase to reach an additional £7 billion in annual funding by 2023/24, compared to 2020/21.<sup>270</sup> Sir Andrew Dilnot similarly recommended that the next Spending Review sets out an increase of at least £2 billion every year for three years, to reach a total £6 billion increase in annual funding. He argued that it is critical that any amount is phased over several years. “Local authorities need reasonable certainty about what they can do,” said Sir Andrew Dilnot; this is not possible if “an extra dollop of money” is allocated at random every year.<sup>271</sup>
180. ***The Government must increase the financial settlement for adult social care over three years and then commit to sustain realistic, long-term and protected funding for the sector to enable robust planning. Funding requirements over and above what has already been committed should be assessed on the best estimates from independent experts and agencies.***

*Investing in skills: “we have a massive problem”*

181. The other outstanding issue that is directly related to funding is the lack of paid care workers, which also creates increasing expectations of unpaid carers. Extremely low wages, inflation and the increase in energy and housing costs have created a perfect storm, making it extremely difficult to retain care workers. A recent survey of directors of adult social care services showed 94% of respondents disagreeing that the workforce in their local area will be sufficient to manage over the next few months, making workforce the area that directors are most concerned about.<sup>272</sup> We were told by Laura Gaudion, the director of adult social care and housing needs at the Isle of Wight Council, that: “Yes, cost will always be a pressure; yes, funding will

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268 Association of Directors of Adult Social Services, *Autumn Survey Report 2022* (November 2022) p 7: [https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS\\_Autumn\\_Survey\\_Report\\_Publication\\_15\\_November\\_2022.pdf](https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS_Autumn_Survey_Report_Publication_15_November_2022.pdf) [accessed 17 November 2022]

269 The King’s Fund, Press Release: *The King’s Fund responds to the Autumn Statement* on 17 November 2022: <https://www.kingsfund.org.uk/press/press-releases/kings-fund-responds-government-autumn-statement> [accessed 17 November 2022]

270 Health and Social Care Committee, *Social care: funding and workforce* (Third Report, Session 2019–21, HC 206) p 37

271 **Q 178** (Sir Andrew Dilnot)

272 Association of Directors of Adult Social Services, *Autumn Survey Report 2022* (November 2022) p 4: [https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS\\_Autumn\\_Survey\\_Report\\_Publication\\_15\\_November\\_2022.pdf](https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS_Autumn_Survey_Report_Publication_15_November_2022.pdf) [accessed 17 November 2022]



always be an issue; but for me, workforce trumps all that.”<sup>273</sup> She argued that, with the right workforce, equipped with the right skills, motivated by the prospect of supporting people to lead fulfilling lives and paid a fair wage recognising those skills, the outcomes of adult social care will radically improve.

182. The barriers that are holding back the workforce in adult social care are both skills shortages and retention. The current figures, released by Skills for Care show that as of October 2022, there were 165,000 vacant posts in the adult social care sector; an increase of 52% in one year, from what was already the highest rate on record.<sup>274</sup> The average vacancy rate across the sector stands at 10.7%, which is more than twice the average in the wider economy.<sup>275</sup> This deterioration can be explained in part by the COVID-19 pandemic. Monthly data submitted to the CQC by providers of residential care, for instance, show that care home staff vacancy rates have almost doubled from 6% at the end of April 2021, to 11.5% at the end of December 2021, and have since not improved.<sup>276</sup>
183. The CQC told us that “urgent action is needed to tackle staffing pressures and the stresses caused by staff shortages.”<sup>277</sup> The high number of vacancies goes together with a turnover rate of 34.8%—compared to 25.5% in April 2021.<sup>278</sup> Existing estimates of future workforce needs in the sector anticipate that an additional 490,000 people will be needed working in adult social care by 2035; leading the All-Party Parliamentary Group on Adult Social Care to conclude that “we have a massive problem.”<sup>279</sup>
184. In addition to creating higher demand for staff, the COVID-19 pandemic has born down heavily on the mental and physical health of the existing workforce, and was described by the Trades Union Congress (TUC) as “traumatic.”<sup>280</sup> A survey of more than 1,200 care workers carried out between December 2020 and January 2021 identified significant negative mental health impacts on care workers: 75% said that their work during the COVID-19 pandemic had a serious negative impact on their mental health. The TUC added that the negative impacts of the pandemic on care services and workers have continued throughout 2021.<sup>281</sup> Levels of staff sickness nearly doubled over the course of the pandemic, with an average of 9.5 days lost to sickness in 2020/21 compared to 5.1 days before the pandemic.<sup>282</sup> 97% of social care workers surveyed in late 2021 reported that their employers were experiencing workforce shortages, with burnout, overwork and low pay

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273 Q 171 (Laura Gaudion)

274 Skills for Care, *The state of the adult social care sector and workforce in England* (October 2022) p 11: <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2022.pdf> [accessed 11 October 2022]

275 *Ibid.*, p 13

276 Written evidence from the Care Quality Commission (ASC0019)

277 *Ibid.*

278 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 87: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

279 Q 19 (Vic Rayner)

280 Written evidence from the Trades Union Congress (ASC0040)

281 *Ibid.*

282 Written evidence from Skills for Care (ASC0068)



cited as the main causes.<sup>283</sup> All of this has contributed, we were told, to social care staff being at a high risk of burnout.<sup>284</sup>

185. Low pay and sometimes challenging working conditions also contribute to the difficulty of recruiting and retaining care staff. In a snap poll of providers conducted by the CQC in August 2022, many cited pay as having an impact on recruitment and retention of staff.<sup>285</sup> Analysis by the Health Foundation found that in 2019/20 in England, the full-time equivalent mean annual pay rate for staff providing direct care in independent residential care settings was £16,800, compared with £30,400 for all full-time jobs in the UK.<sup>286</sup> The analysis concluded that residential care workers are overall more likely to live in poverty than the average worker, and twice as likely to experience food insecurity.<sup>287</sup> This is made even starker in the context of the cost of living crisis: for example, the higher cost of petrol and diesel is particularly detrimental to homecare staff who rely on a car to get them to visits. Up to 90% of directors of adult social care services agree that there has been an increase in the number of people leaving the social care workforce in their local area as a result of the cost of living crisis.<sup>288</sup>
186. Better funding can partly address issues related to low pay. Nine out of 10 directors of adult social services indicated in a recent survey that the action that would have the largest impact from a workforce perspective would be to increase funding sufficiently to enable pay parity between social care roles and NHS roles, as well as other labour market competition.<sup>289</sup>
187. Adult social care is rarely celebrated as a rewarding and fulfilling career. We were frequently told that adult social care lacks clearly defined career pathways and gateways into more senior roles.<sup>290</sup> Significantly, there is no professional recognition or certification of skills acquired in many adult social care roles.<sup>291</sup> All these factors act as a deterrent.
188. The shortage of social care professionals directly impacts the amount of unmet and under-met needs. According to the CQC, in the first three months of 2022, 2.2 million hours of homecare could not be delivered due to insufficient workforce capacity. The figure is seven times greater than it was in spring 2021 and represents an average of 170,000 hours of homecare not being delivered each week.<sup>292</sup> The CQC spoke of a “social care workforce crisis,” a view shared by 99% of NHS leaders.<sup>293</sup>

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283 Written evidence from the Trades Union Congress (ASC0040)

284 Written evidence from Skills for Care (ASC0068)

285 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 88: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

286 The Health Foundation, *The cost of caring: poverty and deprivation among residential care workers in the UK* (October 2022) p 8: <https://www.health.org.uk/sites/default/files/pdf/2022-10/2022%20-%20The%20cost%20of%20caring.pdf> [accessed 11 October 2022]

287 *Ibid.*, p 9

288 Association of Directors of Adult Social Services, *Autumn Survey Report 2022* (November 2022) p 8: [https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS\\_Autumn\\_Survey\\_Report\\_Publication\\_15\\_November\\_2022.pdf](https://mcusercontent.com/83b2aa68490f97e9418043993/files/0c1fb681-8955-aab3-9c2f-f9a3979ea32c/ADASS_Autumn_Survey_Report_Publication_15_November_2022.pdf) [accessed 17 November 2022]

289 *Ibid.*, p 10

290 Written evidence from Sense (ASC0091)

291 Written evidence from Dimensions (ASC0098)

292 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 35: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

293 *Ibid.*, p 85

189. The Government has acknowledged that reforming the workforce in adult social care is a priority. In the 2021 ‘Build Back Better’ plan, they proposed to make care a more rewarding vocation by offering a career where people could develop new skills.<sup>294</sup> The December 2021 White Paper set out that at least £500 million would be spent on ensuring the social care workforce has the right training and qualifications.<sup>295</sup> This included creating a Knowledge and Skills Framework (KSF) to articulate the knowledge and skills required for roles within the sector and set out clear pathways for career progression. The White Paper also mentioned new budgets for continuous professional development, training routes, and a new digital hub for the workforce to access support and advice.<sup>296</sup> We were told by Gillian Keegan MP, then Minister of State for Care at the Department of Health and Social Care (2021-2022), that the Government is concerned with attracting many more people to working in social care, and that “the reforms will make a massive difference to the visibility and the profile of the role.”<sup>297</sup> The 2022 Autumn Statement, however, has made it unclear whether these reforms will be brought to life in the next few years.
190. What is certain is that nothing strategic can be achieved without an equivalent to the NHS ‘People Plan’,<sup>298</sup> which sets out its workforce strategy and is key to delivering its objectives over the next 10 years. England stands alone in not having developed a similar workforce plan for adult social care. The Scottish Government recently published a five-year ‘Health and social care national workforce strategy’ backed by £1 billion.<sup>299</sup> The Welsh Government’s 10-year workforce strategy for health and social care was published in 2020.<sup>300</sup> Many witnesses pointed to the need for a long-term national workforce plan to meet immediate and future needs, and to address the factors that make adult social care an increasingly unattractive proposition: low pay, difficult working conditions, lack of career structure and lack of status.
191. This requires more than increasing the pool of workers to reduce shortages. It is also necessary to understand what kind of workers will be needed in which roles. The CQC, for example, states that to maintain and develop the workforce, and to plan for the future, it is necessary to review workforce needs

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294 HM Government, *Build Back Better: Our Plan for Health and Social Care*, CP 506, September 2021, p 19: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1015736/Build\\_Back\\_Better-Our\\_Plan\\_for\\_Health\\_and\\_Social\\_Care.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1015736/Build_Back_Better-Our_Plan_for_Health_and_Social_Care.pdf) [accessed 26 September 2022]

295 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 8: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

296 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 68: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

297 Q 149 (Gillian Keegan MP)

298 NHS England, *We Are the NHS: People Plan 2020/21: action for us all* (July 2020): <https://www.england.nhs.uk/wp-content/uploads/2020/07/We-Are-The-NHS-Action-For-All-Of-Us-FINAL-March-21.pdf> [accessed 30 September 2022]

299 Scottish Government Cabinet Secretary for Health and Social Care, *Health and social care national workforce strategy* (March 2022): <https://www.gov.scot/publications/national-workforce-strategy-health-social-care/pages/6/> [accessed 30 September 2022]

300 Health Education and Improvement Wales, *Social Care Wales, A Healthier Wales: Our Workforce Strategy for Health and Social Care* (October 2020): <https://heiw.nhs.wales/files/workforce-strategy/> [accessed 30 September 2022]

for the longer term, including skills sets.<sup>301</sup> For example, in an independent report, Lady Cavendish explains that it is clear that an ageing population will need a different skills mix as demand for geriatricians, community and district nurses will increase.<sup>302</sup> It is necessary, therefore, to anticipate and plan for these new demands. This can only be achieved in partnership with people who have lived experience of the social care system. It is key, therefore, that any workforce strategy is drawn together with people who draw on and work in adult social care.

192. ***The Government must prioritise, with people who work and draw on adult social care, a comprehensive long-term national workforce and skills plan for adult social care, including a commitment to remedy low pay in the sector.***

### **Creating a national identity for adult social care**

193. While the fundamental weaknesses of adult social care policy and provision demand priority, they will take time to put right. It is possible, however, to immediately strengthen the voice and identity of the sector, with the objective of creating more energy and advocacy for change.
194. The NHS has “one employer, national terms and conditions for all staff, and a plethora of esteemed institutions including Royal Colleges”.<sup>303</sup> This creates a sense of identity, pride and belonging to the NHS, which the Future Social Care Coalition presented in stark contrast to the situation in adult social care.<sup>304</sup> We discussed in previous chapters how the development of a local and diverse market in adult social care has meant that the sector has never had a unified national focus or profile. There is not one national representative body that acts as a point of reference, advocacy and appeal. There is no way and no one who can speak for the sector, celebrate its purpose and success, or challenge the Government to do better.
195. As the National Care, Support and Independent Living Service (NaCSILS) told us, without one central visible entity, it is difficult to address most social care concerns.<sup>305</sup> Without a unified, central entity, it is more challenging to have a cohesive and organised response to the issues facing the sector, or to hold local providers accountable. Improvements tend to be on a local scale, rather than consistent across the country.
196. In Scotland, this is a challenge that is being addressed by the establishment of a National Care Service. The National Care Service (Scotland) Bill<sup>306</sup> was introduced to the Scottish Parliament in June 2022 and the Scottish Government has committed to creating a functioning National Care Service by the end of this parliamentary term in 2026. With the Bill, the Scottish Government is hoping to ensure that care services are offered in the same way and at the same standard throughout Scotland; and one witness told us

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301 Care Quality Commission, *The state of health and adult social care in England: 2021/22*, HC 724 (October 2022) p 99: [https://www.cqc.org.uk/sites/default/files/2022-10/20221024\\_stateofcare2122\\_print.pdf](https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf) [accessed 26 October 2022]

302 Baroness Cavendish of Little Venice, *Social care: Independent report by Baroness Cavendish* (February 2022) p 37: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf) [accessed 22 November 2022]

303 Written evidence from Future Social Care Coalition ([ASC0123](#))

304 *Ibid.*

305 Written evidence from National Care, Support and Independent Living Service ([ASC0114](#))

306 [National Service \(Scotland\) Bill 2022](#)

that they were confident that the new service will “drive up quality in social care.”<sup>307</sup>

#### Box 4: The Scottish National Care Service

The National Care Service (Scotland) Bill establishes Scotland’s National Care Service. It was introduced by the Scottish Government to improve the quality of social care and social work, and to ensure that people can receive high-quality care services regardless of where they live.

The Bill is rooted in a series of principles:

- The services provided by the National Care Service are an investment in society that is essential to the realisation of human rights, enables people to thrive and fulfil their potential, and enables communities to flourish and prosper.
- The services provided by the National Care Service must be financially stable in order to give people long-term security.
- The services provided by the National Care Service are to be centred around early interventions that are preventative in nature.
- Services provided by the National Care Service are to be designed collaboratively with the people to whom they are provided and their carers.
- Opportunities should be sought to improve the services provided by the National Care Service in ways which promote the dignity of the individual and advance equality and non-discrimination.
- The National Care Service, and those providing services on its behalf, are to communicate with people in an inclusive way.
- The National Care Service is to ensure that the people working for it are recognised and valued for the important work that they do.

Source: *National Care Service (Scotland) Bill*, [clause 1](#)

197. We are not convinced that establishing a National Care Service in England is the most appropriate response to solve the challenges facing adult social care. The local nature, local delivery, local demographics and the local market are key to services, which must meet different situations and needs. Different solutions must be found and one design would not fit all.

198. However, what is missing is a robust, realistic and coherent plan of action. We were frequently told, for example, that adult social care lacks a suitable national long-term plan, which could help bring a cohesive response to the challenges faced by the sector, while raising the profile and voice of adult social care. The Government’s December 2021 White Paper set out a 10-year “vision” for adult social care;<sup>308</sup> but stakeholders agreed that this falls short of a “proper” plan. Mr Hunt, for example, told us:

“You can find words where the Government have claimed they have a 10-year plan for social care. However, I do not really see one. I see

307 [Q 105](#) (Theresa Shearer)

308 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 30 September 2022]

plans for the short and medium term, not a really big vision answering questions such as whether we want to keep building more care homes.”<sup>309</sup>

We were told that the White Paper is “a starting point with very much more detail needed to try and operationalise that vision.”<sup>310</sup> For example, the Government’s recent funding announcements have not clearly established that there will be any investment dedicated to the White Paper’s proposals in the next three years.

199. This is again in contrast to the NHS, which in 2019 published a ‘Long-Term Plan’.<sup>311</sup> Although not a panacea, this was described as “enormously beneficial” by Mr Hunt, who argued that it enabled the sector to unite behind a common overarching vision.<sup>312</sup> The Governments of Scotland and Wales have each published a plan for health and social care.<sup>313</sup> On the other hand, in England, one witness described to us that “there is a sense that there is no plan, no north star, and no real clarity about where we want to get to in 10 years and what steps we need to take to get there.”<sup>314</sup>
200. A national plan for adult social care would be bound not only to encompass a comprehensive workforce strategy, but also a national strategy for unpaid carers, the lack of which was described to us as “absolutely appalling”. “We need leadership from Government on this from No 10 downwards,” wrote the We Care Campaign,<sup>315</sup> to ensure that it is heard from senior leaders and resonates nationally.<sup>316</sup>
201. *The Government must put in place, with people who work in and draw on adult social care, a national long-term plan for adult social care, exemplifying the vision set out by Social Care Future—“we all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.” This should include a National Carers Strategy.*

*Raising a banner for adult social care*

202. Raising the profile of adult social care also means enabling a national conversation about what affects us all as an ageing society—what the role of adult social care is and can become. As discussed in Chapter 3, stigma and discrimination against older adults and disabled people must be challenged, just as the entitlement to choice and control at every stage of life needs to be normalised.
203. While a stronger and more resilient care sector is needed at the local level, we also believe that some new and effective national leadership that focuses attention on adult social care is urgently needed. This would stand above

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309 [Q 16](#) (Jeremy Hunt MP)

310 [Q 18](#) (Vicky Davis)

311 NHS England, *The NHS Long Term Plan* (January 2019): <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> [accessed 30 September 2022]

312 [Q 16](#) (Jeremy Hunt MP)

313 Scottish Government, *Health and Social Care Delivery Plan* (December 2016): <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2016/12/health-social-care-delivery-plan/documents/00511950-pdf/00511950-pdf/govscot%3Adocument/00511950.pdf> [accessed 30 September 2022] and Welsh Government, *A Healthier Wales: our plan for Health and Social Care* (June 2018): <https://gov.wales/sites/default/files/publications/2021-09/a-healthier-wales-our-plan-for-health-and-social-care.pdf> [accessed 30 September 2022]

314 [Q 17](#) (Dr Anna Dixon)

315 Written evidence from the We Care Campaign ([ASC0032](#))

316 [Q 44](#) (Katy Styles)



the local and national discourse to represent the real lives, real needs and ambitions of those who value and use care services. With a louder voice and visibility, it could make the case for action and change.

204. Many stakeholders felt that the Government needed to lead on changing public attitudes by “challenging and changing the narrative through legislation and other approaches.”<sup>317</sup> We were told by experts by experience that a representative for the sector at the highest levels of Government is missing, with one unpaid carer saying: “There is no one entity or one person looking after carers. A Carers’ Champion would be brilliant, to hold other people to account.”<sup>318</sup>
205. The NHS has, within Government itself, the role of a Chief Executive, which is currently held by Amanda Pritchard and previously by Sir Simon Stevens, and which has been seen to be “very significant” in recent years.<sup>319</sup> The fragmentary and local delivery of funding and services in adult social care does not lend itself to such an equivalent. But accountability can be delivered through visibility and voice, by having a champion for the social care sector, described to us by Sir Andrew Dilnot as “a single person whose job it is to think or worry about social care and do that publicly.”<sup>320</sup> One effective way of doing so would be to establish a Commissioner for Care and Support, tasked with acting as an effective champion and upholding the rights of disabled adults and older people, as well as unpaid carers. The Commissioner would also embed more accountability and challenge in the system.
206. Such a model already exists for older people in Wales, in the form of the Older People’s Commissioner for Wales, tasked with promoting and protecting the rights of people aged 60 and over. To achieve this, the Older People’s Commissioner was given specific functions and powers in the Commissioner for Older People (Wales) Act 2006.<sup>321</sup> They consist of:
- promoting awareness of the interests of older people in Wales and of the need to safeguard those interests;
  - promoting the provision of opportunities for, and the elimination of discrimination against, older people in Wales;
  - encouraging best practice in the treatment of older people in Wales; and
  - keeping under review the adequacy and effectiveness of law affecting the interests of older people in Wales.<sup>322</sup>
207. In practice, this means that the Commissioner scrutinises and reviews Government announcements and policies that affect older people, for example in relation to care homes or the treatment of older people in hospitals. They can also influence policy and practice by responding to Government consultations, engaging with Welsh Government Ministers, or providing guidance and briefing materials to various stakeholders in adult social care.<sup>323</sup>

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317 [Q 81](#) (Luke Price)

318 [Q 141](#) (Katy Styles)

319 [Q 187](#) (Sir Andrew Dilnot)

320 *Ibid.*

321 [Commissioner for Older People \(Wales\) Act 2006](#)

322 Commissioner for Older People (Wales) Act 2006, [section 2](#)

323 Supplementary written evidence from the Centre for Ageing Better ([ASC0154](#))



In 2014, for example, the Commissioner published a report, *A Place to Call Home?*, which outlined the changes needed in care homes in Wales. In the impact analysis of the report, it was found that this directly led to a range of legislative changes designed to tackle the challenges that were identified, for example with the introduction of a new inspection regime in local authorities that acknowledged the importance of upholding older people’s rights.<sup>324</sup> The Commissioner and their office can also undertake various pieces of legal case work to help individuals with issues such as treatment and care in hospitals and residential care settings, financial disputes, domestic abuse or failure of prosecution.<sup>325</sup>

208. We believe that existing examples powerfully demonstrate the potential benefits of creating a new Commissioner role to uphold the rights and increase the visibility of those drawing on care. We propose the creation of a Commissioner for Care and Support to represent all of those drawing on adult social care, which includes older people, disabled adults and unpaid carers. This Commissioner should undertake the following roles:

- promote awareness of and champion the rights and interests of older adults, disabled people and unpaid carers;
- challenge discrimination against older adults, disabled people and unpaid carers;
- encourage best practice in supporting older adults, disabled people and unpaid carers; and
- advise on whether new legislation prejudices older adults, disabled people and unpaid carers.

209. We are not the first to see the value in the role of a Commissioner. Many Commissioners exist (Information Commissioner, Small Business Commissioner, Children’s Commissioner) with different remits and powers. But there is no one as yet who speaks for adult social care, can identify failure and missed opportunity in the sector, as well as defend and promote social care and everyone affected by it. It is vital that such a role has power to effect and argue for change by holding failure up to the light and revealing the realities of the adult social care system as well as its possibilities. We believe the best way to do this is to take a developmental approach to the Commissioner role, reflecting and developing the powers and duties that are already known to work most effectively and are most likely to empower the Commissioner to bring about tangible change.

210. For a Commissioner for Care and Support to achieve these goals, it is critical that they actively listen to the groups concerned and that lived experience feeds into their work. One way of doing this is to ensure that the role is taken by or shared with someone who has lived experience of the social care system.

211. ***The Government should establish in the next 12 months a Commissioner for Care and Support to act as a champion for older***

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324 Older People’s Commissioner for Wales, *A Place to Call Home: Impact and Analysis* (January 2018) p 14: <https://democracy.gwynedd.llyw.cymru/documents/s500004203/Item%2012%20-%20Appendix%201%20-%20A%20Palce%20to%20Call%20Home%20-%20Impact%20and%20Analysis.pdf> [accessed 21 September 2022]

325 Supplementary written evidence from the Centre for Ageing Better ([ASC0154](#))

*adults and disabled people and unpaid carers, and to accelerate a more accessible adult social care system. The Government should ensure this role is filled by, or shared in equal measure, with a person who has lived experience.*

### Revisiting the Care Act 2014

212. The tragedy of the situation facing adult social care is that the right prescription for many changes have been nearly to hand for eight years in the shape of the Care Act 2014. The Act effectively outlines that the first general duty of a local authority in relation to adult social care is to promote individuals’ wellbeing. Wellbeing is defined as relating to the following:
- personal dignity;
  - physical and mental health and emotional wellbeing;
  - protection from abuse and neglect;
  - control by the individual over their day-to-day life, including over the care and support that is provided to them;
  - participation in work, education, training or recreation;
  - social and economic wellbeing;
  - domestic, family and personal relationships;
  - suitability of living accommodation; and
  - the individual’s contribution to society.<sup>326</sup>
213. Other general responsibilities of local authorities as outlined in the Act include preventing the development of needs for care and support, promoting the integration of care and support with health services, providing information and advice and promoting diversity and quality in the provision of services.<sup>327</sup>
214. The Act states that where it appears that an adult may have needs for care and support, the local authority must assess what those needs are and how they impact on an individual’s wellbeing; the assessment must also account for the outcomes that the adult wishes to achieve in day-to-day life and the extent to which the provision of care and support could contribute to the achievement of those outcomes.<sup>328</sup> Crucially, the Act also recognises the key role played by unpaid carers. Local authorities must effectively assess unpaid carers when it appears that they may have a need for support. The assessment must include whether the unpaid carer is able to provide unpaid care; whether the carer is willing to carry out unpaid care; the impact of unpaid care on the carer’s wellbeing; the outcomes that the unpaid carer wishes to achieve in day-to-day life and the extent to which support could contribute to achieving those outcomes.<sup>329</sup>
215. In principle, therefore, the Act enshrines in law many of the principles that we endorse for adult social care, including the right for individuals to determine the relationships they wish to have with their families and friends,

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326 Care Act 2014, [section 1](#)

327 *Ibid.*, [sections 2–5](#)

328 *Ibid.*, [section 9](#)

329 *Ibid.*, [section 10](#)

and the right for unpaid carers to be appropriately supported when they wish to provide unpaid care and support. One witness told us: “What you have is policy and law rooted in a lot of the right stuff. It is rooted in wellbeing, community, choice and control; it puts people in control and at the heart of their care and support.”<sup>330</sup>

216. There is consensus, however, that the Act has never been implemented in practice and has resulted in little change on the ground for older adults and disabled people as well as unpaid carers. Since 2014, the Department of Health and Social Care has commissioned various projects looking at the implementation of the Act and how far it has achieved its aims. While some reported positive progress, for example in the implementation support programme which aimed to assist local authorities to prepare for the changes created by the new law,<sup>331</sup> most found that the impact of the Act has been limited. One report explored the impact of the Act on the support provided to unpaid carers. It concluded that while the Act had increased the recognition of the importance of unpaid carers’ wellbeing at both national and local levels, the challenging financial context has led to a reduction in the support provided to unpaid carers. Unadjusted figures showed that the number of carer assessments in England has declined steadily from 450,000 per year in 2009/10 to just over 350,000 per year in 2017/18.<sup>332</sup>
217. Even the Government admitted in its December 2021 White Paper that “the full spirit of the Care Act is not currently being met.”<sup>333</sup> Throughout our inquiry, we heard that this is reflected on the ground. “There is nothing in the policy that prevents everybody having decent lives but, somehow, it is not happening,” said one expert by experience.<sup>334</sup> As discussed in Chapter 3, the reality of drawing on adult social care for older adults and disabled people, as well as for unpaid carers, illustrates the shortcomings of the Act. Far from ensuring individuals’ wellbeing, care services tend to be reduced to a minimum and designed to enable people to survive, rather than to live and thrive. Choice and control seem to exist mostly in legislation, whether for older adults and disabled people, or for unpaid carers. Many witnesses directly linked the failures of the social care system to the failure to implement the Act, pointing to the “disparities” between the ambitions laid out in the Act and the experiences of practitioners, unpaid carers and people with lived experience on the ground.<sup>335</sup> The challenges faced by the social care sector today were therefore largely attributed to the difficulties that local authorities face to fulfil their duties as outlined in the legislation.<sup>336</sup>
218. The process of assessing individuals’ and unpaid carers’ needs, which is described at length in the Act, is particularly problematic. As stated

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330 Q 86 (Ian McCreath)

331 Stephen Peckham *et al*, *Improving choices for care: a strategic research initiative on the implementation of the care act 2014* (May 2020) p 10: <https://kar.kent.ac.uk/81218/1/Revised%20final%20report%20Care%20Act%20Implementation%20Support%20Programme.pdf> [accessed 22 September 2022]

332 Jose-Luis Fernandez *et al*, *Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention* (January 2021) p 14: <https://www.lse.ac.uk/cpec/assets/documents/cascfinalreport.pdf> [accessed 22 September 2022]

333 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 30 September 2022]

334 Q 142 (Tricia Nicoll)

335 Written evidence from Rethink Mental Illness (ASC0125)

336 Written evidence from Daniel Reed (ASC0050)

in the Act, for both individuals with care needs and unpaid carers, an assessment must consider the impact of the person’s needs for support on their wellbeing, as well as the outcomes they wish to achieve in their day-to-day life, and whether the provision of care and support can contribute to achieving these outcomes. Instead, we were told that the assessment of older adults and disabled people often “places the emphasis on what is wrong” in a person’s life.<sup>337</sup> The testimonies we describe in Chapter 3 further illustrate the irrelevance and inappropriateness of assessments.

219. Professor Jerry Tew, who carried out research on the impact of the Act for the Department of Health and Social Care, told us that instead of focusing on what a better life could look like and how to get there, assessments consist of ticking off as many deficits as possible in order to claim services.<sup>338</sup> People feel the need to focus on and emphasise their challenges as much as possible in order to access support that is guarded by strict eligibility criteria. This is a reductive approach that is far removed from the purpose of assessment as outlined in the Act. For many people, it has resulted in assessments being a source of distress. The Strategic Director for Social Care and Education at Leicester City Council, Martin Samuels, recounted how he had realised that people who draw on care services in his local area felt a sense of “dread” and “real concern” when they received paperwork for their annual review, which came out of fear that the system “was going to do something to them.”<sup>339</sup>
220. We heard similar stories from unpaid carers, who described carers’ assessments as a process ranging from irrelevant to intimidating. One unpaid carer told us, referring to the assessment questions related to a carer’s willingness to carry out unpaid care: “If you want a laugh, tell them that, no, you are not willing to be a carer. A social worker always steps over the question and completely ignores it.”<sup>340</sup> Another unpaid carer described how she did not feel listened to and was even “belittled” during assessments, with few examples where the process led to her getting any support.<sup>341</sup>
221. Our attention was drawn to the fact that in some cases, this constitutes a legal failing of local authorities to fulfil their duties. Ms Schwehr pointed to the lack of knowledge that staff might have of their legal duties under the Act, which makes it impossible for them “to understand when they are abiding by the law, when they are sailing a bit close to the wind, and when they are going well over the borderline.”<sup>342</sup> This in turn leads to the rights of older and disabled people, and of unpaid carers, not being implemented in practice. As one unpaid carer told us, carers therefore have rights in principle but rarely in practice.<sup>343</sup> This is also the case for older adults and disabled people.

### *Why has the Care Act 2014 failed?*

222. In the December 2021 White Paper, the Government pledged to introduce heightened scrutiny of local authorities’ performance in adult social care, which included a new duty for the CQC to independently review and assess local authority performance in delivering their adult social care duties under

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337 Written evidence from Wiltshire Centre for Independent Living ([ASC0010](#))

338 [Q 125](#) (Professor Jerry Tew)

339 [Q 166](#) (Martin Samuels)

340 [Q 36](#) (Norman Phillips)

341 [Q 36](#) (Helen Spalding)

342 [Q 123](#) (Belinda Schwehr)

343 Written evidence from Sue Gerrard ([ASC0110](#))

Part 1 of the Act.<sup>344</sup> While this change is welcome, the LGA pointed out to us that “things need to be put right first”.<sup>345</sup> Before their performance is assessed, local authorities need to be given the resources to carry out their duties successfully; otherwise closer scrutiny of their activities runs the risk of being an unhelpful exercise. “There is a great danger in labelling all our services with a ‘failure’ tag, which will make the situation worse,” said the LGA.<sup>346</sup> Understanding why the Act has not been implemented in practice and remedying those challenges therefore needs to go hand in hand with the CQC’s future assessments.

223. The tangible explanations for the shortcomings of the Act start and finish with funding. Faced with stretched budgets, local authorities cannot afford to provide services that go beyond minimum support. The charity Rethink Mental Illness argued that the financial context within which the Act was rolled out has contributed to its failure to meet expectations.<sup>347</sup> The Carers Trust also pointed to the insufficient funding provided to local authorities by central government as a key reason that explains why carers’ rights are not met under the Act.<sup>348</sup> Professor Tew explained that, in order for the Act to be implemented effectively, a share of local authority funding and activity should be ringfenced for the promotion and enablement of citizens’ and unpaid carers’ wellbeing.<sup>349</sup>
224. One witness also identified a lack of funding for the training of social workers and for their continuing professional development, which has led to social care staff not being aware of their legal duties under the Act. They told us that this lack of legal training “is like sending a surgeon into an operating room without a scalpel.”<sup>350</sup> They recommended, therefore, that more funding be made available to reform the social work degree course curriculum, with a stronger focus on the legal framework of adult social care.
225. We also heard that, to an extent, the shortcomings of the Act are linked to the cultural issues outlined earlier in this chapter: the Act is an example of a policy change implemented without a cultural change. While the Act embraced the principle of greater autonomy, choice and control, both for those in need of care and unpaid carers, that conviction failed when it came to the greater challenge, described to us by one expert by experience:
- “I think the reason why it does not work keeps coming back to how we perceive people’s lives. People think they know what a mental health service user looks like; people think they know what a wheelchair-user’s life is like. We have stereotypical views.”<sup>351</sup>
226. We were also told that, while the Act intended to set out a new vision for adult social care, which came in the form of new duties for local authorities, it did not provide enough guidance and support to assist local authorities in

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344 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 78: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 30 September 2022]

345 [Q 172](#) (David Fothergill)

346 *Ibid.*

347 Written evidence from Rethink Mental Illness ([ASC0125](#))

348 Written evidence from Carers Trust ([ASC0097](#))

349 Supplementary written evidence from Professor Jerry Tew ([ASC0146](#))

350 [Q 126](#) (Belinda Schwehr)

351 [Q 31](#) (Tricia Nicoll)



successfully implementing what constitutes a significant cultural shift. Under the Act, some statutory guidance was published to provide local authorities with key information about the obligations placed on them by the Act.<sup>352</sup> This guidance, however, was not seen as sufficient to assist local authorities in generating the significant cultural changes that were required by the Act. Local authorities told us that the radical shifts that were envisioned by the Act should have come with more support and guidance to put these changes into practice. Laura Gaudion, the Director of Adult Social Care and Housing needs at the Isle of Wight Council, said:

“While the Care Act provides us with an overarching vision that is only to be commended in terms of what it delivers for local people, it stops short of providing the support that local authorities needed to change that culture, to shift how things were done.”<sup>353</sup>

227. This is particularly relevant when it comes to understanding the purpose of needs assessments for older adults and disabled people, as well as unpaid carers. Professor Tew highlighted that people should have the right to a needs assessment that is very different to most people’s current experience of assessments. An assessment should denote “a collaborative exploration of what a good life would mean to a person and how this might be achieved,”<sup>354</sup> he wrote, instead of merely establishing a person’s eligibility for services based on narrow criteria. The current guidance falls far short of reconceptualising care assessments in such a way.
228. We do not believe that there is a need for further primary legislation. As one witness told us: “We do not have to reinvent the wheel.”<sup>355</sup> Much of the necessary reform already exists in law; but there is a need for a better understanding of how the Act could be successfully implemented. It is particularly key to reflect on the practical mechanisms that could be provided to local authorities in order to generate a change of culture and embed the Act’s principles in the narrative and delivery of adult social care.
229. *The Government must commission an independent public review of the Care Act 2014 and work with local authorities to ensure that the Act is fully implemented by the end of this Parliament. The Commissioner for Care and Support should make it a priority to ensure that the review, update and implementation of the Act happens in practice.*

### Unlocking the potential of Integrated Care Systems

230. With the Care Act 2014 having lain dormant for eight years, it is important that the most recent and radical attempt at the integration of health and social care succeeds. The introduction of integrated care systems (ICSs) under the Health and Social Care Act 2022 has created new opportunities in a way that engages with local disabled adults and older people.<sup>356</sup>

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352 Department of Health and Social Care, *Care and support statutory guidance* (November 2022): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> [accessed 8 November 2022]

353 Q 171 (Laura Gaudion)

354 Supplementary written evidence from Professor Jerry Tew (ASC0146)

355 Q 63 (Professor Sue Yeandle)

356 The King’s Fund, ‘Integrated care systems explained: making sense of systems, places and neighbourhoods’ (19 August 2022): <https://www.kingsfund.org.uk/publications/integrated-care-systems-explained> [accessed 28 September 2022]



231. ICSs have existed in various forms since 2016, but were formalised as legal entities with statutory powers and responsibilities through the Health and Care Act. There are 42 ICSs covering between 500,000 and 3 million people, that bring together NHS organisations and local authorities, but also other key local stakeholders such as the voluntary, community and social enterprise sector (VCSE) and people who live and work in that area, to take collective responsibility for planning services, improving health and reducing inequalities across geographical areas. They consist of two key components:
- integrated care boards (ICBs): statutory bodies that are responsible for planning, funding and commissioning most NHS services in the area;<sup>357</sup>
  - integrated care partnerships (ICPs): statutory committees that bring together a broad set of system partners (including local government, the VCSE, NHS organisations, housing associations and others) to develop a health and care strategy for the area.<sup>358</sup>
232. ICSs have four key aims:
- improving outcomes in population health and healthcare;
  - tackling inequalities in outcomes, experience and access;
  - enhancing productivity and value for money; and
  - helping the NHS to support broader social and economic development.<sup>359</sup>
233. The Health and Care Act 2022 also introduced a duty on the CQC to review healthcare and adult social care in each ICB, including looking at how partners in the ICS are working together.<sup>360</sup> This will start in April 2023. ICSs were created with the intention of integrating care, so that different parts of health and social care work in a more joined-up way.<sup>361</sup> Through this, ICSs have the potential to reduce the invisibility of adult social care by creating a more equal footing between adult social care and the NHS, for instance through shared knowledge, a unified voice and cross-sector strategy on issues such as workforce recruitment and retention.<sup>362</sup> COVID-19 has arguably already started this trend, resulting in co-working between the NHS, local authorities and voluntary sector.<sup>363</sup>
234. As part of this, ICSs also have great potential to raise the profile of social care locally;<sup>364</sup> especially with representation from people with lived experience and from carers’ organisations who would ensure that their voices are heard in the design and delivery of services, offering an opportunity for co-production.<sup>365</sup> They could also be held accountable for the quality, range and integration of services.

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357 Health and Care Act 2022, [sections 18–25](#)

358 Health and Care Act 2022, [section 26](#)

359 The King’s Fund, ‘Integrated care systems explained: making sense of systems, places and neighbourhoods’ (19 August 2022): <https://www.kingsfund.org.uk/publications/integrated-care-systems-explained> [accessed 28 September 2022]

360 Health and Care Act 2022, [section 31](#)

361 The King’s Fund, ‘Integrated care systems explained: making sense of systems, places and neighbourhoods’ (19 August 2022): <https://www.kingsfund.org.uk/publications/integrated-care-systems-explained> [accessed 28 September 2022]

362 Written evidence from Care England ([ASC0034](#))

363 Written evidence from Bristol City Council ([ASC0076](#))

364 Written evidence from the Local Government Association ([ASC0042](#))

365 Written evidence from Think Local Act Personal ([ASC0054](#))

235. However, there are barriers to integration: England has legally distinct health and social care systems; and the NHS is free at the point of use, while local authorities typically only pay for individual packages of care for adults assessed as having high needs and limited means.<sup>366</sup> We also heard from Mr Hunt that the NHS “will be very reluctant to form big, deep relationships” with social care because of the possible financial liabilities that could come with integration.<sup>367</sup>
236. Integration is an elusive grail. ICSs are one in a long line of attempts to integrate health and social care, for instance through the 2010 Spending Review, the Better Care Fund (2013), the Integrated Care and Support Pioneers Programme (2013) and NHS England’s *Five Year Forward View* (2014).<sup>368</sup> Further back, we have had Care Trusts, the Health Act flexibilities, Local Area Agreements, Local Strategic Partnerships, Health Action Zones, the New Deal for Communities and many, many more initiatives and mechanisms. One witness therefore expressed scepticism, saying:
- “There are at least five pieces of legislation I can think of already which talk about joint working and yet, though a lot is talked about (particularly with ICS), I’m doubtful whether they will work together as long as there are two separate pots of money.”<sup>369</sup>
237. Despite good faith there is a real fear than the NHS will inevitably dominate ICSs. We heard that “any attempts at fostering genuine integration will continue to fail unless greater emphasis is placed on achieving parity between the sectors”.<sup>370</sup> The TUC argued that the lack of funding for social care, the failure to provide a pay uplift for care workers and the lack of ambition of the 2021 White Paper in terms of major system reform place “a serious question mark against the government’s claims that ICSs will be able to bring about greater integration.”<sup>371</sup> Mencap expressed concern that collaboration is based on “better delivering against NHS priorities such as the NHS Mandate rather than against shared health and social care objectives”. They described ICBs as “largely a health body with very little oversight of, or alignment with, the provision of social care.”<sup>372</sup> Ealing Reclaim Social Care Action Group worried that ICSs could even increase the invisibility of social care, with it being “next to impossible for care-users, or their supporters, to influence these mega-bodies”.<sup>373</sup> NHS domination of ICSs could also result in emphasis on the “medical model” of disability (people are disabled by their impairments or differences) rather than the “social model” (disability is caused by the way society is organised).<sup>374</sup>
238. It is vital that adult social care is represented within ICSs to advocate for the sector’s needs and that this includes social care for disabled adults of

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366 National Audit Office, *Health and social care integration* (Session 2016–17, HC 1011), p 5: <https://www.nao.org.uk/wp-content/uploads/2017/02/Health-and-social-care-integration.pdf> [accessed 30 September 2022]

367 Q 14 (Jeremy Hunt MP)

368 National Audit Office, *Health and social care integration* (Session 2016–17, HC 1011), p 6: <https://www.nao.org.uk/wp-content/uploads/2017/02/Health-and-social-care-integration.pdf> [accessed 30 September 2022]

369 Written evidence from Halobletec (ASC0005)

370 Written evidence from the Trades Union Congress (ASC0040)

371 *Ibid.*

372 Written evidence from Mencap (ASC0046)

373 Written evidence from Ealing Reclaim Social Care Action Group (ASC0072)

374 Written evidence from Dimensions (ASC0098)

working age as well as older people. ICSs therefore need to produce a clear strategy on how they plan to engage with adult social care and deliver on its priorities.<sup>375</sup> The voluntary sector must also be included as an equal partner.<sup>376</sup> Encouragingly, this was acknowledged by Jason Yiannikou, Director of Integration and Legislation, Department of Health and Social Care, who stated:

“There is a profound interdependency between the different services and sectors that the ICS covers, and the importance of drawing in voices from users and carers as part of the development of services has been strongly felt in health as well as in care... this is a moment that I hope we can seize upon.”<sup>377</sup>

239. ICSs also offer a practical opportunity to embed co-production in the design and delivery of adult social care at a local level.<sup>378</sup> This will happen by ensuring that the voice of lived experience is meaningfully represented, heard and included in ICSs. One witness told us that it is crucial to reflect on how older adults and disabled people will be supported to “come to the table as equal partners with the ICSs, local authorities or with other bodies” so that they can have a “civic role” in shaping services and public policy.<sup>379</sup> Unpaid carers should equally be represented in ICSs, and appropriate support should be provided to them if necessary to ensure that they are included. For example, one expert by experience pointed out that unpaid carers may need training and support to participate in local policy making, which should be made available to them.<sup>380</sup> Equally, ICS staff may need training in how to work on a basis of equality and shared power with people who draw on care services.
240. As discussed in written evidence from Chapter 5, the Government’s White Paper includes plans for the CQC to assess local authorities, ICSs and providers using a new single assessment framework, which will be built on principles of co-production. We also heard from civil servants that guidance is currently being designed for ICSs to encourage the representation of different stakeholders.<sup>381</sup> We believe that in addition to guidance, ICSs should ensure that the voice of lived experience is appropriately represented—and so that stated commitment to co-production leads to genuine change, rather than a resurgence of more tokenistic, paternalistic approaches.
241. Despite the potential risks, therefore, ICSs present a significant opportunity to reform adult social care and could be a vehicle for change. It is important that ICSs are designed and function in a way that benefits adult social care—and which seeks to bring formal services together in order to help people achieve the lives they want to lead.
242. ***For the new ICSs to deliver for adult social care and unpaid carers, the Government must introduce an obligation to include older adults and disabled people, and unpaid carers, in the design and delivery of care; as well as ensure parity between adult social care and healthcare within ICSs.***

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375 Written evidence from Care England ([ASC0034](#))

376 Written evidence from Mencap ([ASC0046](#))

377 [Q 2](#) (Jason Yiannikou)

378 [Q 21](#) (Vic Rayner)

379 [Q 83](#) (Fazilet Hadi)

380 Supplementary written evidence from Katy Styles ([ASC0142](#))

381 [Q 162](#) (Michelle Dyson)

*The role of ICSs in delivering place-based approaches: the challenge of rurality*

243. Operating at a local level, ICSs can be expected to develop and invest in place-based solutions to adult social care, which are tailored to the challenges and opportunities that are specific to local communities. For example Nick Sinclair, the Director of the Local Area Coordination (LAC) Network said that he saw ICSs as a key structure to enable the spread of LAC, with local area coordination constituting the “hyper local” reach of each ICS.<sup>382</sup>
244. This has the potential to bring more effective services that are tailored to the needs of all local communities, but our attention was brought in particular to the possible benefits for rural areas. The nature of the care needs of rural residents does not differ from the rest of the population; but we were told that rurality creates “substantial differences” when it comes to meeting these needs.<sup>383</sup>
245. Although differences exist between each rural area, there are common challenges to the delivery of social care outside of urban environments, which need to be taken into account. The first is demographic: older residents are disproportionately represented in rural settings, with 5.8 million residents aged 65 or over currently living in rural areas. This represents 55% of all those in England, a number which continues to grow, and gives rise to more complex and expensive care needs.<sup>384</sup>
246. In parallel, rural areas are faced with significant issues in relation to workforce recruitment and retention; not only because of the smaller proportion of working age population to draw from, but also because of the availability of other, potentially more attractive jobs that are available, particularly in the summer in coastal and tourist areas.<sup>385</sup> This is further aggravated by the lack of affordable housing in rural areas, which contributes to driving working age people to other, less expensive localities.<sup>386</sup>
247. The geography of rural areas also gives rise to specific challenges: providing adult social care in large and remote rural areas means that there is more time and costs involved in delivering care over large distances, a lack of economies of scale and weaker markets.<sup>387</sup> The distance travelled to work is also a key factor in retaining social care staff—even more key, according to models developed by Skills for Care, than contract type and zero-hour contracts.<sup>388</sup> In rural areas, workers travel on average longer distances to work and between jobs compared to urban areas, which, together with the lack of affordable housing, further aggravates the workforce challenges in these localities.
248. The design and delivery of adult social care policy currently does not account for these local characteristics. Witnesses described this as a failure to “rural

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382 Supplementary written evidence from Nick Sinclair ([ASC0132](#))

383 [Q 129](#) (Graham Biggs)

384 Rural Services Network, *The State of Care in County & Rural Areas* (September 2021) p 8: <https://rsonline.org.uk/images/publications/the-state-of-care-in-counties-full-report.pdf> [accessed 12 October 2022]

385 [Q 129](#) (Graham Biggs)

386 *Ibid.*

387 *Ibid.*

388 Skills for Care and Workforce Intelligence, *Workforce Intelligence Summary: Rural adult social care workforce information: 2018/2019* (March 2019) p 1: [https://www.ncrhc.org/assets/downloads/Rural\\_v\\_Urban\\_report.pdf](https://www.ncrhc.org/assets/downloads/Rural_v_Urban_report.pdf) [accessed 17 October 2022]

proof” social care policy,<sup>389</sup> which means examining policies from a rural perspective and adjusting them as needed to ensure that their intended outcomes can be realised in rural areas.<sup>390</sup> Instead, we were told that “we see a one-size-fits-all approach.”<sup>391</sup> This was illustrated in the Government’s pledge as part of the December 2021 White Paper to invest £150 million of additional funding to drive greater adoption of technology and the widespread digitisation of adult social care.<sup>392</sup> The investment, said one witness, is “absolutely useless” without broadband or mobile connectivity, which some rural areas do not have; and by the time they do, it is unlikely that any of the funding will be left to serve them. “What is the rural proofing in that?” they asked.<sup>393</sup>

249. As a result, the provision of care services in rural, remote and coastal areas can be inadequate. An inquiry led in 2022 by the APPG in Rural Health and Social Care found that the provision of services in rural, remote and coastal areas is generally poorer than in more heavily populated parts of the country. For example, access to maternity care is more challenging, as well as to wider community services for children and young people; and the provision of services for the growing proportion of older adults was described as “inadequate”.<sup>394</sup> This highlights the need for locally appropriate approaches. Kate Garner, the Service Manager at Shropshire Council, illustrated this as she told us that delivering centralised services in her local area “does not work” because it would require reaching more than 150 parishes, 18 market towns, as well as smaller towns, villages, hamlets and clusters.<sup>395</sup> Designing and delivering adult social care therefore requires taking a more flexible and creative “locality approach”, which accounts for the strengths and opportunities that exist within the area.<sup>396</sup> We were told that “it is about doing things that matter and supporting the kind of life that people want in those local communities and in the context of those local communities.”<sup>397</sup>
250. We heard that ICSs could play a key role in enabling this “locality approach”. By acting at the local level, ICSs effectively have the potential to rural proof the design and delivery of adult social care. “When the ICSs start to develop their plans, strategies, service commission, and all those sorts of things, the starting point needs to be genuinely to rural proof the needs of those rural communities,” said one witness.<sup>398</sup> The APPG on Rural Health and Care also argued that ICSs will enable a simpler and better coordinated system, which will foster local and place-based flexibility.<sup>399</sup> For example, fostering

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389 [Q 129](#) (Graham Biggs)

390 *Ibid.*

391 *Ibid.*

392 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 7: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 12 October 2022]

393 [Q 129](#) (Graham Biggs)

394 APPG Rural Health & Care, *Inquiry Overview* (February 22) p 4: <https://rsnonline.org.uk/images/publications/RuralHealthandCareAPPGInquiryOve.pdf> [accessed 17 October 2022]

395 [Q 132](#) (Kate Garner)

396 *Ibid.*

397 [Q 129](#) (Graham Biggs)

398 [Q 131](#) (Graham Biggs)

399 APPG Rural Health & Care, *Inquiry Overview* (February 2022) p 8: <https://rsnonline.org.uk/images/publications/RuralHealthandCareAPPGInquiryOve.pdf> [accessed 17 October 2022]

micro providers, as is the case in Somerset through the Somerset Micro-enterprise programme.<sup>400</sup>

251. To be successful, therefore, ICSs must adopt a sub-regional approach to the design and delivery of care, which will mean understanding the diversity of strengths and challenges that are specific to the area, including within the same locality. This will offer scope to tackle longstanding issues by developing approaches that are more attuned to the needs of local people. It is only based on this locally-appropriate approach that flexible and effective social care services can be designed.
252. ***ICSs must listen and adapt to local communities, in particular those in rural and remote areas; and the Government must monitor them on an annual basis to ensure that they do so.***

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400 Community Connect, ‘Micro Providers information and advice’: <https://somersetcommunityconnect.org.uk/help-at-home-micro-providers/micro-providers-information-and-advice/> [accessed 1 November 2022]



## CHAPTER 5: EQUAL PARTNERS, BETTER LIVES: CO-PRODUCTION IN PRACTICE AND POLICY

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253. This chapter looks at how, by moving social policy from its present detached position to a new model of co-production, the benefits of better design and delivery will benefit everyone. Co-production is one of the most urgent areas already within reach of change. It is grounded in a fundamental principle: older adults drawing on care to live as full lives as possible. This underpins the greater autonomy and respect that we also seek for the unpaid carer.
254. To achieve this, social care services must move from a transactional exchange to one which explicitly values and builds on positive relationships. To enable this, our attention was frequently brought to the principles and practice of co-production—a process in which decisions are made together as equal partners—through which disabled people and older adults can make their own choices and lead chosen, ordinary lives.
255. At the individual level, co-production means that people who draw on care can make better choices when it comes to designing and delivering their own care, in a process that places power and decision making into their hands. It ensures a more sustainable and effective service for the future.
256. Co-production also makes for better social care policy. The most systemic challenge, therefore, is the need to change the way social care policy is made. People who receive care or provide it currently have little or no voice or locus in saying what works best.

### Co-production in practice

257. As discussed in previous chapters, the discriminatory narrative that surrounds older adults and disabled people has a direct impact on the support that is offered. The present transactional basis of the system is designed, as one witness described it, to “keep people out”, often by telling them to “go away, get worse and come back when you are in a worse position” in order to be able to access care and support.<sup>401</sup>
258. Moreover, we heard from experts by experience that they are often presented with services that are considered by social workers to be sufficient to meet their needs but might in fact be irrelevant or inadequate. One witness told us: “I am not seen as someone who is expert in me.”<sup>402</sup> She recounted how, as a younger woman with mental ill health, she knew that acupuncture, a gym subscription or a walk on the beach would help her to get better, but social services would only offer her a day service, which she did not find helpful. “The starting point is that they do not listen,” she said.<sup>403</sup> The National Care Forum also emphasised that people are not “properly” listened to when it comes to understanding what they want and need from care and support services.<sup>404</sup> The consequence is that older adults and disabled people too often receive a service that does not respond to their needs. In the long term, this is ineffective and costly.

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401 [Q 87](#) (Professor Donna Hall)

402 [Q 25](#) (Tricia Nicoll)

403 *Ibid.*

404 Written evidence from the National Care Forum ([ASC0060](#))

259. There are different ways to define co-production, and there is no one agreed definition. However, the Social Care Institute of Excellence says that co-production happens when people who use services and carers work with professionals in equal partnerships towards shared goals, a definition which we endorse.<sup>405</sup> Similarly, the Association of Directors of Adult Social Care describes co-production as a way of involving people “from the very beginning”, by listening to them when it comes to identifying problems that need to be solved or questions that need to be answered. “Co-production means that power is shared more equally between those who use services and those who provide them,” says the organisation.<sup>406</sup>
260. Co-production is not a new concept. Although co-production is not specifically referred to in the Care Act 2014, the term appears in the legislation’s statutory guidance, which offers the following definition: “‘Co-production’ is when an individual influences the support and services received or when groups of people get together to influence the way that services are designed, commissioned and delivered.”<sup>407</sup> More specifically, the guidance recommends that local authorities “actively promote” participation in interventions that are co-produced with individuals, families, friends, carers and the community.<sup>408</sup> The Government’s 2021 White Paper also included plans for the CQC to assess local authorities, ICSs and providers using a new assessment framework that will be based on standards of co-production.<sup>409</sup> Personalised care and support, choice, control, independence, and principles established in the Care Act 2014 and in the White Paper will be at the heart of this framework.<sup>410</sup>
261. Policy pledges made on paper, however, must translate on the ground as a genuine understanding and implementation of what co-production is and what it entails. Co-production is not a tick-box exercise: it is a process that celebrates ambitions and desires. It sees individuals as active agents of change who can contribute to society, rather than passive recipients of basic care. In a co-produced model of care, therefore, people are resources, experts and citizens, rather than ‘patients’, ‘service users’ or a ‘drain’ on the system.
262. The process of co-production starts by enabling individuals to tell care professionals what they would like, expect, want or need, and to be listened to. It requires a genuine conversation between the individual and the professional, which also includes the individual’s family or friends if that is the person’s wish. At the heart of a co-produced model is the imperative to create a sustained and two-way relationship between the individual and the care professional.
263. While co-production is so much more than this, many witnesses highlighted that it is also a more efficient way of working, by drawing analogies to business. “If you were a business, why would you design services without

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405 Written evidence from the Social Care Institute for Excellence ([ASC0081](#))

406 Written evidence from ADASS (Association of Directors of Adult Social Services) ([ASC0135](#))

407 Department of Health and Social Care, *Care and support statutory guidance* (November 2022): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> [accessed 8 November 2022]

408 *Ibid.*

409 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 84: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 27 September 2022]

410 [Q 86](#) (Ian McCreath)

thinking about the needs of customers and service users?”<sup>411</sup> asked one witness, while another one compared co-production to supermarkets who empower their customers to do their own food shopping.<sup>412</sup>

264. We were told that co-production “is about listening, understanding the world through people’s eyes and then doing something differently with that knowledge and information, and doing it together.”<sup>413</sup> Les Billingham, Assistant Director for Adult Social Care and Community Development at Thurrock Council, described it as moving away from professionals’ tendency to think that they “know best”, to the point where the person drawing on care is “in control.”<sup>414</sup> Co-production in social care, therefore, ensures that services are personalised and tailored to individuals’ needs and desires, because support has been co-designed in a spirit of equal relationships.
265. One expert by experience explained to us what a co-produced assessment should feel like in practice:

“I would like to abandon all the forms... This is my ideal world and I would start with the person. It would just be so nice if you went and asked the person, ‘What are you hoping to achieve, and what would help you to get there’—two really simple questions. We do not need all this, ‘Tick here,’ and, ‘Tick there.’”<sup>415</sup>

This would be more aligned with the purpose of social care than current processes. In essence, it re-establishes the meaning of ‘social’ in ‘social care’.

266. Co-production works. It optimises individual resources and capacity; but it is also cost-effective because it is essentially preventative. The escalation of needs can be prevented, for example by keeping people out of institutional care. Mr Billingham, who introduced LAC’s co-produced approach to care (see Box 5) in Thurrock Council, told us that Coordinators “have had dramatic success,” for example in resolving both the symptoms and longer-term challenges faced by people hoarding—a mental disorder characterised by the accumulation of possessions due to the excessive acquisition of or difficulty to discard possessions.<sup>416</sup> The LAC network also told us that there have been several independent academic evaluations carried out on the model since 2009, which have consistently shown reductions in: visits to GP surgeries and A&E; dependence on formal health and social services; referrals to Mental Health Teams and Adult Social Care; safeguarding concerns; evictions and costs to housing; smoking and alcohol consumption; dependence on day services; and out of area placements.<sup>417</sup> An analysis carried out specifically in Derby City Council, who introduced LAC in 2012, found that the model is delivering “significant” social value with up to £4 of value for every £1 invested.<sup>418</sup>

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411 Q 87 (Professor Donna Hall)

412 Q 29 (Tricia Nicoll)

413 Q 90 (Nick Sinclair)

414 Q 93 (Les Billingham)

415 Q 24 (Sue Bott)

416 Q 93 (Les Billingham)

417 Local Area Coordination Network, ‘How do we know it works?’: <https://lacnetwork.org/evidence-base/> [accessed 27 September 2022]

418 Derby City Council, *Social Value of Local Area Coordination in Derby* (March 2016) p 2: <https://www.derby.gov.uk/media/derbycitycouncil/contentassets/documents/healthandsocialcare/adultsocialcare/social-value-of-local-area-coordination-executive-summary-march2016.pdf> [accessed 27 September 2022]

### Box 5: Strength-based approaches

We heard various examples of best practice demonstrating that co-production is not an abstract concept, but a viable approach that can be implemented in practice and bring about tangible benefits. Many witnesses referred to “strength-based” or “asset-based” approaches, meaning that the emphasis is placed on people’s aspirations and existing gifts and strengths, alongside their needs. One witness told us that this means “thinking about what is strong, not what is wrong.”<sup>419</sup> These strengths could include personal resources, such as relationships, skills or experience; or resources in their community, such as people, spaces, networks or services. A ‘strength-based’ or ‘asset-based’ approach seeks to identify these strengths and enhance them, if necessary thanks to additional care and support, to enable individuals to achieve the life they would like to lead.

#### Local Area Coordination: A strength-based model in practice

Local Area Coordination (LAC) has existed in England and Wales for over 10 years, and there are now 12 local authorities across England and Wales that have implemented it. The LAC Network relies on Local Area Coordinators, who are employed by local councils and work across neighbourhoods of approximately 10,000 people. Coordinators are integrated into the local community: they have hyper-local knowledge of people, families, groups, organisations and services. Their role consists of approaching individuals who might have care and support needs, or be at risk of needing support, and to help them build their own vision for a better life, with the objective of drawing on personal, family and community resources to find pragmatic solutions to any challenges they face.<sup>420</sup>

For example, one case study in Derby City Council saw a resident get in touch with a Local Area Coordinator because she was dealing with various physical and mental health issues following the recent loss of her husband. After several conversations, an opportunity to improve her life emerged as it became clear that she had enjoyed looking after her garden with her husband but was not capable of gardening anymore due to her declining health. The Coordinator arranged for her to meet with a local resident who they had also been helping, and who had been looking for opportunities to volunteer. They agreed to help with her gardening, in an arrangement that also resulted in both residents feeling less socially isolated.<sup>421</sup>

#### *Valuing the local community*

267. In many cases, successful co-production is grounded in the local community, which is key to weaving the web of local relationships that enables people to live an independent and meaningful life. Therefore, as one expert by experience told us: “I think an essential part of the role of social care is being involved in community development, knowing what is going on in the community and being able to connect people with one another.”<sup>422</sup> The local community can often offer support that is nearer and more adapted to people’s needs, and more likely to enable them to achieve their goals. It often emerges, during conversations between practitioners and people with care needs, that joining a local group, meeting local people, finding out

419 Q 90 (Nick Sinclair)

420 *Ibid.*

421 Derby City Council, *Local Area Coordination: Ethel’s Story* (September 2014): <https://www.derby.gov.uk/media/derbycitycouncil/contentassets/documents/healthandsocialcare/adultsocialcare/derbycitycouncil-lac-in-action-ethels-story.pdf> [accessed 27 September 2022]

422 Q 32 (Sue Bott)

about volunteering opportunities or accessing advice and information is an effective way to ensure their wellbeing. In many cases, it is more effective than being signposted to institutional services that are not tailored to their personal needs.

268. For example, Martin Samuels, the Strategic Director for Social Care and Education at Leicester City Council, told us that when the council’s meals on wheels provider gave notice on their contract, he was initially tempted to find another partner to deliver the same service; but then decided to first engage with each person who received the service to find out if they could find an appropriate alternative in the local community. From lunch clubs to local pubs running a group: “For every single one of them, we were able to identify a means by which they could engage with their local community, so that they were able to address that need and ensure that they received meals,” he told us.<sup>423</sup> We heard that this “fine-grained” knowledge of local communities is what has been lost in social care.<sup>424</sup>
269. We were also presented with evidence that investing in the local community comes with significant benefits. Somerset City Council, for example, started a programme of change in 2014 to help people start and run small, independent enterprises offering various forms of care and support in their local area. This ‘micro-provider’ initiative has been extremely successful, and ranges from groups taking people with dementia out to give their carers a break, to peer support groups for people with mental ill health.<sup>425</sup> There are currently 849 micro-providers registered on Somerset City Council’s community directory;<sup>426</sup> and the additional capacity that has been created is saving the council around £2.9 million per year.<sup>427</sup>
270. The local community cannot be a replacement for regulated care. Witnesses stressed that regulated care is necessary, but that developing a local offer alongside it means that people with a lower level of need are likely to find appropriate support without drawing on formal services.<sup>428</sup> This means that a stronger offer of support in the local community has the double benefit of better serving citizens, while protecting regulated services for those who most need them.
271. This proved to be correct when the social care system came under pressure during the COVID-19 crisis. We were told that local authorities who had been funding local micro-organisations had created an “effective safety net and support structure” that was more resilient and respondent when the pandemic suddenly hit, and institutional services found themselves overwhelmed.<sup>429</sup> We heard that:

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423 [Q 170](#) (Martin Samuels)

424 [Q 127](#) (Professor Jerry Tew)

425 [Q 91](#) (Rhys Davies)

426 Somerset Community Connect, ‘Community Directory’: <https://somersetcommunityconnect.org.uk/community-directory/> [accessed 28 September 2022]

427 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 47: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 28 September 2022]

428 [Q 95](#) (Rhys Davies)

429 [Q 124](#) (Professor Jerry Tew)



“For local authorities that had invested in that [micro-organisations] there were people on the ground who knew who would need prescriptions, who would need food, and so on.”<sup>430</sup>

272. The COVID-19 pandemic also saw people and communities come together to look out for each other, which was better harnessed in communities where investment in community-minded approaches was already happening.<sup>431</sup> Gillian Keegan MP, then Minister of State for Care (2021-2022), told us that the Government is “very keen” to learn from and build on the lessons from the COVID-19 pandemic; she argued that this means commissioning and increasing the offer of local care and support to enable people to remain independent.<sup>432</sup> We agree that this should be the direction of travel for the Government. As one witness told us: “We want more groups, clubs, associations and services that are going to be a menu of support for people who might need a bit of help to live their lives in the future.”<sup>433</sup>
273. Stronger local communities are a key part of achieving the vision of choice and control that is needed in social care. We were told that both unpaid carers and individuals who draw on social care have often chosen to use community support and activities rather than organised day services.<sup>434</sup> Future policy must be based on this lived experience—which is also an opportunity to redefine the relationship between state intervention and citizen action, and re-establish the place of care in the social fabric.<sup>435</sup> This will require genuine commitment from the Government and local authorities towards organising social care differently, based on co-production, and therefore focusing on community-based services that are new and transformative. This commitment must come in the form of dedicated funding to support community capacity, local people and organisations.
274. *The Government should recognise the potential cost-effectiveness of co-production, and the role of local communities and micro-providers in enabling co-production, choice and control for disabled adults and older people by ringfencing funding for local authorities to dedicate to investment in building community capacity, learning from what is working well, and to connect residents to local offers for care and support that are tailored to their needs.*

### Co-production in social care policy

275. Co-production is a key way to enable individuals with care needs to co-design the care and support they receive at a personal level, but it can also be used at a policy level, to ensure that local and national reforms are grounded in lived experience.
276. Policy that is co-produced with people who have lived experience, like care that is co-produced with the individual, is more likely to be effective. It is more certain to lead to a system designed to respond to the needs that individuals have expressed themselves, rather than to the needs that have been identified by people who are further removed from the social care system. This also

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430 *Ibid.*

431 Written evidence from Think Local Act Personal ([ASC0054](#))

432 [Q 158](#) (Gillian Keegan MP)

433 [Q 91](#) (Rhys Davies)

434 Written evidence from Think Local Act Personal ([ASC0054](#))

435 *Ibid.*

“helps inject a much-needed degree of positivity and optimism into the debate about the future of care and support”.<sup>436</sup>

277. Research undertaken by the Centre for Seldom Heard Voices at Bournemouth University with a range of diverse communities illustrates how co-produced participatory research can lead to wider social impact and awareness of those that rely on social care—for example, the experiences of LGBTQ+ citizens, older male carers, young disabled people and homeless people.<sup>437</sup> It is vital that social care practice and research work in partnership with individuals and communities to achieve best outcomes for those who require social care support.
278. We heard from Ms Dyson at the start of our inquiry that while her definition of co-production did not reach “the high standards” set by the Committee, the Government is “really happy to learn and to do it better in the future.”<sup>438</sup> Ms Dyson explained that while the 2021 White Paper has been produced in consultation and collaboration with more than 200 organisations and individuals, the challenge now consists of embedding co-production as the Government puts its commitments into practice.<sup>439</sup> It is essential, therefore, that individuals with lived experience are encouraged and supported to come to the policy-making table “as equal partners,” so that their role in shaping the design of adult social care at the local and national levels becomes central to the process of policy making.<sup>440</sup>
279. Co-production is already in place in some local authorities and is making a difference. Box 6 demonstrates examples of best practice in co-production in policy making.

### **Box 6: Best practice in co-production**

#### **Croydon Council**

Croydon Council set up the Croydon Adult Social Services User Panel (CASSUP) bringing together service users, carers of service users and Croydon residents who have a strong commitment to improving adult social services. The panel meets six times a year and works in partnership with decision makers. They represent the views of the community to improve service delivery and access to social care services.<sup>441</sup>

#### **Leicestershire County Council**

Leicestershire County Council have co-produced their new review form and process. It went from being a form “focussed on tasks such as washing and dressing” to one that is “largely blank and starts with ‘what matters to you?’”. This enabled people who draw on care to “feel more in control.”<sup>442</sup>

436 Written evidence from the Local Government Association ([ASC0042](#))

437 Written evidence from Professor Lee-Ann Fenge and Dr Andy Pulman ([ASC0023](#))

438 [Q 4](#) (Michelle Dyson)

439 [Q 155](#) (Michelle Dyson)

440 [Q 83](#) (Fazilet Hadi)

441 Croydon Council, ‘Service user involvement’: <https://www.croydon.gov.uk/health-and-wellbeing/service-user-involvement/> [accessed 22 September 2022]

442 Care Talk, ‘Making Everyday Co-production Real’: <https://www.caretalk.co.uk/opinion/making-everyday-co-production-real/> [accessed 21 November 2022]

### Devon County Council

The Council highlights the number of ways they ensure disabled adults and older people and unpaid carers can have their say. Adult social care engagement within Devon is coordinated by Devon’s Involvement and Equality Team, based within the adult commissioning part of the Council. They work in partnership with Living Options Devon as holders of a contract to provide local engagement activities, and undertake some activities themselves. The Council also commissions Healthwatch Devon, the local statutory consumer voice organisation and works with the County Council’s independent Equality Reference Group.<sup>443</sup>

280. We have already set out evidence that unpaid carers do not feel acknowledged, let alone represented or valued in society. This is particularly the case in policy making: there is no specific plan or strategy to support unpaid carers and they are not given a voice at senior levels of Government. One witness stated that “one of the fundamental problems about social care is that it is based on kindness and this does not seem to be valued by society in general.”<sup>444</sup>

### Learning from the best: the role of local authorities in generating and spreading change

281. As we have seen, some local authorities and local communities are already putting cultural change in place across social care to enable co-production, both at the level of residents’ individual care and at the level of policy design and delivery across the locality. These examples demonstrate the possibility of moving beyond policy pledges towards the effective implementation of co-production in social care. They provide avenues to explore to develop the practical tools that can lead to a genuine cultural change.

### *Embracing a new narrative*

282. A particular example that we would like to highlight is that of Wigan, presented as a “fantastic example of co-production.”<sup>445</sup> In 2011, Wigan Council kick-started a major project named the Wigan Deal, intended to bring a new approach to public services, and which launched initially in adult social care. Professor Hall, who was the chief executive of Wigan Council at the time, explained to us why this was the case: “We realised we were spending money on lots of things that were not very good and people did not actually enjoy them, but we thought they were the right thing for people because we had not listened,” she said.<sup>446</sup> In reality, the services that were provided were not what people needed or wanted.
283. The Deal was introduced in an attempt to become more efficient as the council faced drastic funding cuts. The project radically shifted the narrative from looking at residents as a collection of needs and problems to be fitted into a range of services, to viewing people as individuals who have strengths and talents, and who can be enabled to live the best life they can. It meant considering the strengths of individuals when carrying out assessments, such as their environment, life stories and interests; and looking at the bigger picture of peoples’ lives to enable them to take steps to improve their health

443 Devon County Council, ‘Adult Social Care Involvement and Equality’: <https://www.devon.gov.uk/haveyoursay/adult-social-care-and-health-engagement/> [accessed 22 September 2022]

444 Written evidence from Sandra Joyce (ASC0007)

445 Q 87 (Professor Donna Hall)

446 *Ibid.*

and wellbeing. Instead of letting professionals assume, often wrongly, what someone with a need for care or support might want, explained Professor Hall, the council prioritised having a conversation with the person to find out how they could be empowered to live a better life, “based on what they like doing rather than what we think they like doing.”<sup>447</sup> This narrative reflects the vision of adult social care that we endorse, in which people are treated and valued as equals, and in which it is understood that they are best placed to know the solutions that are most effective for them.

284. To enable this change, which was both practical and cultural, Professor Hall explained that staff in front-line teams were given “absolute permission to innovate,”<sup>448</sup> with the objective of enabling staff to rethink how they worked based on their conversations with residents. For instance, one member of the Wigan adult social care team took an older person roller-skating, in contrast to the typical trip to Marks & Spencer. While they broke their wrist, roller-skating was something that the older person had wanted to try and they made an informed decision to do so. As a result, the team member was backed by their manager. This compares with a feeling that social services often go too far to protect people from risk.<sup>449</sup> Thanks to this new way of working, the council was able to make savings, which it reinvested into the community and voluntary sector, as well as in preventative services, particularly in reablement, to ensure that people coming out of hospital stayed in their community.
285. The Wigan Deal illustrates the point made in a recent report led by Lady Cavendish that “there is a huge prize to be won” if the commissioning and regulation of care services is transformed.<sup>450</sup> She argues that commissioning services should be based on outcomes and truly focus on the individual, and that this can have a significant positive impact on costs and people’s wellbeing.<sup>451</sup> Achieving this requires a new model for the regulation and oversight of services, as well as giving care staff the autonomy to adopt a new approach to the delivery of care, in which they look after a whole person instead of merely following a process. The report points to the example of the not-for-profit home care provider Buurtzorg, which is based in the Netherlands, and is known for giving staff far greater autonomy and control over their daily work. Independent studies have found that in addition to higher levels of patient satisfaction, Buurtzorg’s costs are almost 40% less overall than competitor services.<sup>452</sup>
286. A study carried out by the King’s Fund into the impact of the Wigan Deal on adult social care established that the approach has similarly had promising results in the locality, both for professionals and residents. The CQC assessments show that the quality of social services in Wigan has improved, that the healthy life expectancy of residents has increased, and that the council performs well when it comes to supporting people to leave hospital and remain in the community. Staff engagement has also improved, as professionals feel

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447 Q 87 (Professor Donna Hall)

448 *Ibid.*

449 The King’s Fund, *A citizen-led approach to health and social care: Lessons from the Wigan Deal* (June 2019) pp 27–8: [https://www.kingsfund.org.uk/sites/default/files/2019-06/A\\_citizen-led\\_approach\\_to\\_health\\_and\\_care\\_lessons\\_from\\_the\\_Wigan\\_Deal\\_summary.pdf](https://www.kingsfund.org.uk/sites/default/files/2019-06/A_citizen-led_approach_to_health_and_care_lessons_from_the_Wigan_Deal_summary.pdf) [accessed 29 September 2022]

450 Baroness Cavendish of Little Venice, *Social care: Independent report by Baroness Cavendish* (February 2022), p 11: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1059888/social-care-reform-Baroness-Cavendish-report.pdf) [accessed 22 November 2022]

451 *Ibid.*, p 5

452 *Ibid.*, p 12

liberated to practice in a different and better way.<sup>453</sup> Crucially, the Wigan Deal was shown to be more sustainable, including economically. Working in this innovative way meant that people’s needs were better met, that they were more able to live healthy and fulfilling lives, and that they became less likely to constitute a strain on the social care system, as well as other public services. Professor Hall told us that before the Deal, Wigan City Council was spending on average £250,000 per year on families in need without seeing any significant improvements to these families’ situations; in contrast, since the Deal was established, the council made significant savings across all public services.<sup>454</sup>

287. The King’s Fund analysis of the success of the Wigan Deal states that “above all else, the Wigan Deal is a story of profound cultural change within the council and its partners.”<sup>455</sup> This came from a new set of “positive beliefs” about the purpose and outcomes of adult social care, and trust in the potential of staff and local residents to bring about the necessary change. The council succeeded in enabling this cultural change because it consistently embedded its new narrative across the local authority. The King’s Fund describes that “a common vision was forged early on” and “a clear narrative” was developed for all staff to refer to.<sup>456</sup>
288. The importance of having a clarity of purpose and a cohesive narrative to steer local authorities’ work in adult social care was also highlighted by Professor Tew, who argued that ensuring the “crystallisation of a vision” is key to successful change.<sup>457</sup> He explained that local authorities rarely manage to put the changes they would like to make into a “very clear, simple vision that everybody gets.”<sup>458</sup> Without this, however, it is challenging to ensure the success or the continuity of any reform. Professor Hall told us that “very often, people come in in a heroic leadership way, whether as a political leader or executive leader. They set out a vision; that person leaves and then there is a new version when a new person starts.”<sup>459</sup> In contrast, the Wigan Deal was designed as a long-term, more bottom-up cultural change across the whole community.
289. For this vision to be effective and successful, it must be co-produced with carers and older adults and disabled people, as well as building on the expertise of people who work in adult social care.<sup>460</sup> Many witnesses pointed to Think Local Act Personal’s (TLAP) framework ‘Making It Real’. This is a framework for how to do personalised care and support, for people working in health, adult social care, housing and for people who access services. TLAP described it to us as a way to take the principles and values that should underpin social care, as well as the existing policy and law, such as the Care Act 2014, and transform them into something “real and tangible”.<sup>461</sup>

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453 The King’s Fund, *A citizen-led approach to health and social care: Lessons from the Wigan Deal* (June 2019) p 5: [https://www.kingsfund.org.uk/sites/default/files/2019-06/A\\_citizen-led\\_approach\\_to\\_health\\_and\\_care\\_lessons\\_from\\_the\\_Wigan\\_Deal\\_summary.pdf](https://www.kingsfund.org.uk/sites/default/files/2019-06/A_citizen-led_approach_to_health_and_care_lessons_from_the_Wigan_Deal_summary.pdf) [accessed 29 September 2022]

454 Q 87 (Professor Donna Hall)

455 The King’s Fund, *A citizen-led approach to health and social care: Lessons from the Wigan Deal* (June 2019) p 5: [https://www.kingsfund.org.uk/sites/default/files/2019-06/A\\_citizen-led\\_approach\\_to\\_health\\_and\\_care\\_lessons\\_from\\_the\\_Wigan\\_Deal\\_summary.pdf](https://www.kingsfund.org.uk/sites/default/files/2019-06/A_citizen-led_approach_to_health_and_care_lessons_from_the_Wigan_Deal_summary.pdf) [accessed 29 September 2022]

456 *Ibid.*

457 Q 127 (Professor Jerry Tew)

458 *Ibid.*

459 Q 87 (Professor Donna Hall)

460 Q 127 (Professor Jerry Tew)

461 Q 86 (Ian McCreath)



Making it Real takes the form of a set of principles called ‘I’ statements, which describe what good looks like from the perspective of people with care needs; and ‘We’ statements, which describe how organisations can meet the ‘I’ statements. All of the ‘I’ statements have been co-produced, meaning that the framework can be used as a tool to frame the conversation in a way that ensures a vision, purpose and focus that are rooted in co-production.<sup>462</sup>

290. The framework is designed to help decision makers understand what their actions and priorities should be in order to achieve principles such as choice, control or person-focused care and support. The CQC is adopting it as part of its new assurance framework from 2023.<sup>463</sup> TLAP has been working with several local authorities to implement the framework, including Leicester City Council, who told us that Making It Real has played a significant role in helping the council to work more closely with residents and to put people’s voices at the centre of reform.<sup>464</sup>

*The workforce: a key to unlocking cultural change*

291. Better training and upskilling for social workers was frequently described as critical to enable the success of co-production and cultural change within local authorities. Professor Hall said that bringing the workforce onboard with the project was crucial. She hired an anthropologist to retrain all of the council’s adult social care workers “to listen deeply” rather than “just assume what we knew was best for people”; and a ‘Different Conversation Toolkit’ was designed for staff.<sup>465</sup>
292. We heard from Martin Samuels, Strategic Director for Social Care and Education at Leicester City Council, who told us that the council is now undertaking work to understand the challenges to engaging with residents, in an effort to bring “user-led” voices to the centre of services. This has meant revising guidance and policy to make processes more person-centred; changing the assessment and review process; and retraining staff to ensure that they “focus on the individual.”<sup>466</sup> For example, staff have been trained to move away from processes and towards individuals—making them accountable for the outcome of the individual rather than simply being able to say that they followed the process.
293. Mr Samuels noted that some staff found it challenging: “They have found it culturally a real threat to their position in the system and their way of thinking.”<sup>467</sup> This was echoed by Mr Billingham, Director, Adult Social Care, Thurrock Council, who noted professional scepticism and cultural resistance when Thurrock Council introduced Local Area Coordination. This was particularly the case as budgets reduced, and LAC increasingly became perceived as a non-statutory service that could more easily be stopped. He described how concerns dissolved after people started seeing the positive outcome of the scheme.<sup>468</sup> “We held our nerve and our ground, and I am so pleased we did, because it has been the fulcrum upon which all of our transformation since has been built,” concluded Mr Billingham.<sup>469</sup>

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462 *Ibid.*

463 [Q 86](#) (Ian McCreath)

464 [Q 167](#) (Martin Samuels)

465 [Q 87](#) (Professor Donna Hall)

466 [Q 167](#) (Martin Samuels)

467 [Q 166](#) (Martin Samuels)

468 [Q 92](#) (Les Billingham)

469 *Ibid.*

294. The British Association of Social Workers also highlighted that meaningful participation with people, families and carers requires “a skilled approach” or runs the risk of becoming “tokenistic”.<sup>470</sup> Improving the assessment of local authorities’ performance regarding co-production is encouraging, therefore, and we welcome official commitments to the principles of co-production. The challenge, however, lies in enacting these principles in practice. To enable this, it is necessary to reskill the workforce, to ensure that co-produced approaches to care are embedded in professionals’ processes.
295. *The Government should ensure that the definition and vision for social care that is proposed by Social Care Future, as specified previously, is endorsed in principle by all national social care bodies (such as Social Work England, the Care Quality Commission and Skills for Care) to put the best ambitions and values of the workforce into policy and practice more effectively.*
296. *The Government should work with local authorities, the voluntary sector and social care providers to embed the principles of co-production. This means working with social care staff to enable them to acquire the support and skills necessary to co-produce care and enable a shift in power from staff to individuals who draw on care and support.*

*Sharing good practice and robust data*

297. The benefits of co-production are also evident in the innovative ways that have emerged in terms of developing, embedding and scaling-up good practice through, for example, informal channels of sharing information. For instance, national innovations such as the Local Area Coordination Network bring together a diverse range of stakeholders working to develop strength-based approaches. Likewise, academics at the University of Birmingham have studied practice across local authorities, examining the development of preventative and capacity building activities through a range of models.<sup>471</sup> Just as people who draw on care and support, local authorities and their partners benefit from peer support: “There is a chance for them to compare notes, support each other, and learn from each other’s mistakes in a wider community of practice.”<sup>472</sup>
298. However, existing networks are often informal and underutilised. For instance, Shared Lives highlighted how there is a Shared Lives scheme in most local authorities, yet these are relatively unpublicised compared to traditional methods of care.<sup>473</sup> There is also a lack of reliable data and evidence-based research that could help identify the exact costs and benefits of new approaches to social care. It can also be difficult for local authorities and other stakeholders to evaluate new ways of working and to understand the costs, benefits and limitations of new models. However, there are lots of positive examples and a growing range of support available from organisations such as the Social Care Institute for Excellence, the NIHR School for Social

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470 Written evidence from the British Association of Social Workers England ([ASC0087](#))

471 University of Birmingham, ‘Implementing the Care Act 2014: Building social resources to prevent, reduce or delay needs for care and support in adult social care in England’: <https://www.birmingham.ac.uk/schools/social-policy/research/adult-social-care/care-act.aspx> [accessed 29 September 2022]

472 [Q 127](#) (Professor Jerry Tew)

473 Written evidence from Shared Lives Plus ([ASC0052](#))

Care Research and IMPACT (the new UK centre for implementing evidence in adult social care).<sup>474</sup>

299. *Good policy and practice have been conspicuously inhibited by a lack of data. The Government, as a priority, should invest in robust data collection to reveal the conditions and characteristics of the social care sector and inform effective practice.*

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474 Social Care Institute for Excellence, ‘SCIE latest’: <https://www.scie.org.uk/> [accessed 17 October 2022]; NIHR School for Social Care Research, ‘Home’: <https://www.sscr.nihr.ac.uk/> [accessed 17 October 2022] and IMPACT, ‘Home’: <https://more.bham.ac.uk/impact/> [accessed 17 October 2022]

## CHAPTER 6: INDEPENDENT LIVING: “MAKING IT REAL”

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300. This chapter looks at how, if the adult social care system optimised independence and offered appropriate alternatives and choices for people who draw on care, the situation of unpaid carers could in many ways be transformed. The solutions for independent living, including direct payments, adaptable and appropriate housing, and the better use of enabling technologies, are all within reach with investment and political determination.
301. Much of this chapter emphasises the need to make what exists already to support independent living work better and universally, rather than being confined to instances of local good practice. In many cases, this means putting the choice of a personal assistant through direct payments within the reach of more people.
302. Alongside personal assistance, accessible and inclusive housing is key to enabling independent living. This chapter will explore the importance of finally grasping the necessity of providing adaptable, accessible and appropriate housing for people and families with care needs. Linked to this is the challenge to take advantage of the difference that new technologies can make in housing and in everyday life, to the benefit of disabled adults and older people, and unpaid carers.
303. For individuals who draw on care, the key question in this process is: ‘who’ and ‘how’. As one expert by experience told us:

“It is a universal proposition that if you want to live your own lifestyle and make your own choices about what you do, one of the prime ways of doing that is to have control over who provides your assistance and, importantly, how they provide that.”<sup>475</sup>

In other words, people with care needs must be able to choose whether they prefer to draw on care from unpaid carers, from paid carers, or from a mix of both. The first step towards exercising this choice is to have access to reliable advice and information about the options that are available.

### Reliable advice and information: the key to achieving independent living

304. There are already options in place to enable people to have greater independence. We were repeatedly told, however, that the first barrier to accessing these options is the lack of information about them. It is local authorities’ duty under the Care Act 2014 to establish a service that provides information and advice relating to care and support to individuals who draw on care in their area,<sup>476</sup> yet people with care needs are often not even aware of the fact that they have a choice when it comes to determining the nature of their care and support and of the relationships with their friends and families, because they are not proactively given meaningful information about possible alternatives. One expert by experience told us that a key barrier was “not knowing what was available from social care”: his local authority gave him “very little support” and he had to rely instead on advice from charities and

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475 Q 51 (Ian Loynes)

476 Care Act 2014, [section 4](#)

others who were more familiar with the system. He told us: “It was a chasm of the unknown.”<sup>477</sup>

305. We were told by many witnesses that the best source of information for older adults and disabled people is their peers, and that the highest quality of advice and support comes from “people who have been there and done that.”<sup>478</sup> One witness told us: “If you want a plumber, you ask your friend who you know has recently had a plumber because they know, so it is exactly the same principle.”<sup>479</sup> People who draw on care are the best problem solvers for others who draw on social care; they know what solutions might work and what is unlikely to bring positive change, simply by living their lives and going through similar challenges.<sup>480</sup> Some people sometimes need specific input from well-trained and expert health professionals, but everyone needs peer support.

306. In some places, people who need to find the right care are well supported. Local organisations led by people who draw on care include, for example, centres for independent living or disabled people’s organisations. These organisations are intended to provide advice, information and support to people with care needs, to enable them to achieve independent living, whether that is with or without the support of an unpaid carer. We visited a highly effective and popular disabled people’s organisation in London, where we were told that there were hundreds of examples of similar organisations helping their peers “get their rights”.<sup>481</sup> Ian Loynes, the CEO of a centre for independent living called SPECTRUM, told us that peer support is “critical” to help people be informed, and he described his work as passing on “the knowledge and experience of how to live independently to others”.<sup>482</sup> Adolf Ratzka, the father of the independent living movement in Sweden, who created the first Swedish peer-led organisation in 1984, described to us how members would help each other prepare for assessments:

“We trained each other in defining our needs in sessions for preparing ourselves for the needs assessment ... We all went through these processes to defend our own needs assessments to get a reasonable evaluation of what someone needed in terms of the number of assistance hours so that they could convincingly convey that to the assessors of the Social Insurance Fund.”<sup>483</sup>

307. In 2009, the Health and Social Care Independent Living Bill [HL], a Private Members’ Bill, was introduced in the House of Lords, which proposed to make it a duty for every local authority to secure the availability of “an appropriate and sufficient range of independent advocacy services for disabled persons.”<sup>484</sup> The Bill never received Royal Assent. Witnesses told us that the current situation is far removed from what it had set as an objective. Mr Loynes told us:

“I have never seen a commissioning document that places some value on the principle of informing, peer support and making sure that people

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477 [Q 23](#) (Andy McCabe)

478 [Q 142](#) (Tricia Nicoll)

479 *Ibid.*

480 [Q 32](#) (Sue Bott)

481 Summary of Adult Social Care Committee visit to Real, 6 September 2022: Appendix 4

482 [Q 50](#) (Ian Loynes)

483 [Q 100](#) (Adolf Ratzka)

484 [Health and Social Care \(Independent Living\) Bill \[HL\]](#), clause 6(2)(b) (2009–10)



have informed choice about how they choose to live their life and get the help they need in a social care setting.”<sup>485</sup>

Enabling access to peer-led organisations, therefore, is currently not a priority. Instead, the situation has got worse. Many of these organisations have lost “massive amounts of funding” over the last decade<sup>486</sup> or even ceased to exist. As a result, one witness described to us how peer-led organisations “are being decimated.”<sup>487</sup>

308. If disabled people and older adults are to have equal access to peer-led organisations, there needs to be a dedicated strategy to bring back to life the objective laid out in the Health and Social Care Independent Living Bill, and ensure that every local authority commissions one or several peer-led organisations as part of its adult social care strategy.
309. These organisations must be seen as a ‘critical friend’ that is independent from the local authority to ensure that the advice and information provided are truly needs led, instead of financially led.<sup>488</sup> There needs to be scope for these organisations to challenge the assessment process and the level of provision of support given by the local authority where this is necessary. Witnesses warned us, however, that there is a risk, from the moment that a local authority is funding an organisation, that the funding is withdrawn if the organisation becomes a source of challenge to the council, which ultimately would be counterproductive.<sup>489</sup> Only total independence will guarantee a level of protection against the risk of intimidation and the withdrawal of funding. One witness recommended that one way forward would be to base commissioning and funding decisions on the feedback provided by receivers of the organisation’s services, rather than on the views of the local authority on the effectiveness of the organisation.<sup>490</sup>
310. **Under the Care Act 2014, local authorities have a duty to provide information and advice to residents about care and support. *The Government should enable local authorities to extend local support to those who need advice and information because they have care needs or provide unpaid care. This should be done through specific funding to commission peer-led independent organisations over at least a three-year period to enable innovation and capacity building.***

### **Empowering the individual: expanding direct payments and personal assistance**

311. The one scheme that is universally and currently available to enable disabled adults and older people to live independently, direct payments, has so far failed to live up to expectations.
312. Direct payments mean that, instead of receiving care services that the local authority has arranged, individuals with care needs are given payments that they can use to organise their own care. These payments are tailored to the amount of money their needs have been assessed to cost. The major difference they bring is that they can be used to hire personal assistants,

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485 [Q 53](#) (Ian Loynes)

486 [Q 83](#) (Fazilet Hadi)

487 [Q 142](#) (Tricia Nicoll)

488 [Q 33](#) (Andy McCabe)

489 [Q 144](#) (Andy McCabe)

490 *Ibid.*

who can be employed directly or indirectly by the person, so that the person controls the ‘who, when, what and how’ of how care is delivered.

313. Direct payments are used in several countries. In Sweden, for example, the legislation that enables direct payments and personal assistance was introduced in 1993, as the Independent Living movement grew across the country. Mr Ratzka told us that the uptake of direct payments and personal assistance once the legislation was implemented was “incredibly fast”: “so many people wanted to have the scheme, so many people had been marginalised, kept at home or in institutions, and had not been able to be part of the community,” he said.<sup>491</sup>
314. In Australia, a National Disability Insurance Scheme was introduced in 2013 to provide funding directly to eligible people with a disability, to enable them to pursue the support and services they need.<sup>492</sup>
315. Direct payments have the potential to make a significant difference. Experts by experience agreed that direct payments and personal assistance are currently the most effective way to achieve independent living. Mr Loynes, for example, told us that while he feels that care and support provided by his family will never enable him to live on his own terms,<sup>493</sup> the PA model of care is empowering. “I employ my PAs and therefore I can dictate what they do. They get paid for what they do and there is a proper relationship there, not a kind of lopsided relationship.”<sup>494</sup> Another witness told us that the PA model enabled him to train people up to the way he likes to live and the things he likes to do, allowing for care and support that is much more tailored to his personal life.<sup>495</sup>
316. There are many indications from the evidence we received and the broader literature to suggest that direct payments can bring greater choice and control, and that this can help some people achieve more ordinary lives.<sup>496</sup> Mr Ratzka also pointed to the fact that the PA model of care has enabled him to contribute to society far more than if he received institutional services: he has been able to move from Germany to the US to be educated, completed a PhD, then moved back to Sweden to carry out academic research. “Personal assistance has given me a rich and fulfilling life. It has given me the ability to contribute to society,” he concluded.<sup>497</sup>
317. However, there remain cultural and practical barriers which stop this being the case for everybody. For instance, one study suggested that while direct payment users appreciated the control conferred by budget ownership, in

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491 [Q 98](#) (Adolf Ratzka)

492 National Disability Insurance Scheme Act 2013, [section 8](#)

493 [Q 46](#) (Ian Loynes)

494 [Q 50](#) (Ian Loynes)

495 [Q 145](#) (Andy McCabe)

496 British Council of Organisations of Disabled People, *Cashing In on Independence* (1994) p 6: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Zarb-cashing-in-on-indep.pdf> [accessed 28 September 2022]; Jon Glasby and Rosemary Littlechild, *Direct payments and personal budgets: putting personalisation into practice*, 3rd edition (Bristol: Policy Press, 2016) and Catherine Needham, and Jon Glasby (eds), *Debates in personalisation* (Bristol: Policy Press, 2014).

497 [Q 99](#) (Adolf Ratzka)

practice for many it did not translate into improved living arrangements.<sup>498</sup> People’s experiences can also vary in different parts of the social care system. For example, some older people may receive support which has been reduced to the bare minimum, so that it is often not possible to do anything other than meet basic needs, whether the person has a direct payment or receives a direct service. Moreover, widespread provision of advice and information by local authorities to recipients is crucial for the success of direct payments.

318. Economic evidence is also patchy, making it difficult for the Government and local authorities to invest in such ways of working with full confidence. It is difficult to estimate the cost and benefits of direct payments and personal assistance, because of the need for counter-factual evidence as to what the alternatives might have cost; but as one witness argued, “people who make an informed choice will have better outcomes and be less expensive for the state to look after when things go wrong.”<sup>499</sup> We therefore call for a cost-benefit analysis of independent living, to give future governments the evidence they need when devising future policy in such a crucial area of practice and of people’s lives.
319. For many years, it has been the policy of successive governments to expand direct payments and the PA model of support. As early as 1989, the BCODP Independent Living Committee was set up and initiated the Direct Payments campaign, with the objective of changing the legislation to make it easier for local authorities to establish direct payment schemes.<sup>500</sup> In 1997, after the Committee published its report on the efficiency of direct payments, the Direct Payments Act was implemented, allowing local authorities to make payments to individuals to enable them to secure the provision of care services.<sup>501</sup>
320. Since then, direct payments have found growing political support. Today, direct payments are described by Government and policy makers as the most desirable solution for people with care needs. The statutory guidance for the Care Act 2014 states that direct payments are “the Government’s preferred mechanism for personalised care and support.”<sup>502</sup> The Government’s 2021 White Paper also included a commitment to ensuring that direct payments are understood and encouraged across the NHS, local authorities, care providers, voluntary and community groups, and the wider sector.<sup>503</sup> Box 7 shows some examples of best practice by local authorities in relation to direct payments.

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498 John 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 person budget or a direct payment’, *Ageing & Society*, vol. 37, (2017), pp 961–984: <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/772F12193787151D336404176681E79E/S0144686X15001531a.pdf>

499 Q 50 (Ian Loynes)

500 Independent Living Institute, *The Independent Living Movement in the UK* (2003): <https://www.independentliving.org/docs6/evans2003.html> [accessed 18 September 2022]

501 The Community Care (Direct Payments) Regulations 1997 (SI 1997/734)

502 Department of Health and Social Care, *Care and support statutory guidance* (November 2022): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> [accessed 8 November 2022]

503 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 16: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 28 September 2022]

### Box 7: Direct payments example of best practice: Hammersmith and Fulham Council

In 2018, an independent review carried out by an organisation run and controlled by disabled people, looked at direct payment support in the borough and made several recommendations to improve things. Residents who use direct payments have worked with the council to find new ways to support better use of direct payments in response to the report’s recommendations. Work has included:

- With disabled residents, setting out what good direct payment support looks like. This has set the standard of what people can expect and makes up part of what the direct payment support service must deliver.
- Setting up a new direct payment support service, funded by the council from January 2020, based at Action on Disability, a local disabled people’s organisation. The service delivers all aspects of direct payment advice and support as well as facilitating peer support so direct payment users learn and gain strength from each other.
- Direct payment users have been team members of the steering group to support and oversee the contract for the direct payment support service.
- Residents working with the council to co-produce improvements to make it easier and smoother to set up direct payments.

Source: Hammersmith and Fulham Council, ‘What Are We Doing?’: <https://www.lbhf.gov.uk/councillors-and-democracy/co-production/what-are-we-doing> [accessed 28 September 2022]

321. Despite these efforts, the take-up of direct payments remains low. Only a quarter of eligible individuals use them. Data from NHS Digital shows that in 2020/21, the proportion of people who use services who received direct payments stood at 26.6%.<sup>504</sup> The crucial barriers, in addition to a cultural context which makes genuine choice and control difficult to exercise for disabled adults and older people, seem to be the lack of accessible information, the lack of support for managing the day-to-day employment of PAs; and the sheer shortage of PAs.
322. We were told, in effect, that one of the first barriers to accessing direct payments and personal assistance is the lack of knowledge and access to information about this option.<sup>505</sup> As we have already suggested, this can be resolved in part by expanding the availability of peer-led organisations, many of which actively work to support other disabled adults and older people to understand and implement their own PA scheme. According to Mr Loynes, peer-led organisations are the most effective way to normalise personal assistance and bring the model to more people. He argued that the current number of individuals who receive personal assistance is largely due to “word of mouth and background knowledge,” rather than to any official promotion campaign about what the system is.<sup>506</sup>
323. These organisations can also support older adults and disabled people in overcoming some of the barriers they face while setting up a PA scheme. For example, we were told that for many people, the perspective of becoming an employer of personal assistants, and of managing human resources-

504 NHS Digital, *Measures from the Adult Social Care Outcomes Framework* (October 2021) p 17: <https://files.digital.nhs.uk/57/AB0038/meas-from-asc-of-eng-2021-ASCOf-report.pdf> [accessed 29 September 2022]

505 [Q 145](#) (Andy McCabe)

506 [Q 52](#) (Ian Loynes)

related issues, can be overwhelming. In addition, the service provided can be unpredictable. As Mr Loynes explained, if a PA fails to turn up in the morning because of an emergency, the impact on the person who needs their support can be traumatic.<sup>507</sup> In many cases, peer-led organisations can help with these issues. SPECTRUM, for instance, helps members with recruiting staff and dealing with human resources, while enabling the older or disabled person to have control over who they are employing.<sup>508</sup> This, however, is not universal practice. Another barrier is the unnecessary and burdensome amount of monitoring information recipients are required to provide in some local authorities.

324. However, the overwhelming problem made forcefully and consistently seems to be the difficulty of recruiting PAs and retaining them. We were told that there is a severe lack of supply of personal assistants, leaving many people without critical care and support, and affecting their mental and physical health. A survey carried out among 1,000 people using personal assistance between 2020 and 2022 showed that 77% of respondents have found it more difficult than before to recruit a PA. The main reason for this, according to the survey, is that people are taking jobs with better pay.<sup>509</sup>
325. The report also found that people are finding it difficult to recruit PAs who have the appropriate skills for the role: 59% of respondents said that they were finding it harder to find the right PAs for them.<sup>510</sup> This echoes what we heard during a Committee visit to a disabled people’s organisation in London, where we were told that many of the people who come to the sector do not have the appropriate training or values.<sup>511</sup> In addition to technical skills related to care and support, being a PA requires empathy and being prepared to understand how a person likes to live their life and adapt to their own terms. It is a profession that involves crucial personal skills and finding candidates who have these skills and values is becoming increasingly difficult for people looking to recruit a PA. This is compounded by the fact that most debates about the current challenges faced by social care focus on care workers in domiciliary and residential care, which means that the difficulties of recruiting PAs have been largely invisible. Best practice in recruitment is described in Box 8.
326. Another high barrier is that not enough is known about what PAs do and what their role consists of. One witness told us that, while many people would currently never consider becoming a PA, it is in reality “quite flexible” and different from a usual “nine-to-five job”.<sup>512</sup> Another user of personal assistance argued that if personal assistance were to be re-established as a valuable and highly skilled role, “many will intuitively see that as a vocation, as a career.”<sup>513</sup> Increasing people’s awareness of the nature and value of personal assistance, therefore, could attract more people into the profession. More, however, is needed than publicity. A precursor to this change would be to re-evaluate the pay and working conditions for personal assistance; as

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507 Q 51 (Ian Loynes)

508 *Ibid.*

509 Think Local Act Personal, *The forgotten workforce: Recruiting and retaining personal assistants* (July 2022) p 4: <https://www.thinklocalactpersonal.org.uk/assets/Reports/Personal-Assistant-Survey-The-Forgotten-Workforce.pdf> [accessed 29 September 2022]

510 *Ibid.*, p 8

511 Summary of Adult Social Care Committee visit to Real, 6 September 2022: Appendix 4

512 Q 145 (Andy McCabe)

513 Q 52 (Ian Loynes)



well as to ensure that PAs have appropriate training, so that they understand what providing personal care and support involves. This should be prioritised as part of the workforce strategy that the Government should put in place, as we recommended in Chapter 4.

**Box 8: ENABLE Scotland: Best practice in enabling the recruitment of personal assistants**

ENABLE Group provides self-directed health and social care to people in Scotland, through the PA model. ENABLE supports individuals in planning and designing the services they want, so that they can build their own bespoke team of PAs.

The CEO of ENABLE Theresa Shearer told us that the main barrier to implementing a PA scheme is the lack of confidence that individuals and families have when it comes to being a recruiter and an employer. The organisation therefore runs an internal recruitment agency that facilitates the recruitment and onboarding processes for PAs. The agency works to people’s demands and criteria to ensure that the personal assistants hired are tailored to each individual’s needs.

In parallel, the agency ensures that it attracts the right people into the profession. Individuals are recruited for their values and experiences, but not necessarily their social care experience. The emphasis is placed on their soft skills. ENABLE also pays PAs more than the Scottish living wage. According to Theresa Shearer, one-third of the organisation’s workforce earns between £11 and £12 an hour.

ENABLE’s model, therefore, ensures that older adults and disabled people can recruit PAs that are right for their individual needs, without worrying about the recruitment process or human resources-related challenges. It also means that those joining the recruitment agency are driven by the right motivations, and that they have the appropriate soft skills to be a PA. This in turn enables personal assistance to become more attractive as a profession.

Source: [Q 104](#) (Theresa Shearer)

327. Normalising direct payments and personal assistance needs to become more than a policy pledge. The mechanisms exist to drive direct payments into the mainstream and to ensure that people who wish to achieve independent living without the support of unpaid carers, whether by choice or because they do not have friends or family members available to provide care and support, are aware of the options that are available to them. As one expert by experience told us, it is necessary to ensure that families and individuals who require support are given a free choice in how it is provided. This means that:

“The options given are clear, and that includes the option of saying, ‘Yes, I live with my parent, parents or partner but I don’t want them to have to provide X amount of care; I would like my care package to reflect this,’ without a battle.”<sup>514</sup>

328. This is only possible if there is an easy access to direct payments and personal assistance. More needs to be done, therefore, to understand how direct

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514 [Q 145](#) (Andy McCabe)

payments and personal assistance can be made easier and smoother to set up, drawing on examples of best practice such as those described in Box 7.

329. *As part of its adult social care workforce plan, the Government must commission an independent review of the pay and working conditions for personal assistants.*
330. *The Government should set aside some of the specific funding identified in the White Paper to develop innovative models to make direct payments and personal assistance easier to access and manage, and to simplify the recruitment of personal assistants.*

### **The importance of accessible and inclusive housing**

331. Accessible and inclusive housing is central to enabling independent living. As one expert by experience told us: “When the disabled people’s independent living movement first listed the conditions that need to be in place in order for disabled people to choose how and where they live, suitable housing was at the top.”<sup>515</sup>
332. General Comment No. 4 of the UN Committee on Economic, Social and Cultural Rights enshrines a human right to adequate housing.<sup>516</sup> However, for people with care needs and disabilities, this human right has never been within reach. For decades the lack of accessible and inclusive housing, the failure to invest strategically and sustainably in ‘Care and Repair’ schemes and the failure to plan at market level for an ageing society which wants to remain independent for as long as possible and ‘age in place’ and therefore needs housing which is flexible and adaptable, has not been a significant housing priority. The voice of disabled adults and older people has simply not been taken into account when housing is planned or designed. Too often, people having to make a sudden choice about where to move to are unaware about the alternatives to institutional care offered by supported housing or adaptations to existing homes.<sup>517</sup>
333. The Government has started to address the problem. The Disabled Facilities Grant is available for disabled people who wish to make changes to their home, although this can be a lengthy process—changes require council approval and only need to be completed within 12 months of the grant being approved.<sup>518</sup> The 2021 White Paper recognised the importance of making homes fit for purpose, including plans to encourage more development of supported and retirement housing and extra care schemes, and made a funding commitment of £300 million to help health, local authority and other partners to plan strategically across housing, health and care to meet the needs of local communities.<sup>519</sup> In June 2019, the Government also

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515 [Q 113](#) (Clive Gilbert)

516 United Nations Committee on Economic, Social and Cultural Rights, ‘General comment No. 4: The right to adequate housing (art. 11 (1) of the Covenant)’, Sixth Session (1991) p 1: [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCESCR%2fGEC%2f4759&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCESCR%2fGEC%2f4759&Lang=en) [accessed 27 September 2022]

517 Written evidence from the Chartered Institute of Housing ([ASC0127](#))

518 HM Government, ‘Disabled Facilities Grant’: <https://www.gov.uk/disabled-facilities-grants/eligibility> [accessed 14 November 2022]

519 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 7: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

published guidance for councils on housing for older adults and disabled people.<sup>520</sup> This is but a start.

334. At transitional points, particularly in relation to discharging patients from hospital into appropriate and safe accommodation, one of the greatest failures in health and social policy has been the neglect of housing as a key determinant of what is necessary and possible. This is exacerbated by the lack of affordable, accessible and inclusive housing and supported accommodation.
335. This problem will only get worse due to the UK’s ageing population and increase in people drawing on care. Investment is needed to ensure that housing stock is adaptable and safe so that people can remain independent.<sup>521</sup> The Welsh Government, for instance, has announced a £181.5 million Housing with Care Fund to increase the stock of housing to meet the needs of people with care and support needs.<sup>522</sup> Unsuitable housing can result in residents being trapped at home, the indignity of not being able to live independently, poorer mental health, a reduction in the ability to work and feelings of social isolation and anxiety.<sup>523</sup> Without accessible and adaptable housing, disabled adults and older people risk facing not only discrimination and disadvantage in housing, but also isolation and poorer health.
336. Moreover, according to the Centre for Ageing, across the UK in 2017 21% of homes occupied by someone age 75 or over were classed as “non-decent.”<sup>524</sup> The privately rented sector is particularly challenging: the Equality and Human Rights Commission found that one in three disabled people living in the private rented sector, one in five in social housing, and one in seven in their own home, were in unsuitable housing.<sup>525</sup> Likewise, 50% of Local Plans do not have any provision for retirement housing and only 31.5% of the new homes planned between 2020 and 2030 will meet accessibility standards. Provision varies regionally: in the West Midlands, there are no accessible homes planned.<sup>526</sup> Guy Harris, Director, AccessiblePRS, said that the disabled facilities grant—given by councils to disabled people to make changes to their home—while “wonderful” in theory, in practice it is “a postcode lottery”.<sup>527</sup>
337. Witnesses told us that the lack of choice for individuals with care needs when it comes to accessible and inclusive housing can, once more, be linked to the discriminatory narrative that surrounds older adults and disabled people in wider society. Mr Harris pointed to “the narrative that accessibility and

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520 Department for Levelling Up, Housing and Communities and Ministry of Housing, ‘Communities and Local Government, Housing for older and disabled people’ (26 June 2019): <https://www.gov.uk/guidance/housing-for-older-and-disabled-people> [accessed 27 September 2022]

521 Written evidence from Bristol City Council (ASC0076)

522 Welsh Government, Housing with Care Fund (HCF): *Guidance 2022–2023* (May 2022): [https://gov.wales/sites/default/files/publications/2022-05/housing-with-care-fund-hcf-guidance-2022-2023\\_0.pdf](https://gov.wales/sites/default/files/publications/2022-05/housing-with-care-fund-hcf-guidance-2022-2023_0.pdf) [accessed 26 September 2022]

523 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018): [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

524 Written evidence from Bristol City Council (ASC0076)

525 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018): [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

526 Written evidence from the Chartered Institute of Housing (ASC0127)

527 Q 111 (Guy Harris)

disability are a very foreign concept that has no relevance to our lives”.<sup>528</sup> In other words, building housing that is accessible for older adults and disabled people is not seen as a priority, but as an issue that only affects others. Mr Harris highlighted how “strange” this is, since older age and disability are likely to affect most people.<sup>529</sup> Moreover, there is a need to consider appropriate housing for young adults who desire a choice of who they live with and where. They require the option of living with people of a similar age, with similar interests, rather than living in the same homes as older people. This goes back to the challenge of invisibility discussed in Chapter 2.

338. Social housing is particularly pressured, with long waiting lists. Over one million households are waiting for social homes. Last year, 29,000 social homes were sold or demolished, and less than 7,000 were built.<sup>530</sup> Witnesses emphasised that the Government should increase availability of affordable and social rented housing.<sup>531</sup>
339. Moreover, systems used to identify disabled people’s requirements and deliver accessible houses are weak. Data again is partial and inadequate for good decision making. Only 12% of local authorities rated the data available to them on local disabled people’s needs as ‘good’ or ‘very good’.<sup>532</sup> One notable exception—to which other councils should look—is Hammersmith and Fulham Council, which has produced a disabled people’s housing strategy, which outlines objectives of co-production; improvement of access to housing information; improvement of the council’s services as a landlord for disabled residents; and identification of ways to increase the supply of accessible and affordable housing.<sup>533</sup>
340. Information on the accessibility of properties is particularly poor in the private sector. Estate agents, for example, do not typically provide information about the accessibility of private lets or houses for sale.<sup>534</sup> Among the advice we received was that councils should:
- provide independent sources of information and advice for people on housing, support and care services for people with care and support needs and their carers;
  - develop local and regional registers of existing adapted properties across all tenures which should be part of the information available, help to access this and match households with suitable housing opportunities; and

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528 [Q 106](#) (Guy Harris)

529 *Ibid.*

530 Shelter, ‘Social housing deficit’: [https://england.shelter.org.uk/support\\_us/campaigns/social\\_housing\\_deficit](https://england.shelter.org.uk/support_us/campaigns/social_housing_deficit) [accessed 1 November 2022]

531 Written evidence from the Chartered Institute of Housing ([ASC0127](#))

532 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018): [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

533 Hammersmith and Fulham Council, *Disabled people’s housing strategy 2021* (February 2021): [https://www.lbhf.gov.uk/sites/default/files/section\\_attachments/hf-disabled-peoples-housing-strategy-2021.pdf](https://www.lbhf.gov.uk/sites/default/files/section_attachments/hf-disabled-peoples-housing-strategy-2021.pdf) [accessed 29 September 2022]

534 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018): [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

- combine this information with hubs to help disabled adults and older people access help to repair and improve their homes and get suitable adaptations.<sup>535</sup>
341. Few local authorities across Britain set targets for accessible housing and developers are reluctant to build accessible houses, as they see them as cutting profit margins. Developers are more likely to negotiate to the lowest allowable standards.<sup>536</sup> As put by Mr Harris, a “developer that has bought land is doing what they know best to ensure profit. Getting developers on side has to happen at policy level, and that is a Government issue”.<sup>537</sup>
342. One exception to this trend is London, where higher accessible and adaptable standards have been the default for many years. From 2004 to 2016, the London Plan included requirements for developers in the capital to build homes to the Lifetime Home standard—a concept developed in the early 1990s by a group of housing experts, and which included 16 design criteria that could be applied to new homes to ensure that they were inclusive, accessible, adaptable, sustainable and good value.<sup>538</sup> In 2016, following the Government’s review of housing standards, the London Plan was reviewed to reflect these new standards. The 2021 plan requires all new residential dwellings to be accessible and adaptable, as per the M4(2) standard described below; and at least 10% of new dwellings to be wheelchair accessible.<sup>539</sup> However, an overall lack of affordable social housing in London means that, even if standards are appropriate, supply is still an issue.
343. *Ad hoc* solutions, discretionary guidance, and the goodwill of developers are not enough. There needs to be leadership to ensure that minimum accessible housing standards become the norm not the exception. The most common and persuasive proposal is that the Government amend requirement M4(2) of Schedule 1 to the Building Regulations 2010, so that it is no longer an optional requirement, but instead the mandatory minimum standard for the design and delivery of all new housing.<sup>540</sup> M4(2) states that, where developers choose to adhere to the requirement, “reasonable provision” must be made for people to gain access to and use a residence and its facilities. These should be sufficient to meet the needs of occupants with differing needs, including “some” older or disabled people, and to allow adaptation in case of changing needs.<sup>541</sup> Mr Harris emphatically stated that “nothing will change until the Government mandates minimum accessible housing standards.<sup>542</sup> We therefore welcome the Government’s statement in July 2022 that it will

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535 Written evidence from the Chartered Institute of Housing ([ASC0127](#))

536 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018), p. 8: [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

537 [Q 107](#) (Guy Harris)

538 Mayor of London, *The London Plan: Spatial Development Strategy for Greater London* (February 2004) p 58: <https://www.london.gov.uk/file/177530/download?token=tDX4jWVq> [accessed 28 October 2022] and Habinteg, *Accessible Housing Standards 2015* (November 2015) p 2: [https://www.housinglin.org.uk/\\_assets/Resources/Housing/OtherOrganisation/Accessible-Housing-Standards-2015-WEB.pdf](https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Accessible-Housing-Standards-2015-WEB.pdf) [accessed 28 October 2022]

539 *Ibid.*, p 132

540 Written evidence from the Chartered Institute of Housing ([ASC0127](#)) and Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018) p. 11: [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

541 The Building Regulations 2010 ([SI 2010/2214](#))

542 [Q 108](#) (Guy Harris)



mandate this standard following a consultation<sup>543</sup> and encourage them to urgently find Parliamentary time to do so.

344. Moreover, the M4(2) requirement should also be expanded to cover inclusive design. The focus of standards and guidance is often on older people and people in wheelchairs, to the exclusion of people with sensory impairments, learning disabilities or autism spectrum disorder.<sup>544</sup> Recently the LGA published guidance for councils on considering and meeting the sensory needs of autistic people in housing, which includes guidance on how autistic people may respond to sound, sight, touch and smell.<sup>545</sup> Likewise, the British Standards Institution has published guidance defining good practice relating to neurodiversity and the built environment, including residential accommodation.<sup>546</sup> We commend these guidance documents and encourage their adherence by developers and councils.
345. One proposed solution we heard was that of collaborative housing, which is more available in other European and North American countries. However, it is increasing in popularity in the UK, for example with Housing 21’s programme of older persons’ cohousing development in areas of multiple deprivation in the West Midlands. Early findings of a study of cohousing indicated that collaborative housing models encourage a sense of community that engenders mutual support and residents “looking out for” each other.<sup>547</sup>
346. Better supported housing would also help alleviate the situation. Supported housing gives disabled and older people choice about their lives, enabling them to live in a home environment rather than institutional settings. Better supported housing would also remove the stress that would otherwise be on institutional care, such as care homes and respite centres.<sup>548</sup> According to the Equality and Human Rights Commission, housing that meets people’s requirements will save on health and social care costs in the future, as well as considerably lowering the cost of adaptations when they are needed.<sup>549</sup>
347. Case studies show that when residents are given choices, such as who they want to live with or what they want in their individual kitchens, their quality of life improves.<sup>550</sup> In order for the market to be able to deliver cost effective supported housing that also promotes independence, we heard that commissioners “need to be able to take a strategic overview rather than

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543 Department for Levelling Up, Housing and Communities, *Raising accessibility standards for new homes* (updated 29 July 2022): <https://www.gov.uk/government/consultations/raising-accessibility-standards-for-new-homes/raising-accessibility-standards-for-new-homes-html-version> [accessed 27 September 2022]

544 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018) p. 44: [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

545 Local Government Association, ‘Considering and meeting the sensory needs of autistic people in housing’ (30 June 2020): <https://www.local.gov.uk/our-support/sector-support-offer/care-and-health-improvement/autistic-and-learning-disabilities/autistic/considering-and-meeting-sensory-needs-autistic-people-housing> [accessed 27 September 2022]

546 British Standards Institution, *PAS 6463 Design for the mind: Neurodiversity and the built environment : Guide* (September 2022): <https://knowledge.bsigroup.com/products/design-for-the-mind-neurodiversity-and-the-built-environment-guide/standard> [accessed 27 September 2022]

547 Written evidence from the Centre for Research in Health and Social Care, University of Bristol ([ASC0037](#))

548 Written evidence from Look Ahead ([ASC0092](#))

549 Equality and Human Rights Commission, *Housing and disabled people: Britain’s hidden crisis* (May 2018) p 7: [https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/housing-and-disabled-people-britains-hidden-crisis-main-report_0.pdf) [accessed 29 September 2022]

550 Written evidence from the National Housing Federation ([ASC0088](#))

purchasing care and support based on short-term considerations of unit price.”<sup>551</sup> Housing associations need to engage with commissioners to inform this strategic vision, to help them better understand local supported housing need and how supported housing can deliver cost savings and efficiencies. One route to engagement would be participation in local Health and Wellbeing Boards, for instance.<sup>552</sup>

348. *The Government should follow through on its commitment to mandate minimum accessible standards so that all new build residential properties across all tenures meet standards of accessibility and inclusivity, including for sensory impairments, learning disabilities and autism spectrum disorders.*
349. *The Government must increase capital funding to secure a new supply of purpose-built supported housing and revenue funding for services to help people live independently, if they are to deliver the commitments set out in the Social Care White Paper.*
350. *The Government should introduce an accessibility and inclusivity standard for marketing residential properties for rent, requiring properties to be listed with accessible and inclusive characteristics.*

*Unlocking the potential of digital technologies*

351. Digital technologies, especially in housing, have the potential to transform the lives of older adults and disabled people and to enable them to achieve independent living.<sup>553</sup> This includes the use of smart devices, powered using artificial intelligence, big data, robotics and the Internet of Things.<sup>554</sup> The COVID-19 pandemic acted as a catalyst for the use of technology by older and disabled people: for instance, 5,500 adults with learning disabilities gained access to tablets, data and support via the Digital Lifeline Fund.<sup>555</sup>
352. In its social care White Paper, the Government committed to invest at least £150 million of additional funding over the next three years “to drive digitisation across the sector, and unlock the potential of caretech innovation that enables preventative care and independent living.”<sup>556</sup> If this funding is unlocked, it will be devoted to testing ideas, scaling any benefits and building the case for change. The Government also committed to producing a shared roadmap of priorities with local authorities, the voluntary and community sector, people who draw on care and support and their care networks.<sup>557</sup>
353. The challenge of unlocking the potential of technology, however, is two-fold: there is little awareness of the role of technology among commissioners and service managers in adult social care; and where there is, this understanding

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551 *Ibid.*

552 *Ibid.*

553 Written evidence from the Homecare Association ([ASC0074](#))

554 Policy Connect and All-Party Parliamentary Group for Assistive Technology, *Smarter Homes for Independent Living* (28 April 2022): <https://www.policyconnect.org.uk/research/smarter-homes-independent-living/fulltext> [accessed 27 September 2022]

555 Department for Digital, Culture, Media and Sport, *Impact assessment: Digital Lifeline Fund: Evaluation summary* (24 March 2022): <https://www.gov.uk/government/publications/digital-lifeline-a-qualitative-evaluation/digital-lifeline-fund-evaluation-summary> [accessed 26 September 2022]

556 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 10: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

557 *Ibid.*

is limited. It fails to grasp the full extent of people’s needs and aspirations, and of technology’s potential to enable people to achieve these ambitions.

354. Around 60 years ago, technology-assisted living came in the form of traditional telecare technologies in supported housing and focused on managing risk associated with people living alone or discharged from hospital. Since then, technology has developed significantly, but the thinking on technology in care and housing is still risk-averse and focused on managing that risk.<sup>558</sup> Dr Kate Hamblin, Research Fellow, Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Sheffield, proposed that as there is a duty on local authorities to promote wellbeing under the Care Act 2014, there is an opportunity to reconsider what role technologies can play in accessible housing in supporting people with care needs. She said that “There is now a key driver for change, a key opportunity for change, aside from the advances in technology.”<sup>559</sup>
355. In addition, technology has switched from analogue to digital transmission. Much traditional telecare, such as pendant alarms and environmental sensors, use analogue phone lines, which are being decommissioned, and as a result those devices will not be reliable. They therefore need to be reconsidered. This presents an opportunity for local authorities, service providers and housing providers using traditional telecare to think about how to develop.<sup>560</sup> While there are digital equivalents of old technology, such as a digital pendant alarm, there are questions around factors such as battery life and back-up, “so they are not quite as equivalent as perhaps they could be with some of the standards”. This forces users and providers of technology to “think more broadly about how we can use technology in ways that support well-being and independence as well as manage risk.”<sup>561</sup>
356. We heard that the key to taking advantage of these opportunities is personalisation—“giving people the ability to make those creative decisions, or to be facilitated to make those creative decisions where that is more challenging for them”.<sup>562</sup> However, we were told that:

“The traditional local authority approaches to technology are not really aligned with this personalisation approach. It is the more traditional bulk buy, block contracts, a lot of pendant alarms, rather than finding out what the person would like to achieve and then trying to create a bespoke package of technology to do that.”<sup>563</sup>

While manufacturers have spoken to local authorities about personalisation, we heard that the response seems to be that local authorities “want everything in beige”.<sup>564</sup>

357. Local authorities should make use of their market-shaping duty under the Care Act 2014 to help shift the independent living technology market towards the aspirations, needs and requirements of disabled people and older people. This would require implementing co-production and the codesign of new technologies with disabled adults and older people, whereas currently

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558 [Q 112](#) (Dr Kate Hamblin)

559 *Ibid.*

560 *Ibid.*

561 *Ibid.*

562 *Ibid.*

563 *Ibid.*

564 *Ibid.*

there are limited opportunities for them shaping the design and delivery of technology-enabled care.<sup>565</sup>

358. Therefore, there is a “need to be more ambitious about the role technology can have in supporting people’s needs and desires”. Clive Gilbert, Policy Manager, Policy Connect, pointed out that many older people and disabled adults are already using technology “to do everything from connecting with friends to managing a team at work to booking theatre tickets”. Consequently, while disabled adults and older people “may use a different tech set-up”, the things they do with technology are not “radically different”.<sup>566</sup> In reaching this ambition, it is important that technology is put in the hands of disabled people themselves to avoid “doing technology to people”.<sup>567</sup>
359. It is also not enough simply to provide the technology: older adults and disabled people need to have a full service. This includes installation, ongoing support, reassessment and troubleshooting. Technology on its own is therefore not the silver bullet that it is sometimes presented as.<sup>568</sup> Technology can also bring challenges in consent, data processing and ownership insecurity, which need to be managed by the social care sector.<sup>569</sup> Moreover, there can be too much focus on creating independence. We heard that while “independence is very important ... technology could also be very helpful in terms of interdependence and connections.” Technology can try to reduce the person’s need to engage with other people, particularly the care workforce, raising “bigger questions about what it can do to connect people and to keep people engaged and well that way”.<sup>570</sup>
360. **We welcome the Government’s committed investment in care technology and its testing and scaling of related ideas. The Government must ensure that any testing of ideas related to care technology is done in co-production with people with lived experience.**
361. **The Government should create a research and development network for the sharing of technological innovation between social care stakeholders, similar to the NHS R&D Forum.**

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565 *Ibid.*

566 [Q 113](#) (Clive Gilbert)

567 *Ibid.*

568 *Ibid.*

569 *Ibid.*

570 [Q 115](#) (Dr Kate Hamblin)

## CHAPTER 7: UNPAID CARERS: “WE NEED SUPPORT, WE NEED RECOGNITION”

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362. Unpaid carers keep the adult social care service going. They are a national but neglected source of expertise, skills and knowledge. In the previous chapter we set out how enabling independent living through co-production in policy and practice, wherever possible, will transform the prospects for unpaid carers. This final chapter looks at what needs to change now to support and strengthen the position of carers so that they are more resilient, respected and supported. This starts with improving ways to identify carers appropriately.
363. It is also about ensuring that carers get the support they are entitled to, and that the system is a help and not a hindrance. One priority is therefore to invest in and streamline the navigation process along with recommendations about overdue improvements designed to take carers off the precarious margins of poverty and keep them in work, if that is what they want. The challenge is to local authorities, the Government and employers. But fundamentally, unpaid carers need fairer benefits, not least because they are more likely to face additional costs. They should also be entitled to more short breaks, paid Carer’s Leave and effective support to stay in work if that is their choice.
364. On the broader canvas, we look at the obstacles which marginalise carers and diminish their knowledge and skills and how that can be changed, along with the curriculum for social work training itself.

### Who are the unpaid carers? The paradox of disclosure

365. As we have seen, and as the Family Resources Survey indicates, 4.2 million people, 6% of the UK population, provided unpaid care in 2020/21.<sup>571</sup> Reflecting both the unevenness of data and the difficulty of identifying carers, other estimates are higher. The Joseph Rowntree Foundations estimates that 1 in 12 adults (4.4 million) are unpaid carers, with nearly 6 in 10 living in families where someone is disabled.<sup>572</sup> Based on data from the 2011 Census, Carers UK puts this higher, at 6.5 million total unpaid carers.<sup>573</sup> More recently, based on polling of 3,500 people, Carers UK has estimated that the figure is now closer to 10.6 million unpaid carers in the UK.<sup>574</sup>
366. The range of these assessments reflects the scale of the problem, while at the same time underestimating it because of the chronic problem of partial data. Many unpaid carers do not wish to identify themselves as such. They find it demeaning or intrusive and likely to compromise their relationships and self-esteem.
367. At a fundamental level, many carers do not even recognise the term ‘carer’ as reflective of their relationship with, for example, the parent, child, friend

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571 Department for Work and Pensions, *Family Resources Survey: financial year 2020 to 2021* (31 March 2022): <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021#care-1> [accessed 29 September 2022]

572 Joseph Rowntree Foundation, *UK Poverty 2022: the essential guide to understanding poverty in the UK* (January 2022) p 59: <https://www.jrf.org.uk/report/uk-poverty-2022> [accessed 29 September 2022]

573 Carers UK, *Facts about carers* (August 2019) p 1: [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2019.pdf](https://www.carersuk.org/images/Facts_about_Carers_2019.pdf) [accessed 12 September 2022]

574 Carers UK, *State of Caring 2022* (November 2022) p 4 [https://www.carersuk.org/images/Research/CUK\\_State\\_of\\_Caring\\_2022\\_report.pdf](https://www.carersuk.org/images/Research/CUK_State_of_Caring_2022_report.pdf) [accessed 15 November 2022]



or neighbour that they provide care for.<sup>575</sup> Almost three-quarters of carers (71%) state that seeing themselves primarily as a family member or a friend is a barrier to identifying themselves as a carer.<sup>576</sup> Some carers do not want to be labelled as carers due to concerns it may impact, for example, job opportunities.<sup>577</sup> They may also be worried about the repercussions of identification: will they be asked to take on more care; will there be a risk that the person they provide care for will be taken away from them? Fatima-Khan-Shah, Associate Director, Long Term Conditions and Personalisation at West Yorkshire Health and Care Partnership, said that she could not “emphasise enough the toll and concern that comes with the disclosure that you are somebody who might be referred to as an unpaid carer.”<sup>578</sup> Because unpaid carers do not always provide practical, hands-on intimate care, as opposed to emotional or financial care, they do not always identify.<sup>579</sup> Moreover, being a carer can be an all-encompassing role; carers must manage competing demands; often they feel unable to look after their own needs on top of those of the person they provide care for.<sup>580</sup>

368. There is also a cultural dimension, in that expectations around caring roles in familial relationships in some BAME communities mean that carers go unidentified, and social stigma around accessing help prevents some from accessing support.<sup>581</sup> In some languages such as Gujarati, there is not even a word for carer. Some communities may see it purely as a family affair, where external support is not required.<sup>582</sup> However, this can be a self-fulfilling prophecy—if services are not culturally appropriate (because there is an assumption that some communities ‘look after their own’), then those communities have no choice but to look after their own, thereby reinforcing the view that services don’t need to be more culturally appropriate.
369. Even the term ‘carer’ is a barrier to identification. As put by Professor Nan Greenwood, Centre for Health and Social Care Research, Kingston University London, as “much as ‘Clap for carers’ was wonderful, what a carer is was very confusing for the public”.<sup>583</sup> There is a fundamental confusion around paid carers versus unpaid carers. We heard that there is therefore a need for the language around caring to be both accurate and culturally appropriate. Professor Greenwood said that “we must not force everybody to call themselves a carer, because some people really do not want it. They feel

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575 Carers Trust, *Identification of Carers in GP Practices: a good practice document* (2018) p 1: <https://carers.org/downloads/resources-pdfs/identification-of-carers-in-gp-practices/identification-of-carers-in-gp-practices-a-good-practice-document.pdf> [accessed 29 September 2022]

576 Carers UK, *State of Caring 2022* (November 2022) p 55: [https://www.carersuk.org/images/Research/CUK\\_State\\_of\\_Caring\\_2022\\_report.pdf](https://www.carersuk.org/images/Research/CUK_State_of_Caring_2022_report.pdf) [accessed 8 November 2022]

577 Royal College of General Practitioners, *Involving and Supporting Carers and Families: an educational framework and learning resource for GPs and primary care teams* (2014) p 20: <https://www.oxfordhealth.nhs.uk/library/wp-content/uploads/sites/3/Involving-and-Supporting-Carers-and-Families-RCGP-January-20141.pdf> [accessed 29 September 2022]

578 Q 69 (Fatima Khan-Shah)

579 Q 67 (Prof Nan Greenwood)

580 Emma Carduff et al., ‘Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources’, *BMC Family Practice*, issue 15, no. 48, (2014), p 6: <https://bmcprimcare.biomedcentral.com/track/pdf/10.1186/1471-2296-15-48.pdf> [accessed 22 November 2022]

581 Written evidence from the Joseph Rowntree Foundation and London Unemployed Strategies (ASC0116)

582 Q 67 (Prof Nan Greenwood)

583 *Ibid.*

that it is a really negative thing for them.”<sup>584</sup> Once they have passed the first hurdle of accessing care, they are often more willing to self-identify.<sup>585</sup>

370. But crucially, unless they are identified formally as a carer they may not receive the support they are entitled to.<sup>586</sup> Indeed, 91% of carers said they missed out on financial or practical support as a result of not identifying as a carer.<sup>587</sup>
371. As well as limiting the support that carers can receive, a failure to identify limits the data available for analysis and evidence-based interventions which might benefit the sector. For example, NHS Digital currently undertakes a formal Survey of Adult Carers in England (SACE), which explores the extent to which unpaid carers consider that they have a balanced life alongside their caring duties.<sup>588</sup> This survey is only based on feedback provided by unpaid carers who have been identified by the local authority, meaning that a huge proportion of carers are not represented. Again, this reduces the visibility of unpaid carers, discussed in Chapter 2.

*No wrong door: Identifying and respecting carers*

372. Self-identification is not working. But neither are the formal systems set out in the Care Act 2014, which already require that local authorities and health bodies in England must work together to identify carers and that any carer who appears, or is likely to have, needs for support must be identified and offered a Carer’s Assessment.<sup>589</sup> There are similar requirements in other pieces of legislation applying to Scotland, Wales and Northern Ireland.<sup>590</sup> This requirement is not reflected in the outcomes revealed in the statistics, which also suggested that there is a missing link in the process—the health professionals themselves.
373. A survey of 2,100 carers showed that between 71% and 85% of carers came into contact with health professionals including GPs, doctors and nursing staff. However, health professionals identify only one in 10 carers and GPs just 7%.<sup>591</sup> While existing pressures in the system mean that it can be extremely challenging for GPs to know the circumstances surrounding patients, this suggests a new link could be made by all health professionals without much additional bureaucracy. Caring Together, for example, suggested that the CQC should play a role in ensuring that GP surgeries are registering carers and making effective use of their carers registers. They also suggested that hospitals should play a role in ensuring carers know where to find support.<sup>592</sup>

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584 *Ibid.*

585 *Ibid.*

586 Carers Trust, *Identification of Carers in GP Practices: a good practice document* (2018) p 1: <https://carers.org/downloads/resources-pdfs/identification-of-carers-in-gp-practices/identification-of-carers-in-gp-practices-a-good-practice-document.pdf> [accessed 29 September 2022]

587 Carers UK, *Missing out: The identification challenge* (November 2016) p 11: <https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-the-identification-challenge> [accessed 29 September 2022]

588 NHS Digital, ‘Survey of Adult Carers in England, 2021–22 guidance for local authorities’: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/social-care-carers-survey-2021-22> [accessed 13 September 2022]

589 Care Act 2014, [section 10](#)

590 [Community Care and Health \(Scotland\) Act 2002](#); [Social Services and Well-being \(Wales\) Act 2014](#) and [Carers and Direct Payments \(Northern Ireland\) Act 2002](#).

591 Carers Week, *Prepared to Care? Exploring the impact of caring on people’s lives* (18 June 2013): [https://www.basw.co.uk/system/files/resources/basw\\_113215-2\\_0.pdf](https://www.basw.co.uk/system/files/resources/basw_113215-2_0.pdf) [accessed 29 September 2022]

592 Written evidence from Caring Together ([ASC0025](#))

374. Other ways of identifying carers in order to support them effectively are also within reach. For instance, employers can help to identify the people who work for them and who also have a caring role. They could play a much more proactive role in guiding employees to support. This is already beginning to happen. Carers UK’s employer forum, Employers for Carers (EfC), brings together over 110 businesses to make the case for supporting carers in the workplace. Among other benefits, membership of EfC provides organisations with information, advice, toolkits and workplace sessions for line managers including guidance on identifying and supporting carers at work.<sup>593</sup>
375. For young carers, who are particularly vulnerable, schools could be a more effective way of identifying who needs appropriate help and support. The Children and Families Act 2014 introduced the right to a young carers assessment.<sup>594</sup> However, many young people who provide care to someone, offering physical or emotional support, do not want to be known as carers, considering their caring tasks to be a ‘normal’ part of family life.<sup>595</sup>
376. Box 9 describes examples of best practice in identification of carers.

### Box 9: Identification: examples of best practice

#### Liverpool

Liverpool Council has been developing a ‘no wrong door’ approach to carer identification. This means that carers should be identified, assessed and their families supported regardless of which service is contacted in the first place. This accelerated during the pandemic and the Council was more ready to implement the vaccination rollout as a result. This approach makes it less likely that carers have to repeat information, ensures that public services can alert carers to preventative services and provides a more integrated service to carers.<sup>596</sup>

#### Leeds

Meanwhile, in Leeds, Carers Leeds works with GP practices to identify carers. As well as referring carers to the service, GP surgeries are encouraged to put in place their own additional support for carers by offering things such as annual health checks and flexible appointments. The initiative has led to an increasing number of referrals from local practices. As of 2018, every GP practice in Leeds—over 100 of them—now have access to the scheme. Between them they are responsible for referring over 500 carers a year into the Leeds service, making them one of the core referrers.<sup>597</sup>

593 Carers UK, *Missing out: The identification challenge* (November 2016) p 8: <https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-the-identification-challenge> [accessed 29 September 2022]

594 Children and Families Act 2014, [section 96](#)

595 Carers Trust and the National Centre for Social Research, *Identification Practice of Young Carers in England: Review, Tips and Tools* (2019) p 8: <https://carers.org/downloads/resources-pdfs/identification-practice-of-young-carers-in-england/identification-practice-of-young-carers-in-england-review-tips-and-tools.pdf> [accessed 29 September 2022]

596 Written evidence from Carers UK ([ASC0122](#))

597 Local Government Association, *Supporting carers: guidance and case studies* (December 2018) p 25: [https://www.local.gov.uk/sites/default/files/documents/22.31%20Carers%20publication\\_05.pdf](https://www.local.gov.uk/sites/default/files/documents/22.31%20Carers%20publication_05.pdf) [accessed 11 November 2022]

### Coventry

Young Carers Service Coventry works closely with schools to support young carers. It has a dedicated schools worker and runs an awards scheme, while the council has funded an online training course that is promoted to staff.

There are an estimated 5,000 children and young people under the age of 25 with caring responsibilities in Coventry.

Schools are the major route of referrals, although some do also come in from council staff such as social workers, other professionals and some via self-referrals. As of 2018, the service has around 1,500 children and young people registered.<sup>598</sup>

377. There should be a ‘no wrong door’ approach to unpaid carers in public services, meaning that carers can find a route to identification and signposting regardless of the professional they are speaking to. Priority should be given to making this the norm in health and social care settings, with which carers are highly likely to come into contact, and where, with their consent, their caring status can be formally included in a patient record.
378. *The Government and NHS England should create incentives for secondary and primary care to identify unpaid carers, and to ensure that their unpaid caring status is included in their patient record with their permission. On identification, there should be mechanisms to provide carers with information, self-care and digital resources to support them.*
379. Carers UK has argued that one universal way of improving the identification and support of carers would be to make caring the tenth protected characteristic under the Equality Act 2010. This would increase awareness of carers, as well as improve equalities monitoring and establish a clear public sector duty to support carers.<sup>599</sup> With unpaid carers more visible and valued, identification would inevitably happen earlier. Carers UK also stressed that this would likely result in more carer-friendly employment practices and workplaces, as employers would adopt inclusion policies that would encompass carers.<sup>600</sup> We do not express any view on the proposal as we have received no further evidence but feel it should be explored further. Other initiatives to improve employer practices towards carers are explored further in this chapter.

### Finding solutions: keeping unpaid carers out of poverty and in work

380. The fundamental question is: what are the most effective actions that can be done to bring greater understanding of what unpaid carers do and need, in such a way that relationships are harmonised and supportive?
381. As mentioned in Chapter 3, unpaid carers often live in or on the margins of poverty. The Joseph Rowntree Foundation estimate that more than one million carers are in poverty.<sup>601</sup> This has been made worse by the cost of

598 *Ibid.*

599 Written evidence from Carers UK ([ASC0122](#))

600 *Ibid.*

601 Joseph Rowntree Foundation, ‘Unpaid carers changing the systems that trap them in poverty’ (8 June 2022): <https://www.jrf.org.uk/blog/unpaid-carers-changing-systems-trap-them-poverty> [accessed 17 October 2020]

living crisis. This has resulted in unpaid carers feeling “absolutely abandoned by society”.<sup>602</sup>

382. We heard categorically that Carer’s Allowance “is simply not fit for purpose”.<sup>603</sup> We would describe the benefit as an anomaly. At a minimum of 35 hours per week, the caring hours threshold to access Carer’s Allowance is extremely high, while the earnings limit, at £132 per week, acts as a disincentive for carers to remain in any form of paid work. As noted by Carers UK, the earnings limit does not rise in line with rises to the National Living Wage, which further undermines carers’ ability to remain employed.<sup>604</sup> This must change.
383. Proposed reforms included making Carer’s Allowance “more reflective of a wage”, increasing it to match the minimum wage<sup>605</sup> or the minimum living wage,<sup>606</sup> and reforming the threshold for Carer’s Allowance to ensure that people working a reasonable amount less than 35 hours per week or earning more than £132 per week are eligible.<sup>607</sup>
384. Other witnesses proposed the extension of carers’ benefits to cover the additional costs that come with being an unpaid carer. Unpaid carers are excluded from any provision of statutory sick pay, holiday entitlement, pension arrangements—other than that based on national insurance contributions— or any help with healthcare costs.<sup>608</sup> Unpaid carers in England are at a multiple disadvantage too because many fall outside the exemption from paying for prescriptions based on age and benefit entitlement, which are free for everyone in Scotland, Wales and Northern Ireland.<sup>609</sup>
385. Unpaid carers are also presented with a whole range of expenses above those of people who do not provide care. Caring costs could include extra:
- Transport costs travelling to and from the disabled adult or older person’s home, taking them to appointments, day centres, activities, or visits. Costs including taxi and bus fares, fuel and wear and tear on the carer’s car.
  - Equipment costs that allow for daily living like hoists, wheelchairs, standing aids etc. and the associated higher energy bills linked to these.
  - Home adaptations costs that cannot be met by local authority grants.
  - Clothing costs due to wear and tear, or being damaged by the person who draws on care.
  - Laundry costs from the need for washing clothes, sheets, blankets etc from incontinence and increased electricity and water costs.

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602 [Q 55](#) (Nadia Taylor)

603 Written evidence from the We Care Campaign ([ASC0032](#))

604 Carers UK, ‘New Carer’s Allowance benefit rates and rise in earnings limit, but worries about the future’ (30 November 2021): <https://www.carersuk.org/news-and-campaigns/press-releases/new-carer-s-allowance-benefit-rates-and-rise-in-earnings-limit-but-worries-about-the-future> [accessed 1 November 2022]

605 Written evidence from the Care Workers’ Charity ([ASC0064](#))

606 [Q 55](#) (Nadia Taylor)

607 Written evidence from Bristol City Council ([ASC0076](#))

608 [Q 55](#) (Nadia Taylor)

609 *Ibid.*



- Household product costs: cleaning products, laundry products, sanitiser, gloves, aprons etc.
  - Food costs to maintain a particular dietary requirement, additional cost of nutritional supplements and shakes.
  - Furniture cost: having to buy specialist beds, recliners, or replace items that are damaged more frequently due to unintentional damage.
  - Incontinence needs: bed pads, incontinence pads, specialist wipes, creams to avoid sores, gloves etc.
  - Costs on the long-term financial health due to low income and opportunity costs.<sup>610</sup>
386. Nadia Taylor, Chair of the Board of Trustees, Carers Network, suggested that unpaid carers should be given the same rights and provisions as other benefit recipients who are entitled, among other things, to free prescriptions, eye and dental care and subsidised travelcards.<sup>611</sup>
387. The current situation is a false economy. As noted by Valentina Zigante, Research Officer, Care and Policy Evaluation Centre, LSE, the economic evidence is “in favour of the importance of keeping carers healthy and in a good mental state and supporting their physical and mental well-being.”<sup>612</sup> Ms Zigante also linked poverty and carer strain, noting the abundance of research on how financial strain “feeds into the overall perception of strain in the caring relationship.”<sup>613</sup>
388. It is urgent to reform Carer’s Allowance so that it ceases to discourage carers from remaining in paid work. Access to the benefit should therefore be granted even to those who are caring for fewer hours, leaving more time for paid work, and earning more income. In addition, there should be national recognition that, as the lowest benefit of its kind, Carer’s Allowance is not reflective of the contribution of unpaid carers. It must therefore be reviewed and increased to pay carers a fairer amount.
389. *Access to Carer’s Allowance must immediately be made easier by lowering the threshold of caring hours and ensuring that the earnings limit is uprated, in law, in line with rises to the National Living Wage.*
390. *The Department for Work and Pensions must review Carer’s Allowance, reporting to Parliament within 12 months, and recognising that, as the lowest benefit of its kind, it is not reflective of the value of unpaid carers’ work. The review should also cover the high threshold of caring hours, and the low and inflexible earnings limit, which are both significant barriers to accessing Carer’s Allowance.*

#### *Combining work and care*

391. Many problems could be solved if more carers had the right support to stay in work. The economic case for carers to be able to stay in work if they so

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610 Written evidence from the We Care Campaign ([ASC0032](#))

611 [Q 55](#) (Nadia Taylor)

612 [Q 55](#) (Dr Valentina Zigante)

613 *Ibid.*

choose is certain. The loss to the Exchequer is estimated to be £2.9 billion a year in relation to carers’ benefits and lost tax revenues.<sup>614</sup>

392. However, some carers, because of the complexity of their caring situation, the extent of their caring, or because support arrangements collapse, are required to care full-time. Staying in work should be a choice, not only for financial reasons, but because of the therapeutic effect of working in a context which can so easily bring on anxiety, poor mental health and feelings of low self-esteem.<sup>615</sup>
393. Unpaid carers face different challenges in balancing their work alongside caring. Employment prospects vary greatly, depending on the nature of care offered. Almost half of unpaid carers, for example, provide care to an older person; this typically arises mid-to late-career, tending to be a relatively shorter period of caring. Around a quarter provide care to a spouse or partner. This is often longer term and it is often important for the carer to remain in paid work.<sup>616</sup>
394. The challenges for unpaid carers of children or adults of working age who are disabled from birth are for a lifetime. About one eighth of carers provide care to a son or daughter, starting early in their career and continuing for most of its remainder.<sup>617</sup> We heard from Professor Yeandle that this group is not well served by the current arrangements.<sup>618</sup> Professor Yeandle praised the UK’s lead on flexible working, which is helpful to carers, but she pointed out that the UK still does not have compensated carer’s leave.<sup>619</sup> She stressed the importance of carer’s leave being compensated, as otherwise the poorest carers would not be able to take advantage.<sup>620</sup>
395. However, the Government’s Employment Bill, proposed in the 2019 (but not the 2021) Queen’s Speech and yet to be introduced in Parliament, would only provide for five days of unpaid leave and a ‘day one’ right to request flexible working.<sup>621</sup> The Carer’s Leave Bill (a Private Member’s Bill) was introduced in Parliament in September 2022. This would amend the Employment Rights Act 1996 and make provisions for at least a week of unpaid leave every 12 months for employees with caring responsibilities.<sup>622</sup> While the Bill is still before Parliament, Germany offers an example of a system that already has such an arrangement (see Box 10). We heard that the UK “lags behind established practice in other comparable economies on this issue”, with at least seven other developed countries offering more generous leave than the UK Government has proposed. Most of these other countries also compensate the employee via employment insurance or welfare benefits.<sup>623</sup>

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614 Linda Pickard *et al.*, ‘Public expenditure costs of carers leaving employment in England, 2015/2016’, *Health and Social Care in the Community*, vol. 26, Issue 1, (2017), pp 132–142: <https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12486>

615 Q 63 (Prof Sue Yeandle)

616 Q 60 (Prof Sue Yeandle)

617 *Ibid.*

618 *Ibid.*

619 *Ibid.*

620 Q 60 (Prof Sue Yeandle)

621 Lewis Silkin, ‘The Queen’s Speech 2022’ (11 May 2022): <https://www.lewissilkin.com/en/insights/the-queens-speech-2022> [accessed 20 September 2022]

622 *Carer’s Leave Bill*, Clause 80J, [Bill 23 (2022–23)]

623 Supplementary written evidence from Professor Sue Yeandle (ASC0153)

**Box 10: International example: Germany**

The government of Germany recognised the costs of reduced labour market participation to individuals, employers and the state. As such they introduced legislative reforms to improve carers’ employment flexibility and job security:

- Short-term absence from work (*Pflegezeit; Nursing Care Time*): Since 2008, employees have been entitled to a maximum of 10 days’ emergency leave to organise care for a relative when there is a sudden need. Employees can also be released from full-time work completely or partially for up to six months. In 2015, a carers’ grant was introduced which allows for up to 10 days of emergency leave, set at 90% of the employee’s wage, funded through the LTCI (long-term insurance) of the person in need of care.
- Family caregiver leave (*Familienpflegezeit*): Since 2012, an employee has held the statutory right to reduce their working hours to no less than 15 hours per week for up to two years. In 2015, a government interest-free loan has been available to employees which allows them to reduce their hours while retaining a proportion of their salary. The loan must be repaid upon returning to work full time.

However, uptake of these is low, estimated at 6,750 people in 2018. This is due to low awareness among employees and resistance among employers.

Source: Nuffield Trust, *What can England learn from the long-term care system in Germany?* (September 2019), pp 54–55: [https://www.nuffieldtrust.org.uk/files/2019-09/1568207938\\_ltc-germany-br1924-web.pdf](https://www.nuffieldtrust.org.uk/files/2019-09/1568207938_ltc-germany-br1924-web.pdf) [accessed 21 November 2022]

396. ***The Government must honour its commitment and establish the entitlement to unpaid Carer’s Leave at the earliest opportunity, supporting the speedy passage of the Carer’s Leave Bill.***
397. ***The Government should commission a review with the longer-term objective of legislating for compensated Carer’s Leave.***
398. Employers, as well as the Government, can help unpaid carers who are also employees. The advantage to employers is evident: carers represent one in seven of the entire workforce, with a peak caring age of 50 to 64, when many employees will have gained valuable skills and experience.<sup>624</sup> It is in employers’ best interest, therefore, to retain their employees who have caring responsibilities. Childcare has largely become normalised and supported in the workplace, and parents are often given the flexibility to care for their children. The same must now happen in relation to other forms of unpaid care.
399. We heard that employers should become ‘carer-friendly’ ensuring that HR systems and processes consistently help to identify carers, just as they capture other demographic and equalities information. It should be standard practice that employers and managers are aware of the role that carers play and the challenges that they face. As one carer put it, “Line managers and HR need to be aware that a little bit of compassion and flexibility goes a long way.”<sup>625</sup> The Employers for Carers scheme identified “five Ps” in good employer support:

624 Employers for Carers, ‘Business case’: <https://www.employersforcarers.org/membership/business-case> [accessed 20 September 2022]

625 Written evidence from Caring Together (ASC0025)

- Preparation. This is about identifying carers in the workforce and enabling them to identify and recognise themselves.
- Policies. Behind preparation and identification should be carer support policies and transparency of support.
- Practical provisions and arrangements that support working carers, such as signposting to external wellbeing services.
- Peer support. Employers should engage and connect carers in the workplace.
- Promotion. Employers should raise awareness and make caring visible in the workplace, ensuring that carers feel confident in coming forward for support.<sup>626</sup>

400. Councils in the West Midlands provide examples of best practice for employers (Box 11).

### **Box 11: Employment example of best practice: West Midlands**

Councils in the West Midlands are working to encourage employers to support carers. An employment guide has been produced and now councils are changing their own practices as well as encouraging others to do so.

West Midlands Association of Directors of Adult Social Services represents 14 local authorities. It has a Carers Leads Network. Last year the network produced a guide to encourage employer friendly practices.

The 14 local authorities have signed up to making themselves carer-friendly. All are at different stages, but steps being taken include identifying carers in the workforce, changing HR protocols, appointing carers champions and setting up carers groups so they can offer each other support and represent carers in the workplace.

Source: Local Government Association, *Supporting carers: guidance and case studies* (December 2018) p 31: [https://www.local.gov.uk/sites/default/files/documents/22.31\\_Carers\\_publication\\_05.pdf](https://www.local.gov.uk/sites/default/files/documents/22.31_Carers_publication_05.pdf) [accessed 22 November 2022]

401. In Scotland, employers are encouraged to identify and support their employees who have caring duties thanks to the Carer Positive employer recognition scheme, which is sponsored by the Scottish Government and operated by Carers Scotland.<sup>627</sup> The scheme awards employers in Scotland who have a working environment where carers are valued and supported. In England, Employers for Carers has developed a similar Carer Confident benchmarking scheme, which assists employers to build a supportive and inclusive workplace for staff who are carers. The scheme recognises employers who do this thanks to a certificate of achievement.<sup>628</sup>
402. ***The Government should ensure the wider uptake of the Employers for Carers’ Carer Confident Scheme to raise awareness of unpaid carers in the workplace and encourage employers to support unpaid carers who work for them.***

626 Q 65 (Madeleine Starr)

627 Carer Positive Employer in Scotland, ‘What is Carer Positive?’: <https://www.carerpositive.org/> [accessed 1 November 2022]

628 Employers for Carers, ‘Carer Confident: The Employers for Carers benchmarking scheme’: <https://www.employersforcarers.org/carers-confident> [accessed 1 November 2022]

### A service that cares for them: accessing short breaks

403. As discussed in Chapter 3, despite facing significant physical and emotional challenges, unpaid carers have great difficulty accessing short breaks, with many witnesses telling us that they hadn’t been able to take a break from caring in many years. Recent polling by Age UK showed that 59% of carers felt tired because of the care and support they provide, while 48% felt anxious and 29% felt overwhelmed. The need for short breaks among carers is increasing, wrote the organisation, and yet availability continues to be an issue.<sup>629</sup>
404. Short breaks are key to provide unpaid carers with time and space to rest, see their friends and family, and to tend to their own medical needs. Respondents to a survey carried out by Alzheimer’s Society said that short breaks were a key mechanism to the maintenance of their wellbeing.<sup>630</sup> The organisation therefore called for greater capacity in services that provide short breaks, such as day services, sitting services as well as longer respite breaks.<sup>631</sup> Similarly, the Carers Support Centre said that a key priority in supporting carers should be to create a duty to provide short breaks and respite for carers.<sup>632</sup>
405. The 2021 White Paper addresses the need for greater respite care and breaks and has pledged to dedicate some of the £25 million investment in support for unpaid carers to exploring the different models of respite, how respite services are accessed, and any barriers to accessing these services.<sup>633</sup> If the funding is made available, this commitment will be welcome. Stakeholders have argued, however, that the progress in this space is too slow, and that support will come too late to those who are already struggling, which risks increasing pressure on a system that is already strained.<sup>634</sup>
406. ***The Government should dedicate ring-fenced funding to increase the availability and capacity of services that provide flexible short breaks for unpaid carers.***

### Finding a way through the care system

407. Apart from having the lowest of benefits and challenging work situations, the most frustrating aspects of the adult social care service that we were told about, time and again, was the bewildering difficulties that carers face in finding out and accessing the support to which they and the person they provide care for are entitled. A range of evidence demonstrated the difficulties of navigating the system, often without help, and being left to themselves to figure out where to look and what to look for. Carers UK argued that “the current system is ... difficult to access for many unpaid carers”, partly due to a lack of information and understanding about what support is on offer.<sup>635</sup> Some commentators have compared the system to a “drunken walk”, where

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629 Written evidence from Age UK (ASC0119)

630 Written evidence from Alzheimer’s Society (ASC0086)

631 *Ibid.*

Written evidence from Carers UK (ASC0122)

632 Written evidence from Carers Support Centre Bristol and South Gloucestershire (ASC0101)

633 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 59: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf) [accessed 21 September 2022]

634 Written evidence from Age UK (ASC0119)

635 Written evidence from Carers UK (ASC0122)



the patient “stagger[s] from door to door, from specialist to specialist, seeking bespoke advice and support, only to miss the very door that would lead to some assistance.”<sup>636</sup>

408. It is hardly surprising that it is so challenging to find out who can help, what help is available, and how to make sure it is the right help. Unpaid carers have to deal with a baffling range of organisations with responsibility for the support needed by the older or disabled person, such as NHS hospitals and primary care services, local authority social services, independent care agencies, personal assistants, pharmacists, occupational therapists, district nurses, podiatry services, mental health services, dentists, providers of assistive technology and mobility aids to say nothing of circular and complex bureaucracy. This coordination is often time-consuming and stressful for carers, who are also likely to be managing the personal administration of the older adult or disabled person.<sup>637</sup>
409. The Government recognised this difficulty: Ms Keegan told us that “the challenge we have is knowing who they are, or them being able to access us... information is key.”<sup>638</sup> The Government has legislated to require provision of information to carers. Under section 4 of the Care Act 2014, councils have a duty to “establish and maintain a service for providing people in its area with information and advice relating to care and support”.<sup>639</sup> Under the legislation’s statutory guidance, councils are “expected to understand, coordinate and make effective use of other high quality statutory, voluntary and/or private sector information and advice resources available to people within their areas”.<sup>640</sup> In its social care White Paper, the Government has also committed to creating a new national website to explain upcoming social care changes and £5 million to pilot new ways to help people understand and access the care and support available.<sup>641</sup>
410. However, we heard from the LGA that these responsibilities under the Care Act 2014 cannot be delivered because funding pressures have not allowed it, and they questioned whether the Government’s pledge of £5 million is an adequate response to the scale of the problem, and indeed whether a three-year timeframe is commensurate with the urgency of the need to improve navigation for unpaid carers.<sup>642</sup> It has also been pointed out that cuts to services and loss of funding for voluntary providers mean that people risk being signposted to nowhere, being passed round a circle of referrals to non-existent help.<sup>643</sup>
411. We were also advised that frontline professionals, particularly in primary care, community settings and hospitals, should themselves have the knowledge, skills and training to signpost unpaid carers to the best and clearest pathways

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636 Written evidence from the Society of Later Life Advisers ([ASC0043](#))

637 Supplementary written evidence from Professor Sue Yeandle ([ASC0153](#))

638 [Q 149](#) (Gillian Keegan MP)

639 Care Act 2014, [section 4\(1\)](#)

640 Department of Health and Social Care, *Care and support statutory guidance* (2 November 2022): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> [accessed 8 November 2022]

641 Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021, p 8: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asceform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asceform-accessible-with-correction-slip.pdf) [accessed 29 September 2022]

642 Written evidence from the Local Government Association ([ASC0042](#))

643 [Q 125](#) (Belinda Schwehr)

to resources and support. Too often they did not. Supporting carers involves multidisciplinary input from the health and social care services and the voluntary sector,<sup>644</sup> and the support of primary healthcare professionals can make a significant difference to carers’ health and wellbeing.<sup>645</sup>

412. Another proposed solution was the creation of a care manager “at the heart of the system”,<sup>646</sup> responsible for designing, monitoring and overseeing care plans.<sup>647</sup> Care managers are central to social care in Japan.<sup>648</sup> Creating a role that is consistent across the country would help to offer support and clarity about expectations to those navigating the system and to health and care providers.<sup>649</sup>
413. The Care Policy and Evaluation Centre at LSE found that easily accessible information and advice (on available services, including council, voluntary, support groups, transport and short breaks) all in one place was the top priority for unpaid carers they interviewed.<sup>650</sup> The Association of British Insurers noted the importance of integrating financial information as part of this.<sup>651</sup>
414. The idea of such a ‘one-stop-shop’ or single point of contact, which should not only give information and signpost to other services but offer help and support where possible was popular but it was stressed that it should not supplant the locally tailored information currently available. For instance, Carers UK has comprehensive detailed and expert information on carers’ rights which local organisations such as Care for the Carers East Sussex and others link to, as well as providing more locally sourced information about discretionary services.<sup>652</sup> But there are very few services to which carers have a direct right, and many rights are complex to understand—for example carers council tax discount. While effective websites and tailored information were seen to make for an effective combination, these often need to be backed up locally by a more detailed service because of the complexity of situations and support needed.<sup>653</sup>
415. **Overall, the care system is a labyrinth: carers face bewildering difficulties in finding out and accessing the support to which they and the person they provide care to are entitled. National action is needed to coherently resolve these significant navigation challenges. It must be complemented, however, by advice and information that is tailored to the personal and local nature of social care.**

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644 Royal College of General Practitioners, *Involving and Supporting Carers and Families: an educational framework and learning resource for GPs and primary care teams* (2014) p 27: <https://www.oxfordhealth.nhs.uk/library/wp-content/uploads/sites/3/Involving-and-Supporting-Carers-and-Families-RCGP-January-20141.pdf> [accessed 29 September 2022]

645 Alex Fox, Nigel Sparrow and Jo Webber, ‘Carers and the NHS’, *British Journal of General Practice*, issue 60, vol 575, (2010), pp 462–3: <https://bjgp.org/content/60/575/462.long>

646 Nuffield Trust, *What can England learn from the long-term care system in Japan?* (May 2018) p 43: <https://www.nuffieldtrust.org.uk/files/2018-06/learning-from-japan-final.pdf> [accessed 29 September 2022]

647 Supplementary written evidence from Professor Sue Yeandle (ASC0153)

648 Nuffield Trust, *What can England learn from the long-term care system in Japan?* (May 2018) p 3: <https://www.nuffieldtrust.org.uk/files/2018-06/learning-from-japan-final.pdf> [accessed 29 September 2022]

649 *Ibid.*

650 Written evidence from the Care Policy and Evaluation Centre, LSE (ASC0102)

651 Written evidence from the Association of British Insurers (ASC0118)

652 Written evidence from Carers UK (ASC0122)

653 *Ibid.*

416. *The Department of Health and Social Care and the Department for Work and Pensions must join forces to look at carers’ journeys to find better information and advice combining trusted national sources of information (such as gov.uk or Carers UK) with locally trusted information, advice and support for carers, recognising that they are best placed to advise locally.*

*Navigating transitions*

417. Navigation is especially difficult during transitions, for example during hospital discharge, when transitioning from children’s services to adult social care or when moving houses between different local authorities. These are particular crisis points that can often lead to total frustration. The charity Caring Together carried out an experiment whereby a young adult sought to find out how they could access a transitions assessment by contacting 19 local councils and looking on their websites. Out of these, only eight were able to provide information on how to access an assessment.<sup>654</sup>
418. Sense UK argued that expectations are set too low during transitions, in particular when transitioning from childcare to adult social care. This is partly because there is an assumption by service providers and assessors that young adults will remain at home and that parents will provide unpaid care and support—even though once they leave education, their care needs become even greater. As parents age, they are often forced to leave employment to cover the additional hours. Reflective of this is the fact that only one in 10 parents of children with complex disabilities felt that their child would be able to access the specialist support they would need to fulfil their aspirations as an adult.<sup>655</sup> They therefore suggested expanded information on potential employment to those who desire it; interagency teams working between children’s and adult’s services; and exploration of children’s/young adults’ aspirations.<sup>656</sup>
419. The first transition is possibly the hardest one: the unpreparedness of unpaid carers who suddenly find themselves providing care and support after a member of their family or a friend develop a care need, suddenly, and sometimes overnight. There is a need, therefore, to develop better navigation mechanisms for unpaid carers from day one. We heard of the importance that Government and the sector “increase awareness, drive up the take-up of guidance and advice and increase early engagement.”<sup>657</sup> It is important that this awareness is maintained along the “care journey”. The Association of British Insurers suggested that this should take the form of a national awareness campaign.<sup>658</sup>
420. Another pinch point, as described in Chapter 3, are the conspicuous challenges around hospital discharge which frequently came up as a crucial transition point in the caring process where the relationship between the person, the unpaid carer and formal care services could become particularly problematic for the person who draws on care. We heard that “good practice in involving carers in hospital discharge is not widespread enough”.<sup>659</sup> Poor communication around discharge can lead to the deterioration of the older

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654 Written evidence from Caring Together ([ASC0025](#))

655 Written evidence from Sense UK ([ASC0091](#))

656 *Ibid.*

657 Written evidence from the Association of British Insurers ([ASC0118](#))

658 *Ibid.*

659 [Q 75](#) (Rohati Chapman)

adult or disabled person’s health.<sup>660</sup> One unpaid carer said that it would be helpful for hospitals to provide information about the condition of the older adult or disabled person, such as discharge letters.<sup>661</sup> Improving hospital discharge requires staff to speak to the person first and, with permission, to the unpaid carer, without making assumptions about who might do what. If and once it is established that the person wishes to involve an unpaid carer, there needs to be appropriate recognition of the role that the unpaid carer can play in ensuring the positive outcome of discharge.<sup>662</sup>

421. Discharge from hospital should come with better signposting, advice and information for unpaid carers, who often find themselves having to provide care and support with no preparation or training. We heard that it is important to ensure that the statutory right for carers to be consulted prior to hospital discharge, established in the Health and Care Act 2022 and the accompanying guidance, is being met in practice.<sup>663</sup> Carers have had the right to be consulted prior to discharge since the Community Care (Delayed Discharges etc.) Act 2003,<sup>664</sup> and we were told by Ms Keegan that recent changes to discharge have included “making sure that the person who was caring at home, if that was the situation they were going into, was also part of the conversation and part of the discussion.”<sup>665</sup> This, however, seems to be at odds with the reality on the ground, which we heard from carers themselves, who described that they are not communicated with prior to hospital discharge.<sup>666</sup>
422. The statutory right of carers to be consulted prior to discharge must be enforced. One example of good practice in discharge referred to the Committee is the Kent community hospital accreditation, where there were voluntary discharge champions, who will support community hospitals with the discharge process.<sup>667</sup> Similarly, the Surrey County Council has commissioned the charity Action for Carers, which deploys ‘Hospital Advisors’ to five hospitals in the county to identify carers and support them while the person they provide care for is in the hospital. The Advisors are tasked with identifying carers and approaching them to bridge communication gaps with the hospital, offer advice and information and emotional support. They can also help carers with the discharge process, by signposting them to other organisations. The work of Advisors was described to us as “invaluable” to the carers in helping them “navigate the complexities of the care system.”<sup>668</sup>

### **Recognising the role and value of unpaid carers in the caring relationship: an unrecognised asset**

423. The adult social care system could not survive without the contribution of unpaid carers.<sup>669</sup> Improving ways of appropriately identifying the unpaid

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660 [Q 138](#) (Norman Phillips)

661 Written evidence from Mary Ledgard ([ASC0099](#))

662 *Ibid.*

663 Department of Health and Social Care, ‘Hospital discharge and community support guidance’ (1 July 2022): <https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance#how-nhs-and-local-authorities-can-work-together-to-plan-and-implement-hospital-discharge-recovery-and-reablement-in-the-community> [accessed 22 September 2022]

664 Community Care (Delayed Discharges etc.) Act 2003, [section 2\(4\)](#)

665 [Q 151](#) (Gillian Keegan MP)

666 Written evidence from Caring Together ([ASC0025](#))

667 [Q 75](#) (Rohati Chapman)

668 [Q 119](#) (Jamie Gault)

669 Written evidence from the Local Government Association ([ASC0042](#))

carer in the community is closely linked to the respect and recognition they receive.

424. Our recommendations so far focus on better identification, on the need to improve carers’ benefits and work/care balance and on navigating the system, particularly at the disruptive points of transition where most help is needed. There is, however, a systemic change which would fundamentally make each of these recommendations stick, and that is for a closer and more confident relationship between the service itself (the frontline paid care worker) and the unpaid carer.
425. Following from an increased role for GPs and health professionals as the first step towards identification, there is a natural progression towards those same professionals being more proactive in recognising the role of the unpaid carer.
426. At the moment, that does not appear to happen. Indeed, unpaid carers told us that they often feel invisible because they are not seen as important by health and care professionals despite the fact that they have expert knowledge that can only be an asset to getting the care pathway right—a fact that should be recognised as a priceless asset by professionals.
427. But the greatest impact could be made if the paid and unpaid carer were enabled to work more closely together. We heard, for example that “the job is neither valued nor respected because most people (including professionals) do not understand that it involves far more than just being present and doing tasks.”<sup>670</sup> Also, that “they must not be seen as an alternative to paid workers but an adjunct who should be recognised and supported.”<sup>671</sup>
428. The failure to recognise that unpaid carers are equal partners in care and to value their expertise impacts on relationships between unpaid carers and paid carers and social workers, which can become compromised and sometimes even hostile. Many unpaid carers told us that, far from seen as a partner in the care journey, they are seen and treated as a “nuisance”.<sup>672</sup> One unpaid carer said they were “treated like criminals” and “ignored” by professionals, and that there was “no communication”.<sup>673</sup> This was covered in more detail in Chapter 3.
429. There seems therefore to be an embedded culture in care settings that is not conducive to the recognition of the role and expertise of carers. As put by one unpaid carer, “we are the experts in our own field”.<sup>674</sup> Another described how carers are “challenged by staff almost every time they ask a question in their role as carers, are questioned as to whether they are really a carer or even asked to explain what their role is.”<sup>675</sup>
430. It is in everyone’s interests that the relationship between the carer and the rest of the social care service should be as positive, productive and as respectful as possible if there are to be right and sustainable outcomes for everyone. That means that the carer must not only be a central and valued member of the team, but that their expert knowledge and skills in providing care for the person involved must be audited, accommodated and reinforced.

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670 Written evidence from Diana Pargeter ([ASC0038](#))

671 Written evidence from Reclaim Social Care Greater Manchester ([ASC0121](#))

672 Written evidence from Mary Ledgard ([ASC0099](#))

673 Written evidence from Katherine Eastland ([ASC0009](#))

674 Written evidence from PJ Woolfall ([ASC0103](#))

675 Written evidence from Mary Ledgard ([ASC0099](#))



431. At its worst, the failure to value the role of the carer does not simply mean that a resource is lost to the service; it also can mean negative and sometimes dangerous consequences for older adults and disabled people.
432. That failure of the process is often most acutely seen in the assessment process. The relationship that flows from that is a key part of making carers feel valued. As witnesses told us, assessments should therefore take into account all the resources the carer brings and needs: their mental and physical health, their ability and willingness to care and their relationships with others.<sup>676</sup>
433. One way to achieve this would be to give health and care staff professional training as part of the curriculum to embed a carer-aware and carer-friendly culture throughout their organisations, and to establish better communication with carers. The charity Caring Together, for instance, already provides carer awareness training to health and social care staff in Norfolk.<sup>677</sup> We heard from other organisations that this is a good way to improve recognition of carers.<sup>678</sup> To be most effective, this training should be co-produced with carers, who are best placed to know what best practice should look like.
434. Ms Chapman proposed that carers are consistently involved in the ‘Triangle of Care’ between the care worker, the person who draws on care and the unpaid carer, saying that “there needs to be a culture shift of consistently engaging carers with common-sense confidentiality practices, and Triangle of Care addresses this”.<sup>679</sup> The Triangle of Care was originally conceived in 2010 to highlight the need for better involvement of carers and families in the care planning and treatment of people with mental ill-health,<sup>680</sup> although could equally be applied to adult social care. This requires “time, commitment and senior leadership buy-in to build the relationships and understanding between carers and professionals and service users or patients”.<sup>681</sup> Dan Gower-Smith, Group Director of Operations, Avenues Group, also emphasised the importance of cultural change, saying: “It should be a culture within the organisation that paid and unpaid carers are fundamental to delivering good support and recognising those individuals.”<sup>682</sup>
435. ***The Government should require that carer awareness training becomes a workforce requirement in health and social care settings, and that this training is co-produced with unpaid carers.***

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676 Written evidence from the Local Government Association ([ASC0042](#))

677 Written evidence from Mary Ledgard ([ASC0099](#))

678 Written evidence from Carers Support Centre Bristol and South Gloucestershire ([ASC0101](#)) and Carers in Hertfordshire ([ASC0111](#))

679 [Q 73](#) (Rohati Chapman)

680 Carers Trust, ‘Guidance: The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England’: <https://carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england> [accessed on 28 September 2022]

681 [Q 73](#) (Rohati Chapman)

682 [Q 76](#) (Dan Gower-Smith)

## CHAPTER 8: CONCLUSION: “WHEN IS THE HELP COMING?”

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436. In this report, we have looked at the reasons why adult social care as a whole has been invisible—poorly understood and often neglected by policy makers, the public and the media—and the impact that this has had, in particular, on disabled adults and older people, as well as unpaid carers. We have heard in the powerful and profoundly moving words of many witnesses in different situations, how this has affected them and their hopes and fears for the future. Our report is grounded in this reality. The changes we propose aim to bring increased voice, visibility, independence, choice and control, both to those who draw on care and those who provide it, paid and unpaid—enabling all of us to lead more ordinary, autonomous lives as equal citizens.
437. Our recommendations are also designed to create a more positive and powerful narrative around adult social care services. Throughout, we have had a bifocal lens, concentrating on the relationship between those who draw on care, and their families and friends who provide care and support. What happens to either has an immediate impact on the lives of the other.
438. People who draw on care and support have been clear that they just want to be able to lead the same kinds of lives as everyone else—as one witness described it to us, to live “a gloriously ordinary life”.<sup>683</sup> It is a modest expectation but it challenges the existing dynamics of adult social care, which are framed by limitations and often expressed through frustration, not just by people who draw on care and support and unpaid carers, but also by the committed and skilled people who work in adult social care, who often feel just as limited by the current system.
439. In this report, we challenge ourselves as a society to embrace a new and more positive narrative—one in which care and support enable us to live an equal life. By making this shift, we look afresh at the perceptions as well as the purpose of adult social care.
440. Fundamentally, disabled adults and older people must have the same choice and control over their life as other people. We have made that clear in the emphasis we have put on co-production and the need to share decision making so that the right solutions can be found. All of our recommendations, from increasing funding to improving housing options, through expanding direct payments and disabled people’s organisations, have the objective of enabling people to exercise greater choice over their own care and their own life.
441. The devastating reality, however, is that in many cases neither people who draw on care and support nor unpaid carers feel that they have any choice or control over their relationship with each other. Disabled adults and older people described to us how they feel pressured into drawing on the support of their families and friends, even if they would prefer an alternative arrangement, and often because they cannot access suitable care services. Unpaid carers similarly find that they are largely expected, not only by their local authority but by society as a whole, to step up to provide support.
442. While providing unpaid care is often a source of joy and pride for unpaid carers, the work carried out is taken for granted. We ask too much of unpaid carers without providing reciprocal support. The consequence is that too

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683 Q 23 (Tricia Nicoll)

often they find themselves in desperate situations ranging from extreme poverty to emotional breakdown. One unpaid carer challenged us by asking: “When is the help coming?” and powerfully made the case for change: “If you could deliver one thing for carers, it would be hope that things are going to get better and that the system is going to value us.”<sup>684</sup>

443. We must make things better as a matter of urgency. Part of that is putting a new value on those who care, unpaid and usually unheard. But unpaid carers must also be able to count on a service that helps rather than hinders them—a service that cares about them as well as about disabled adults and older people, which is respectful, clear and compassionate in the way it supports and values their skills and experience in the provision of care. Given the debt which we owe unpaid carers, it is both ethical as well as pragmatic to provide them with greater options and support. They are the foundation of the majority of care provided and as such are the scaffolding around the NHS and its future prospects. As we argue in this report, the invisibility, poverty and isolation of unpaid carers must be relieved, navigation systems must be transformed, essential short breaks must be provided and better support must be put in place to enable unpaid carers to keep working in paid employment if that is their choice.
444. We also set out how these urgent reforms to the social care system can be driven and sustained. In order to do more and more effectively, we need to know more about who social care affects, everywhere and at every level. Without better information, data and research, we cannot make confident change. We have recommended, therefore, that a more systemic approach to data collection and policy making is taken, not only to better identify the needs of people who draw on social care services and unpaid carers, but to assess the efficacy of the solutions that can be offered and establish how they can be universalised. Here, the excellent practice we have identified at a local level comes into its own.
445. There is no way to escape the challenge of funding a system to match an ageing society and the complex support needed by working age adults with lifetime needs—especially one that is relatively invisible and has less political muscle, no matter how deserving it is. Yet adult social care is not only the key to a more efficient health service; it is also the bedrock of a ‘care economy’, the provision of which enables the rest of society to get on with their lives and their jobs. That reality must now be given the weight it commands. The rhetoric has become louder in recent years but no meaningful action has followed. Without a funding settlement that is realistic, predictable and sustained, and which will build capacity at a local level and across the workforce, there will be more failures.
446. It is not, however, all about funding. Many of our recommendations are for a change in perception and delivery. The profile of adult social care must be raised so that it is better understood, better supported and celebrated for the work it does. While we believe that adult social care should remain a local service, we recommend ways of raising its status and profile nationally so that everyone involved can benefit from more advocacy and challenge. We call, therefore, for a national plan for the sector and a Commissioner for Care and Support to act as a champion for disabled adults and older people, and unpaid carers.

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684 [Q 141](#) (Norman Phillips)

447. Greater visibility should also be given to past failures so that the most can be made of mechanisms already in place to bring change without delay. The Care Act 2014 is a supreme example of policy which has failed its purpose, with the right principles and expectations lost in time. This needs to be put right immediately and the legislation that has been introduced must be made to work.
448. In summary, we want to see the adoption of a more positive definition of adult social care, which is based on principles of co-production, choice and control, and celebrates social care as a form of social and economic investment we make as a society. This is encapsulated in the vision of Social Care Future that we have endorsed:
- “We all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.”<sup>685</sup>
449. Whether we are a parent, child, sibling, relative, neighbour or friend, we are all likely to one day, if not already, provide support to someone who we care about, as well as to draw on care and support ourselves. The stories we heard have strongly put into focus that adult social care concerns all of us; and all of us should understand that building a more equal society in which care and relationships are enabled to thrive is a priority.
450. There is much debate about adult social care reform, but little of this has come to fruition in the past. We applaud the ambition of existing legislation and although often insufficient, we welcome the pledges that have been made for the future. We see this as an opportunity to achieve the right transformation for adult social care. We hope that this report can contribute to that transformation, and to ensuring that today’s ambitions can become tomorrow’s reality.

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685 Social Care Future, ‘A vision for the future of social care’: <https://socialcarefuture.blog/2021/04/29/a-vision-for-the-future-of-social-care/> [accessed 15 September 2022]

## SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

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1. Adult social care, with the exception of recent proposals for funding reforms, has been historically relatively invisible in terms of national policy and politics. This is now increasingly damaging to both those who draw on and who provide unpaid care at a time of growing need, rising costs and a shrinking workforce. (Paragraph 80)
2. *The Government should implement mechanisms to collect more accurate data on the number of people ageing without children, including men who do not have children, people who are estranged from their children, or people whose children have pre-deceased them.* (Paragraph 121)
3. *Further research is required to understand the prospects of people ageing without children. The Government should work with charities, civil society and academics to understand how their needs can better be met.* (Paragraph 122)
4. Creating a sustainable social care system in which people, their families and friends can thrive is a national imperative. Investment is cost effective both in economic and social terms, as a sustainable adult social care service is an indispensable partner to the health service. (Paragraph 155)
5. We endorse Social Care Future’s definition of the purpose of social care: to make possible the rightful ambition of people who “all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.” (Paragraph 166)
6. *The Government must increase the financial settlement for adult social care over three years and then commit to sustain realistic, long-term and protected funding for the sector to enable robust planning. Funding requirements over and above what has already been committed should be assessed on the best estimates from independent experts and agencies.* (Paragraph 180)
7. *The Government must prioritise, with people who work and draw on adult social care, a comprehensive long-term national workforce and skills plan for adult social care, including a commitment to remedy low pay in the sector.* (Paragraph 192)
8. *The Government must put in place, with people who work in and draw on adult social care, a national long-term plan for adult social care, exemplifying the vision set out by Social Care Future—“we all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.” This should include a National Carers Strategy.* (Paragraph 201)
9. *The Government should establish in the next 12 months a Commissioner for Care and Support to act as a champion for older adults and disabled people and unpaid carers, and to accelerate a more accessible adult social care system. The Government should ensure this role is filled by, or shared in equal measure, with a person who has lived experience.* (Paragraph 211)
10. *The Government must commission an independent public review of the Care Act 2014 and work with local authorities to ensure that the Act is fully implemented by the end of this Parliament. The Commissioner for Care and Support should make it a priority to ensure that the review, update and implementation of the Act happens in practice.* (Paragraph 229)



11. *For the new ICSs to deliver for adult social care and unpaid carers, the Government must introduce an obligation to include older adults and disabled people, and unpaid carers, in the design and delivery of care; as well as ensure parity between adult social care and healthcare within ICSs. (Paragraph 242)*
12. *ICSs must listen and adapt to local communities, in particular those in rural and remote areas; and the Government must monitor them on an annual basis to ensure that they do so. (Paragraph 252)*
13. *The Government should recognise the potential cost-effectiveness of co-production, and the role of local communities and micro-providers in enabling co-production, choice and control for disabled adults and older people by ringfencing funding for local authorities to dedicate to investment in building community capacity, learning from what is working well, and to connect residents to local offers for care and support that are tailored to their needs. (Paragraph 274)*
14. *The Government should ensure that the definition and vision for social care that is proposed by Social Care Future, as specified previously, is endorsed in principle by all national social care bodies (such as Social Work England, the Care Quality Commission and Skills for Care) to put the best ambitions and values of the workforce into policy and practice more effectively. (Paragraph 295)*
15. *The Government should work with local authorities, the voluntary sector and social care providers to embed the principles of co-production. This means working with social care staff to enable them to acquire the support and skills necessary to co-produce care and enable a shift in power from staff to individuals who draw on care and support. (Paragraph 296)*
16. *Good policy and practice have been conspicuously inhibited by a lack of data. The Government, as a priority, should invest in robust data collection to reveal the conditions and characteristics of the social care sector and inform effective practice. (Paragraph 299)*
17. *Under the Care Act 2014, local authorities have a duty to provide information and advice to residents about care and support. (Paragraph 310)*
18. *The Government should enable local authorities to extend local support to those who need advice and information because they have care needs or provide unpaid care. This should be done through specific funding to commission peer-led independent organisations over at least a three-year period to enable innovation and capacity building. (Paragraph 310)*
19. *As part of its adult social care workforce plan, the Government must commission an independent review of the pay and working conditions for personal assistants. (Paragraph 329)*
20. *The Government should set aside some of the specific funding identified in the White Paper to develop innovative models to make direct payments and personal assistance easier to access and manage, and to simplify the recruitment of personal assistants. (Paragraph 330)*
21. *The Government should follow through on its commitment to mandate minimum accessible standards so that all new build residential properties across all tenures meet standards of accessibility and inclusivity, including for sensory impairments, learning disabilities and autism spectrum disorders. (Paragraph 348)*

22. *The Government must increase capital funding to secure a new supply of purpose-built supported housing and revenue funding for services to help people live independently, if they are to deliver the commitments set out in the Social Care White Paper. (Paragraph 349)*
23. *The Government should introduce an accessibility and inclusivity standard for marketing residential properties for rent, requiring properties to be listed with accessible and inclusive characteristics. (Paragraph 350)*
24. We welcome the Government’s committed investment in care technology and its testing and scaling of related ideas. (Paragraph 360)
25. *The Government must ensure that any testing of ideas related to care technology is done in co-production with people with lived experience. (Paragraph 360)*
26. *The Government should create a research and development network for the sharing of technological innovation between social care stakeholders, similar to the NHS R&D Forum. (Paragraph 361)*
27. *The Government and NHS England should create incentives for secondary and primary care to identify unpaid carers, and to ensure that their unpaid caring status is included in their patient record with their permission. On identification, there should be mechanisms to provide carers with information, self-care and digital resources to support them. (Paragraph 378)*
28. *Access to Carer’s Allowance must immediately be made easier by lowering the threshold of caring hours and ensuring that the earnings limit is uprated, in line with rises to the National Living Wage. (Paragraph 389)*
29. *The Department for Work and Pensions must review Carer’s Allowance, reporting to Parliament within 12 months, and recognising that, as the lowest benefit of its kind, it is not reflective of the value of unpaid carers’ work. The review should also cover the high threshold of caring hours, and the low and inflexible earnings limit, which are both significant barriers to accessing Carer’s Allowance. (Paragraph 390)*
30. *The Government must honour its commitment and establish the entitlement to unpaid Carer’s Leave at the earliest opportunity, supporting the speedy passage of the Carer’s Leave Bill. (Paragraph 396)*
31. *The Government should commission a review with the longer-term objective of legislating for compensated Carer’s Leave. (Paragraph 397)*
32. *The Government should ensure the wider uptake of the Employers for Carers’ Carer Confident Scheme to raise awareness of unpaid carers in the workplace and encourage employers to support unpaid carers who work for them. (Paragraph 402)*
33. *The Government should dedicate ring-fenced funding to increase the availability and capacity of services that provide flexible short breaks for unpaid carers. (Paragraph 406)*
34. Overall, the care system is a labyrinth: carers face bewildering difficulties in finding out and accessing the support to which they and the person they provide care to are entitled. National action is needed to coherently resolve these significant navigation challenges. It must be complemented, however, by advice and information that is tailored to the personal and local nature of social care. (Paragraph 415)

35. *The Department of Health and Social Care and the Department for Work and Pensions must join forces to look at carers’ journeys to find better information and advice combining trusted national sources of information (such as gov.uk or Carers UK) with locally trusted information, advice and support for carers, recognising that they are best placed to advise locally. (Paragraph 416)*
36. *The Government should require that carer awareness training becomes a workforce requirement in health and social care settings, and that this training is co-produced with unpaid carers. (Paragraph 435)*

## APPENDIX 1: LIST OF MEMBERS AND DECLARATIONS OF INTEREST

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### Members

Baroness Andrews (Chair)  
 Baroness Barker  
 Lord Bradley  
 Baroness Campbell of Surbiton  
 Bishop of Carlisle  
 Baroness Eaton  
 Baroness Fraser of Craigmaddie  
 Baroness Goudie  
 Baroness Jolly  
 Rt Hon Lord Laming  
 Lord Polak  
 Baroness Shephard of Northwold  
 Baroness Warwick of Undercliffe

### Declarations of interest

Baroness Andrews (Chair)  
*Governor, Sutton’s Hospital, The Charterhouse.*

Baroness Barker  
*Runs a management consultancy, ThirdSectorBusiness, which works with charities and social enterprises some of whom work in health and social care; Honorary patron of multiple charities, some of which such as OpeningDoors work in health and social care.*

Lord Bradley  
*Non-Executive Chair, Bury Tameside and Glossop NHS Local Improvement Finance Trust (LIFT) Company;  
 Non-Executive Chair, Manchester, Salford and Trafford NHS LIFT Company  
 Trustee, Centre for Mental Health;  
 Trustee, Prison Reform Trust;  
 Honorary Fellow, Royal College of Speech and Language Therapists;  
 Honorary Special Adviser, University of Manchester;  
 Chair of Council, University of Salford.*

Baroness Campbell of Surbiton  
*In direct receipt of a Personal Health Budget and has been a user of health and social care services since the age of 21;  
 Trustee, The Civil Liberties Trust that funds the charity Liberty which has campaigned on issues regarding social care services in terms of human rights;  
 Founder and convener, Not Dead yet UK, which campaigns against a change in the law on assisted suicide, and advocates for fully funded supported living for people with long-term health conditions and disabilities;  
 Patron, Scott Morgan Foundation which raises funds for advanced technology to support Independent Living for disabled people.*

Lord Bishop of Carlisle  
*Co-Chair, Archbishops’ Commission on Reimagining Care;  
 Lead Lord Spiritual on Health and Social Care, Church of England.*

Baroness Eaton  
*No relevant interests to declare*

**Baroness Fraser of Craigmaddie**

*Scotland Member, Board of the British Library (from 19 September 2022);  
CEO, Cerebral Palsy Scotland;  
Board Member, Creative Scotland;  
Trustee, The Neurological Alliance of Scotland;  
Board Member, The Office of the Scottish Charity Regulator (OSCR)  
(until 31 March 2022);  
Chair, Scottish Government National Advisory Committee for Neurological  
Conditions.*

**Baroness Goudie**

*No relevant interests to declare.*

**Baroness Jolly**

*Chair, NHS National Community Nursing Plan Clinical Reference  
Group;  
President, The Royal Society for the Prevention of Accidents (RoSPA);  
Chair, Stakeholder Advisory Panel (SAP) NHS National Community  
Nursing Plan.*

**Lord Laming**

*No relevant interests to declare.*

**Lord Polak**

*Senior Counsellor, International Advisory Counsel of APCO Worldwide;  
Senior Consultant, Marsh Ltd.  
Both these companies will have clients in health and social care areas, Lord  
Polak is not associated with any of these clients.*

**Baroness Shephard**

*Her husband, Thomas Shephard, has been in a care home since July 2020.  
He receives attendance allowance but is otherwise self-funding.*

**Baroness Warwick of Undercliffe**

*Chair, National Housing Federation which represents housing associations  
in England, and has members who are responsible for care homes and  
supported housing, September 2015 - September 2022.*

A full list of Members' interests can be found in the Register of Lords' Interests:  
[http://www.parliament.uk/mps-lords-and-offices/standards-and-interests/  
register-of-lords-interests/](http://www.parliament.uk/mps-lords-and-offices/standards-and-interests/register-of-lords-interests/)

**Specialist Advisers****Professor Jon Glasby**

*Professor of Health and Social Care, University of Birmingham;  
Non-Executive Director, University Hospitals Birmingham NHS  
Foundation Trust;  
Non-Executive Director, Birmingham Children's Trust;  
Director, IMPACT (the UK centre for implementing evidence in adult  
social care);  
Senior Fellow, National Institute for Health and Care Research (NIHR)  
School for Social Care Research.*

**Dr Anna Severwright**

*Commissioner, Archbishops' Commission on Reimagining Care;  
Disabled person who draws on social care;  
Convenor, Social Care Future.*



## APPENDIX 2: LIST OF WITNESSES

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Evidence is published online at <https://committees.parliament.uk/committee/580/adult-social-care-committee/publications/> and available for inspection at the Parliamentary Archives (0207 219 3074).

Evidence received by the Committee is listed below in chronological order of oral evidence session, and then in alphabetical order. Those witnesses marked with \*\* gave both oral evidence and written evidence. Those marked with \* gave oral evidence and did not submit any written evidence. All other witnesses submitted written evidence only.

### Oral evidence in chronological order

|    |  |  |
|----|--|--|
| *  | Michelle Dyson, Director General for Adult Social Care, Department for Health and Social Care                                  | <a href="#">QQ 1–12</a><br><a href="#">QQ 149–164</a>  |
| *  | Tom Surrey, Director of Adult Social Care Policy, Department for Health and Social Care  | <a href="#">QQ 1–12</a>                                |
| *  | Jason Yiannikou, Director of Integration and Legislation, Department for Health and Social Care                                | <a href="#">QQ 1–12</a>                                |
| *  | Vicky Davis, Director for Local Government Value for Money, National Audit Office  | <a href="#">QQ 13–22</a>                               |
| *  | Dr Anna Dixon MBE, Chair, Archbishops’ Commission on Reimagining Social Care   | <a href="#">QQ 13–22</a>                               |
| *  | Rt Hon Jeremy Hunt MP, Chair, House of Commons Health and Social Care Committee  | <a href="#">QQ 13–22</a>                               |
| ** | Professor Vic Rayner OBE, CEO, National Care Forum, representing the All-Party Parliamentary Group (APPG) on Adult Social Care | <a href="#">QQ 13–22</a>                               |
| *  | Tricia Nicoll, Expert by experience  | <a href="#">QQ 23–34</a><br><a href="#">QQ 142–148</a> |
| *  | Andy McCabe, Expert by experience  | <a href="#">QQ 23–34</a><br><a href="#">QQ 142–148</a> |
| *  | Sue Bott CBE, Expert by experience   | <a href="#">QQ 23–34</a>                               |
| ** | Norman Phillips, Expert by experience  | <a href="#">QQ 35–45</a><br><a href="#">QQ 135–141</a> |
| ** | Helen Spalding, Expert by experience   | <a href="#">QQ 35–45</a><br><a href="#">QQ 135–141</a> |
| ** | Katy Styles, Expert by experience  | <a href="#">QQ 35–45</a><br><a href="#">QQ 135–141</a> |
| *  | Ian Loynes, Chief Executive Officer, SPECTRUM Centre for Independent Living  | <a href="#">QQ 46–54</a>                               |
| *  | Kirsty Woodard, Founder and Director, Ageing Without Children  | <a href="#">QQ 46–54</a>                               |
| ** | Nadia Taylor, Chair of the Board of Trustees, Carers Network   | <a href="#">QQ 55–59</a>                               |

- \*\* Dr Valentina Zigante, Research Officer, Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science [QQ 55–59](#)
- \*\* Madeleine Starr, Director of Business Development and Innovation, Carers UK [QQ 60–66](#)
- \*\* Sue Yeandle, Professor of Sociology and Director of Centre for International Research on Care (CIRCLE), University of Sheffield, and Principal Investigator, Economic Social Research Council (ESRC) Centre for Care [QQ 60–66](#)
- \* Professor Nan Greenwood, Centre for Health and Social Care Research, Kingston University London [QQ 67–72](#)
- \* Fatima Khan-Shah, Associate Director of Long Term Conditions and Personalisation, West Yorkshire Health and Care Partnership [QQ 67–72](#)
- \*\* Rohati Chapman, Executive Director of Programmes and Impact, Carers Trust [QQ 73–78](#)
- \* Dan Gower-Smith, Group Director of Operations, Avenues Group [QQ 73–78](#)
- \*\* Luke Price, Senior Evidence Manager, Centre for Ageing Better [QQ 79–84](#)
- \* Fazilet Hadi, Head of Policy, Disability Rights UK [QQ 79–84](#)
- \* Professor Donna Hall CBE, Chair, Bolton NHS Foundation Trust and Former Chief Executive, Wigan Council [QQ 85–89](#)
- \*\* Ian McCreath, Head of Think Local Act Personal (TLAP) [QQ 85–89](#)
- \*\* Kate Sibthorp, Co-chair of the National Coproduction Advisory Group, TLAP [QQ 85–89](#)
- \*\* Nick Sinclair, Director of the Local Area Coordination Network, Community Catalysts [QQ 90–96](#)
- \*\* Les Billingham, Director for Adult Social Care, Thurrock Council [QQ 90–96](#)
- \*\* Rhys Davies, Community Enterprise Service Manager, Somerset County Council [QQ 90–96](#)
- \*\* Adolf Ratzka, Founder, Stockholm Cooperative for Independent Living [QQ 97–105](#)
- \* Theresa Shearer, Group CEO, Enable Group [QQ 97–105](#)
- \*\* Clive Gilbert, Policy Manager, Policy Connect [QQ 106–115](#)
- \*\* Kevin Heaney, Personal Assistant to Clive Gilbert [QQ 106–115](#)
- \* Dr Kate Hamblin, Research Fellow, Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Sheffield [QQ 106–115](#)
- \*\* Guy Harris, Director, Accessible PRS [QQ 106–115](#)

|    |  |                                   |
|----|--|-----------------------------------|
| *  | Jamie Gault, CEO, Action for Carers Surrey   | <a href="#"><u>QQ 116–121</u></a> |
| ** | Chris McCann, Director of Communications, Insight and Campaigns, HealthWatch England                       | <a href="#"><u>QQ 116–121</u></a> |
| ** | Belinda Schwehr, CEO, CASCAIDr (Centre for Adults’ Social Care–Advice, Information and Dispute Resolution) | <a href="#"><u>QQ 122–128</u></a> |
| ** | Jerry Tew, Professor of Mental Health and Social Work, University of Birmingham                            | <a href="#"><u>QQ 122–128</u></a> |
| *  | Graham Biggs, CEO, Rural Services Network  | <a href="#"><u>QQ 129–134</u></a> |
| *  | Kate Garner, Service Manager, Shropshire Council   | <a href="#"><u>QQ 129–134</u></a> |
| *  | Gillian Keegan MP, Minister for Care and Mental Health, Department for Health and Social Care              | <a href="#"><u>QQ 149–164</u></a> |
| ** | Councillor David Fothergill, Chairman, Local Government Association (LGA) Community Wellbeing Board        | <a href="#"><u>QQ 165–177</u></a> |
| *  | Martin Samuels, Strategic Director for Social Care and Education, Leicester City Council                   | <a href="#"><u>QQ 165–177</u></a> |
| ** | Tandra Forster, Executive Director for Adults and Communities, Southend-on-Sea Borough Council             | <a href="#"><u>QQ 165–177</u></a> |
| *  | Laura Gaudion, Interim Director of Adult Social Care and Housing Needs, Isle of Wight Council              | <a href="#"><u>QQ 165–177</u></a> |
| *  | Sir Andrew Dilnot CBE, Warden, Nuffield College, University of Oxford                                      | <a href="#"><u>QQ 178–187</u></a> |

### **Alphabetical list of all witnesses**

|   |  |                                |
|---|--|--------------------------------|
|   | Action Disability Kensington and Chelsea   | <a href="#"><u>ASC0113</u></a> |
|   | Age UK   | <a href="#"><u>ASC0119</u></a> |
|   | All-Party Parliamentary Group on Housing and Care for Older People                 | <a href="#"><u>ASC0141</u></a> |
|   | Alzheimer’s Society  | <a href="#"><u>ASC0086</u></a> |
|   | Richard Amm  | <a href="#"><u>ASC0015</u></a> |
|   | Anchor   | <a href="#"><u>ASC0080</u></a> |
|   | Jane Ashwin  | <a href="#"><u>ASC0124</u></a> |
|   | Associated Retirement Community Operators  | <a href="#"><u>ASC0115</u></a> |
|   | Association for Real Change  | <a href="#"><u>ASC0011</u></a> |
|   | Association of British Insurers  | <a href="#"><u>ASC0118</u></a> |
|   | Association of Directors of Adult Social Services                                  | <a href="#"><u>ASC0135</u></a> |
|   | Avocet Trust   | <a href="#"><u>ASC0041</u></a> |
| * | Graham Biggs, CEO, Rural Services Network<br>( <a href="#"><u>QQ 129–134</u></a> ) |                                |

|    |   |  |
|----|---|--|
| ** | Les Billingham, Director for Adult Social Care,<br>Thurrock Council ( <a href="#">QQ 90–96</a> )                  | <a href="#">ASC0139</a>                            |
| *  | Sue Bott CBE, Expert by experience ( <a href="#">QQ 23–34</a> )   |  |
|    | Bristol City Council  | <a href="#">ASC0076</a>                            |
|    | British Association of Social Workers England   | <a href="#">ASC0087</a>                            |
|    | British Medical Association   | <a href="#">ASC0151</a>                            |
|    | The Bureau of Investigative Journalism  | <a href="#">ASC0096</a>                            |
|    | Lucy Campbell, Right at Home UK   | <a href="#">ASC0075</a>                            |
|    | Care England  | <a href="#">ASC0034</a>                            |
|    | Care Quality Commission   | <a href="#">ASC0019</a>                            |
|    | The Care Workers’ Charity   | <a href="#">ASC0064</a>                            |
|    | Carers in Hertfordshire   | <a href="#">ASC0111</a>                            |
|    | Carers Support Centre Bristol and South<br>Gloucestershire  | <a href="#">ASC0101</a>                            |
|    | Caring Together   | <a href="#">ASC0025</a>                            |
|    | Denise Carlo  | <a href="#">ASC0130</a>                            |
|    | Sandra Carlse   | <a href="#">ASC0152</a>                            |
| ** | Centre for Adults’ Social Care–Advice, Information<br>and Dispute Resolution ( <a href="#">QQ 122–128</a> )       | <a href="#">ASC0062</a><br><a href="#">ASC0136</a> |
| ** | Centre for Ageing Better ( <a href="#">QQ 79–84</a> )   | <a href="#">ASC0154</a>                            |
|    | The Centre for Care   | <a href="#">ASC0058</a>                            |
|    | Centre for Research in Health and Social Care,<br>University of Bristol   | <a href="#">ASC0037</a>                            |
| ** | Rohati Chapman, Executive Director of<br>Programmes and Impact, Carers Trust ( <a href="#">QQ 73–78</a> )         | <a href="#">ASC0097</a>                            |
|    | Chartered Institute of Housing  | <a href="#">ASC0127</a>                            |
|    | CLOSER, Social Research Institute, University<br>College London   | <a href="#">ASC0069</a>                            |
|    | ConnectED Project Service User and Carer<br>Advisory Group, University of Bristol                                 | <a href="#">ASC0027</a>                            |
|    | Dr Anne Cullen and Professor Tony Evans, Labour<br>Social Work Group  | <a href="#">ASC0105</a>                            |
|    | Julie Davies  | <a href="#">ASC0028</a>                            |
| *  | Rhys Davies, Community Enterprise Service<br>Manager, Somerset County Council ( <a href="#">QQ 90–96</a> )        |  |
| *  | Vicky Davis, Director for Local Government Value<br>for Money, National Audit Office ( <a href="#">QQ 13–22</a> ) |  |
|    | Lyn Deakin and Dave Deakin  | <a href="#">ASC0036</a>                            |
|    | Dementia Carers Count   | <a href="#">ASC0095</a>                            |

- \* Sir Andrew Dilnot CBE, Warden, Nuffield College,  
University of Oxford ([QQ 178–187](#))
- Dimensions UK Ltd [ASC0098](#)
- Disability Law Service [ASC0112](#)
- \* Dr Anna Dixon MBE, Chair, Archbishops’  
Commission on Reimagining Social Care ([QQ 13–22](#))
- \* Michelle Dyson, Director General for Adult Social  
Care, Department for Health and Social Care  
([QQ 1–12](#) and [QQ 149–164](#))
- Ealing Reclaim Social Care Action Group [ASC0072](#)
- Katherine Eastland [ASC0009](#)
- Economic and Social Research Council, UK  
Research and Innovation [ASC0035](#)
- Equality and Human Rights Commission [ASC0129](#)
- Professor Lee-Ann Fenge and Dr Andy Pulman,  
Bournemouth University [ASC0023](#)
- Antonia Field [ASC0044](#)
- Alison Forbes [ASC0051](#)
- Joy Ford [ASC0017](#)
- \*\* Tandra Forster, Executive Director for Adults and  
Communities, Southend-on-Sea Borough Council  
([QQ 165–177](#)) [ASC0148](#)
- \*\* Councillor David Fothergill, Chairman, Local  
Government Association (LGA) Community  
Wellbeing Board ([QQ 165–177](#)) [ASC0149](#)
- Future Social Care Coalition [ASC0123](#)
- \* Kate Garner, Service Manager, Shropshire Council  
([QQ 129–134](#))
- \* Laura Gaudion, Interim Director of Adult Social  
Care and Housing Needs, Isle of Wight Council  
([QQ 165–177](#))
- \* Jamie Gault, CEO, Action for Carers Surrey  
([QQ 116–121](#))
- Sue Gerrard [ASC0110](#)
- \*\* Clive Gilbert, Policy Manager, Policy Connect  
([QQ 106–115](#)) [ASC0039](#),  
[ASC0133](#),  
[ASC0145](#)
- Global purple Angel dementia awareness campaign [ASC0006](#)
- Valerie Gough [ASC0031](#)
- \* Dan Gower-Smith, Group Director of Operations,  
Avenues Group ([QQ 73–78](#))



- Greater Manchester Coalition of Disabled People [ASC0126](#)
- \* Nan Greenwood, Professor, Centre for Health and Social Care Research, Kingston University London ([QQ 67–72](#))
- \* Fazilet Hadi, Head of Policy, Disability Rights UK ([QQ 79–84](#))
- Dr Robin Hadley [ASC0002](#)
- \* Professor Donna Hall CBE, Chair, Bolton NHS Foundation Trust and Former Chief Executive, Wigan Council ([QQ 85–89](#))
- Haloabletec [ASC0005](#)
- \* Dr Kate Hamblin, Research Fellow, Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Sheffield ([QQ 106–115](#))
- \*\* Guy Harris, Director, Accessible PRS ([QQ 106–115](#)) [ASC0137](#)
- Lisa Harvey [ASC0029](#)
- The Health Foundation [ASC0020](#)
- \*\* HealthWatch England ([QQ 116–121](#)) [ASC0134](#)
- \* Kevin Heaney, Personal Assistant to Clive Gilbert ([QQ 106–115](#))
- Herts & West Essex Integrated Care Board [ASC0150](#)
- Dr Martin Hewitt [ASC0107](#)
- Hft [ASC0090](#)
- J Hine [ASC0049](#)
- Ann Holden [ASC0016](#)  
[ASC0018](#)
- Homecare Association [ASC0074](#)
- \* Rt Hon Jeremy Hunt MP, Chair, House of Commons Health and Social Care Committee ([QQ 13–22](#))
- Inclusion London [ASC0108](#)
- Joseph Rowntree Foundation, and London Unemployed Strategies [ASC0116](#)
- Sandra Joyce [ASC0007](#)
- Judicial Review Implementation Monitoring Group, Norfolk [ASC0070](#)
- \* Gillian Keegan MP, Minister for Care and Mental Health, Department for Health and Social Care ([QQ 149–164](#))

- \* Fatima Khan-Shah, Associate Director of Long Term Conditions and Personalisation, West Yorkshire Health and Care Partnership ([QQ 67–72](#))  
Mary Ledgard [ASC0099](#)  
Leonard Cheshire Disability [ASC0079](#)
- \*\* Local Government Association ([QQ 165–177](#)) [ASC0042](#)  
London Borough of Hammersmith & Fulham [ASC0078](#)  
London Councils [ASC0131](#)  
Look Ahead [ASC0092](#)
- \* Ian Loynes, CEO, SPECTRUM Centre for Independent Living ([QQ 46–54](#))
- \* Andy McCabe, Expert by experience ([QQ 23–34](#) and [QQ 142–148](#))  
Mencap [ASC0046](#)  
Mending The Gap [ASC0022](#)  
Mental Health Carers Group Stockport [ASC0093](#)  
Methodist Homes [ASC0061](#)  
Mobilise [ASC0100](#)  
National Care Forum [ASC0060](#)  
National Care, Support and Independent Living Service campaign [ASC0114](#)  
National Development Team for Inclusion [ASC0089](#)  
National Housing Federation [ASC0088](#)  
National Institute for Health and Care Excellence [ASC0056](#)
- \* Tricia Nicoll, Expert by experience ([QQ 23–34](#) and [QQ 142–148](#))  
North Somerset Council [ASC0120](#)  
The Nuffield Trust [ASC0104](#)  
Stephanie Oakes [ASC0067](#)  
Older People and Frailty Policy Research Unit, National Institute for Health and Care Research [ASC0053](#)  
Options for Supported Living [ASC0094](#)  
Nicola Pacult [ASC0066](#)  
Diana Pargeter [ASC0038](#)  
Barry Parnaby and Denise Jackson [ASC0030](#)
- \*\* Norman Phillips, Expert by experience ([QQ 35–45](#) and [QQ 135–141](#)) [ASC0143](#)  
PJ Woolfall [ASC0103](#)  
Anne Pridmore [ASC0024](#)

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|    | Pupils 2 Parliament  | <a href="#">ASC0063</a>                            |
| ** | Adolf Ratzka, Founder, Stockholm Cooperative for Independent Living ( <a href="#">QQ 97–105</a> )  | <a href="#">ASC0140</a>                            |
| ** | Professor Vic Rayner OBE, CEO, National Care Forum, representing the All-Party Parliamentary Group on Adult Social Care ( <a href="#">QQ 13–22</a> ) | <a href="#">ASC0004</a>                            |
|    | Reclaim Social Care Greater Manchester   | <a href="#">ASC0121</a>                            |
|    | Daniel Reed  | <a href="#">ASC0050</a>                            |
|    | Relatives & Residents Association  | <a href="#">ASC0128</a>                            |
|    | Rescare  | <a href="#">ASC0065</a>                            |
|    | Rethink Mental Illness   | <a href="#">ASC0125</a>                            |
|    | The Richmond Group of Charities  | <a href="#">ASC0117</a>                            |
|    | The Royal British Legion   | <a href="#">ASC0055</a>                            |
|    | The Royal College of Nursing   | <a href="#">ASC0077</a>                            |
|    | Royal National Institute of Blind People   | <a href="#">ASC0033</a>                            |
| *  | Martin Samuels, Strategic Director for Social Care and Education, Leicester City Council ( <a href="#">QQ 165–177</a> )                              |  |
|    | Sense  | <a href="#">ASC0091</a>                            |
|    | Shani Shamah BCav  | <a href="#">ASC0013</a>                            |
|    | Shared Lives Plus  | <a href="#">ASC0052</a>                            |
|    | Julie Sharp  | <a href="#">ASC0012</a>                            |
| *  | Theresa Shearer, Group CEO, Enable Group ( <a href="#">QQ 97–105</a> )   |  |
| ** | Nick Sinclair, Director of the Local Area Coordination Network, Community Catalysts ( <a href="#">QQ 90–96</a> )                                     | <a href="#">ASC0132</a>                            |
|    | Skills for Care  | <a href="#">ASC0068</a>                            |
|    | Social Care Institute for Excellence   | <a href="#">ASC0081</a>                            |
|    | Society of Later Life Advisers   | <a href="#">ASC0043</a>                            |
| ** | Helen Spalding, Expert by experience ( <a href="#">QQ 35–45</a> and <a href="#">QQ 135–141</a> )   | <a href="#">ASC0003</a><br><a href="#">ASC0144</a> |
|    | Spinal Injuries Association  | <a href="#">ASC0106</a>                            |
| ** | Madeleine Starr, Director of Business Development and Innovation, Carers UK ( <a href="#">QQ 60–66</a> )   | <a href="#">ASC0122</a><br><a href="#">ASC0155</a> |
| ** | Katy Styles, Expert by experience ( <a href="#">QQ 35–45</a> and <a href="#">QQ 135–141</a> )  | <a href="#">ASC0142</a>                            |
|    | Jan Taranczuk  | <a href="#">ASC0071</a>                            |
| ** | Nadia Taylor, Chair of the Board of Trustees, Carers Network ( <a href="#">QQ 55–59</a> )  | <a href="#">ASC0109</a>                            |

- \*\* Jerry Tew, Professor of Mental Health and Social Work, University of Birmingham ([QQ 122–128](#)) [ASC0146](#)
- \*\* Think Local Act Personal ([QQ 85–89](#)) [ASC0054](#)
- Thompson [ASC0001](#)
- Ann-Marie Towers, Kathryn Almack, Rasa Mikelyte, Wenjing Zhang, Jolie Keemink, Penelope Welbourne, Geraldine McDonald, Olivia Trapp, John Potts, Nick Smith, Yvonne Birks and Annette Boaz [ASC0057](#)
- Trades Union Congress [ASC0040](#)
- Understanding Society, the UK Household Longitudinal Study, Institute for Social and Economic Research, University of Essex [ASC0059](#)
- United Response [ASC0045](#)
- Voluntary Organisations Disability Group [ASC0073](#)
- We Care Campaign [ASC0032](#)
- David Wilks [ASC0048](#)
- Wiltshire Centre for Independent Living [ASC0010](#)
- Dr Raphael Wittenberg, Care Policy and Evaluation Centre, London School of Economics and Political Science [ASC0102](#)
- \* Kirsty Woodard, Founder and Director, Ageing Without Children ([QQ 46–54](#))
- \*\* Sue Yeandle, Professor of Sociology and Director of Centre for International Research on Care (CIRCLE), University of Sheffield, and Principal Investigator, Economic Social Research Council (ESRC) Centre for Care ([QQ 60–66](#)) [ASC0153](#)
- \*\* Dr Valentina Zigante, Research Officer, Care Policy and Evaluation Centre, London School of Economics and Political Science ([QQ 55–59](#)) [ASC0102](#)

## APPENDIX 3: CALL FOR EVIDENCE

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### Lifting the veil: Removing the invisibility of adult social care

#### *Overview*

The House of Lords Adult Social Care Committee was established in 2022 to consider how to improve the planning for, and delivery of, adult social care services in England.

The Committee is now launching a major inquiry, ‘Lifting the veil: Removing the invisibility of adult social care’. Adult social care provides services for people from young to old; from those with inherited disabilities from birth to those who become ill, frail and dependent as they move into later life. Across these many different conditions and personal circumstances, people with care needs rely for much of their support, care and independence on unpaid carers; and in many ways, both the people who draw on care and support and their carers are largely invisible.

The inquiry will, therefore, consider how that entrenched invisibility of adult social care impacts on the lives of people across the spectrum who draw on care and support and their carers. It will explore what needs to change to create a fair, resilient and sustainable care system that better enables everyone to have choice and control over their life. In doing so, it will acknowledge the diversity of ambitions and aspirations that individuals with specific care needs have for their lives across all age ranges, and consider how adult social care should enable them to achieve these different goals. This includes understanding the kind of relationships that young and older people who draw on care and support and their families want to have with each other. It will mean looking at how the system can remove barriers to people being full and equal citizens and how formal services can recognise and support the role that carers play.

The Committee invites written contributions by 27 May 2022. It will be holding oral evidence sessions from March 2022 and expects to publish its final report in November 2022. The Committee is keen that the voices of people who draw on care and support and carers are central to its work and wants to hear from people who do not usually feel able to take part in these kinds of discussions, as well as from people who contribute regularly. If there is anything that would help you to contribute, please contact the Committee ([hladultcare@parliament.uk](mailto:hladultcare@parliament.uk)) to discuss how your participation could be supported.

The Committee is also keen to hear from people with a wide range of experiences of the adult social care system, for example from people who receive state-funded care, as well as those who fund their own care.

#### *Aims of the inquiry*

Given the congested and contentious landscape of adult social care, the Committee is aiming to produce an inquiry that is useful and does not duplicate previous work. This inquiry, therefore, is intended to fill a gap by exploring neglected or underdeveloped areas of provision or policy within the short time period that has been allocated for the inquiry and report. The Committee aims to conclude with practical, near-term recommendations that will add value by effectively contributing to shaping policy-making in that area. We kindly ask colleagues to keep these criteria in mind when submitting written evidence.



*Background to the inquiry*

Adult social care, as a whole, is often described as ‘invisible’. While people often talk and know about the health service, for example, very few people understand what adult social care is, how it works and why it matters. This means that it can be difficult to bring about positive change on the ground, compared to other, more popular and better understood services such as health or education. This invisibility extends to the millions of unpaid carers across England, whether family members or friends, who support their loved ones to live their lives, often providing more care and support than formal services. People who draw on care and support and carers are incredibly diverse and some people can be very isolated. Many family carers do not define themselves as ‘carers’ and, therefore, do not necessarily benefit from some of the support that is available.

Among the key questions we will ask are: How can we raise the profile of adult social care and increase everyone’s understanding of the important contribution which care makes to society and people’s lives? How can we stop people who draw on care and support and carers from being marginalised and taken for granted? How can people exercise genuine choice and control over their own care and support if society makes assumptions about who is available to provide care and what kinds of relationships families should have with each other? And how can the social care system continue to support people who need it in the future if it does not acknowledge some of the assumptions that it is built upon, such as around the availability of carers, are becoming out-of-date?

In asking these and other related questions, the Committee will seek to reflect on what the meaning of social care should be, and assess how far the system remains from realising that meaning in the everyday lives of people who draw on care and of their families. The inquiry will consider the practical reforms and innovations that, by making care more visible, might enable the delivery of better care and support, and will reflect the ambitions expressed by Social Care Future: ‘We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us.’

*What we want to learn from you*

The following questions are intended to provide a framework for those who wish to offer their views. You do not need to answer all the questions, just those that are relevant. The Committee welcomes reference to other questions that are relevant and that you wish to draw its attention to. It is helpful if opinions are supported by factual evidence and examples where appropriate. Comparisons with practice in the devolved administrations and other countries are particularly welcome. Above all, the Committee wants to build on the lived experience of people who draw on care and support and their carers and recognises that this is a powerful and important form of evidence in its own right.

The Committee is seeking input on the following questions:

*The invisibility of adult social care and its consequences*

- (1) One of the fundamental challenges facing adult social care is that it is ‘invisible’. Do you agree? What do you think explains this?
- (2) What are the key changes that need to be made to reduce the invisibility of adult social care?

- (3) How does this invisibility reflect the experience of social care for people who draw on care and support and their carers, and how is this experience different depending on the age range and particular circumstances of those who draw on care and support and their carers?
- (4) How would you define the purpose of adult social care? How does the invisibility of adult social care get in the way of achieving this purpose?
- (5) To what extent does the definition of the purpose of adult social care differ for younger and for older adults? How can future reform of the adult social care system best address these differences?
- (6) What are the key challenges that people who draw on care and support and carers will face in the future, which are not factored into current assumptions related to the social care system, for example the fact that some families will age without children to care for them? How are these challenges different for younger and for older adults who draw on care? What should be done now to address them?
- (7) How can other public services (such as the NHS) play their part in tackling the invisibility of adult social care?
- (8) What effect has the COVID-19 pandemic had on adult social care?

*Better support for unpaid carers*

- (9) What, in addition to the support that has already been pledged by the Government, would be the most effective thing that could be done to raise the profile, as well as to improve the identification and support of carers? What examples exist to demonstrate that better identifying and supporting of carers leads to better outcomes for those for whom they care?
- (10) How can carers who wish to do so be better enabled to stay in work or rejoin the workforce? What needs to change to achieve this?
- (11) What are the key priorities for carers in terms of their own support, wellbeing and resilience? How and where can these best be provided?
- (12) To what extent do carers make use of alternative forms of support, such as the voluntary community? Is there any scope for them to draw on those assets more and how might they be enabled to do that? Are there examples where this happens successfully now?
- (13) How valued and respected are carers in the overall adult social care system and what are the consequences of failing to value and respect them?
- (14) What can be done to make sure that social care professionals recognise the expertise of carers and value them as full and equal partners in care, who are included as part of the whole team, so that there is greater synergy between paid and unpaid care?
- (15) Why is the current care system so difficult to access for carers? What needs to be put in place so that carers can simply understand what is available to them as a right and discretion, and the person they support?

Do you know of good practice examples? How can these examples be expanded more widely across the system?

*Putting co-production at the heart of care*

- (16) To what extent are the voices of people who draw on care and support and carers shaping the design and delivery of social care, irrespective of their age or circumstances? If these voices are not sufficiently heard, what is the impact of this on those who draw on care and support and carers?
- (17) It is often difficult for people who draw on care and support and carers to exercise choice and control if they do not know what good support looks like or what kinds of care and support might be available. What information and support could be helpful to address this and how could it be made available more easily?
- (18) We recognise that people with long-term conditions require different support at different points in their lives and that transitions, such as a change in health needs, moving from children to adult services, leaving education, starting a job or moving home, can be particularly challenging. Can you describe the key moments of transition from your experience? How have the formal processes worked during these periods of transition? What could or should have been in place to make these transition moments easier?
- (19) What does truly co-produced care look like for younger and for older people with differing challenges and needs? Have you got any good examples to share?
- (20) How can we design care and support arrangements which work both for the person drawing on care and support and for those who care for them?
- (21) How can people who draw on care and support and carers both be involved in the planning of future services?

*Who we want to learn from*

*Experts by experience*

In line with the principled approach that the Committee has committed to adopt, and which is described above, we wish to ensure that every stage of our work is informed by the views of people who draw on care and support and carers. The Committee’s ambition is to embed co-production in its deliberations and final report. We encourage, therefore, experts by experience to contribute their perspectives on the questions raised by the Committee. If you feel that there are any barriers to you contributing, please contact the Committee ([hadultcare@parliament.uk](mailto:hadultcare@parliament.uk)) to see how best you could be supported to share your experiences

*People with different backgrounds*

The Committee encourages people from all backgrounds, with experience of, or expertise in, the issues under investigation, to share their thoughts with the Committee, in the full knowledge that their views have value and are welcome. Diversity comes in many forms, and hearing different perspectives means that committees are better informed and are better able to scrutinise public policy and

legislation. They can undertake their role most effectively when they hear from a wide range of individuals, sectors or groups affected by a particular policy or piece of legislation. We are particularly keen to learn from people whose voices are seldom heard and would encourage everyone who wants to contribute to share their views and experiences.

## APPENDIX 4: SUMMARY OF ADULT SOCIAL CARE COMMITTEE VISIT TO REAL, 6 SEPTEMBER 2022

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On 6 September 2022 the Committee visited Real, a Disabled Person’s Organisation based in Tower Hamlets, London. All participants that we heard from had lived experience of adult social care.

Mike Smith, CEO of Real, and Baroness Andrews, Chair of the Committee, opened the session. This was followed by case studies from two participants of their experience of adult social care. We then held a series of breakout-groups, finishing with a discussion and summary of the outcomes of the groups.

### Case studies

#### *Participant one*

The first participant is paralysed from the neck down and dependent on their personal assistant to undertake basic tasks. She works full-time as a radio producer and lives in Hammersmith and Fulham.

She argued that social care is in crisis, consisting of two components:

- Many people are not getting the care they need. For instance, she only receives funding to live independently for five days per week so has had to rely on parents for additional support. She asked “Just imagine how you would have felt if you had had to depend on your parents to help you with the most basic aspects of living when you were in your 20s and 30s?”
- There is a severe shortage of PAs. Overly last 18 months she lost and recruited 34 PAs. Many have left to higher paid jobs, including supermarket roles. It is also hard to find high quality PAs. For instance, she had to dismiss three PAs for misconduct in the last three months.

Moreover, she noted how “almost all” councils charge disabled people for social care, describing this as “not ethical” and a “tax on being disabled”. She asked: “Authorities don’t charge householders for collecting their rubbish, they don’t charge parents for sending their children to school, they don’t charge for NHS treatment so why is it considered acceptable for them to charge disabled people for their care?”

Furthermore, she described how disabled people “face needless bureaucracy”. She described the complexity of having to work with both the local authority and the Department for Work and Pensions and having to fill in long claim forms and regular time sheets.

To remedy these issues, she proposed the following:

- The Government needs to recognise that “social care is not a luxury but a fundamental human right. Disabled people should be able to live with independence and autonomy.” She said that this is only possible if social care is fully funded and every disabled person has the opportunity to control their care funding through direct payments.
- The Government needs to address the shortage in PAs. She said that a key factor in the shortage is the impact of Brexit. Following Brexit, care workers are no longer automatically eligible to work in the UK as they are not classed as “skilled workers”. She proposed that immigrants should be given a work



visa on the condition they find a job as a PA within six months of arriving the UK and should retain the visas as long as they are a PA.

- The Government should stop the practice of councils charging for care and replace the money that councils lose as a result.
- The Government should streamline the social care system by treating funding for PAs in a work environment in the same way as funding for other PAs, and give councils responsibility for funding all PAs.

### *Participant two*

The second participant works full-time as a lawyer and needs social care to hold down a job. He is a single parent.

He said that his local authority’s approach to social care has “at times been the thing that has disabled me the most”, with social care currently being under strain to a degree that he has never seen.

He described how he started being charged for services by his local authority upon qualifying as a solicitor. This meant he would only keep 5% of his pay-rise. He also described how, upon living with his wife, the local authority cut his night-time care and made large cuts to day-time care. He said that the local authority refused to send him their assessment of these cuts. His package was restored after a complaint to the Local Government Ombudsman. However, it still took five years to end up with a properly costed care package. After this the local authority did not bother him, which he described as “sad” as “getting the right support shouldn’t be about who shouts the loudest”.

This recently changed, however, with the local authority changing his budget without saying so.

He described how “social care can make a huge difference if done right”, “but at the moment getting the right social care and the barriers Local Authorities put up can be the thing that disables a person the most.”

### **Break-out groups**

#### *Topic one: absence of meaningful choice and control*

One participant described social workers as the gatekeepers of social care, controlling how the disabled adult or older person receives care. For instance, one carer insisted the participant wear pads all night when this was not their wish. They also said that the local authority provides care on time-tasks, rather than understanding the bigger picture. We heard that “people must fit the offer that is given to them”, with no or little use of co-production.

We heard that there is no flexibility or creativity in care packages: rather, people have to fit boxes. There is also a stigma and discrimination against disabled people, who are not seen as productive or contributors to society. The purpose of social care in enabling people to live a full and meaningful life has been forgotten.

One participant highlighted the benefits of peer-support groups, which enable disabled people to realise their rights and potential, giving them the means to fight for what they are entitled to. However, we heard that peer-support groups and Disabled People’s Organisations do not receive sufficient funding.

*Topic two: personal assistants*

One participant noted the lack of communication from PA agencies. In one instance, the agency sent a PA without making the person aware, resulting in the police being called.

Moreover, social workers are often poorly trained. In reality, they require basic training alongside the open-mindedness required to adapt to each person they care for. However, participants expressed concern at the idea of national training for PAs as this could result in a ‘tick-box exercise’. One participant suggested a portal where disabled adults and older people could view qualifications. Real created a similar platform to match PAs and people seeking care, which has now been taken over by a national provider.

Participants expressed the need to increase the visibility and attractiveness of PAs as a profession, to attract people who are values-driven.

One participant suggested that the compliance guidelines which supplement the Care Act 2014 should be reviewed and that carers need better training on the law around social care.

Participants stressed the importance of acknowledging the majority of disabled people who do not have the means to fight local authorities for their rights. We heard that Disabled People’s Organisations are the most efficient way to reach out to these people and to empower them.

*Topic three: one size fits all*

Participants said that there is a struggle to recruit PAs, possibly due to Brexit. During the COVID-19 pandemic, PAs were often workers who had been made unemployed due to the pandemic, such as bar staff and personal trainers. This is no longer the case. One participant recounted that in the late-1980s there were often 100 applicants for a PA role - now 20 would be considered very high.

One participant suggested that local authorities should fund disabled people to create cooperatives/collectives for recruitment of PAs.

We also heard that there needs to be increased awareness around what PAs do and that the role should be seen as fulfilling and paid well.

We heard that the safeguarding checks for PAs undertaken by agencies are not thorough and that disabled people therefore have to balance between not having a carer at all and taking the risk of having someone who may present safeguarding risks. On the other hand, carrying out a full DBS check would take too long.

Participants said that there has not been enough research into the unmet needs of disabled people.

*Topic four: social care charging*

We heard that recently local authorities have started charging for social care more often than they did previously. Participants said that costs and quality of care were regionally variable, calling it a “postcode lottery”.

One participant said that the social care cap is unfair on those from low-income backgrounds. Another said that they could only survive because their family contributed to costs. We heard that sometimes people decline care because they simply cannot afford it. Care then falls onto family, friends and charities.

We heard that some disabled people are at risk of financial abuse by their carers. Some disabled people cannot manage their care package alone, but as a result are being financially abused by their family. They said that financial abuse grown with the COVID-19 pandemic and the cost of living crisis. However, the disabled person may not be able to afford to leave such a relationship.

One participant compared social care policy to tending a garden—it keeps people safe, but it does not allow them to flourish. As part of this, we heard that social services have become gatekeepers rather than actively promoting independence.

We also heard that the Government and society do not value the contribution of social care. This is made worse by regular negative media stories, when there are many instances where social care has enabled people to live full lives.

#### *Topic five: independent living*

We heard that participants struggle to live independently under the current system. One participant described how their young daughter was taken away from them as the local authority did not wish to provide 24-hour care, only being re-united six years later. Afterwards, the participant was presented with two options for care of her daughter: someone moves in with her or she moves into a care home. The participant is now reliant on their ex-boyfriend to take her out of the house.

Another participant described that, despite a physical disability, he is unable to adapt his flat as doing so would result in the Council removing him from the waiting-list for accessible housing. He said that there is poor communication between the Council’s housing and social care services.

We heard from one participant that they have struggled to find a carer to accompany them to activities, such as therapy, the gym or a short walk. He described how, despite living very close to Victoria Park, the council pays for taxis but not for someone to accompany him on a walk.

## APPENDIX 5: LETTER FROM CHAIR OF THE ADULT SOCIAL CARE COMMITTEE TO THE CHANCELLOR OF THE EXCHEQUER AND SECRETARY OF STATE FOR HEALTH AND SOCIAL CARE

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The House of Lords Adult Social Care Committee will soon publish its report concluding more than 10 months of inquiry, during which we took evidence from many disabled adults, older people and unpaid carers. All of them shared their hope that social care can be profoundly transformed, so that it can enable better and richer lives for everyone.

Although our inquiry did not focus specifically on funding, it has been impossible not to be systematically brought back, not least by Mr Hunt, to the crippling failure to sustainably invest in our social care system. This is why so many questions have been raised by the Government’s Autumn Statement. In this letter, we would like to prompt the Government to address those questions.

### **Insufficient funding and the lack of a strategic vision**

During our inquiry, we saw the mental anguish felt by people who face excessive costs and receive inadequate care, as well as the despair of partners, children or siblings who are living in poverty to provide unpaid care to their family members, facing additional costs with insufficient support. Unfortunately, we do not believe that the funding settlement and the proposals in the Autumn Statement will successfully relieve those who need it most.

We welcome the additional £4.7 billion that has been unlocked for social care in the next three years. But this falls short of what was recommended to our Committee by Mr Hunt himself only a few months ago, when he pointed to the estimate produced by the Health and Social Care Committee, which he Chaired at the time, and indicated the need to reach an additional £7 billion in funding for adult social care in 2023/24.<sup>686</sup>

In addition, in a context marked by significant inflationary pressures including increases to the national living wage and growing energy prices, we remain concerned about the real-term impact of this additional funding. It does not constitute the sustainable and long-term investment that the social care system desperately needs.

Even more importantly, the announcement reflects a failure to grasp a strategic approach to meeting the challenges faced by adult social care. Increasing funding through Council Tax is a regressive solution which will not allow for a properly and sustainably funded system. It does not translate as ring-fenced investment dedicated to adult social care. It is likely to create further inequalities from one locality to the next. In short, it is not a long-term plan for funding.

Equally regressive is the Government’s decision to delay the long overdue cap on care costs and extension to the means test. Although this is intended to unlock more funding for local authorities and provide them with breathing space, it also reflects the lack of a coherent strategy across adult social care. Delaying one policy to support another will ultimately compound problems; and it certainly does not allow for any priority to be given to choice, control and equality in the provision of adult social care. Everybody deserves an equal opportunity to live a rich and

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<sup>686</sup> Health and Social Care Committee, *Social care: funding and workforce* (Third Report, Session 2019–21, HC 206) p 37

fulfilling life, and this should be at the centre of ambitions for adult social care policy.

Similarly, the announcement made no reference at all to unpaid carers, even though they constitute the backbone of our health and social care systems. The evidence we heard showed, shamefully, that the families and friends that provide unpaid care and support for each other are at breaking point and we cannot afford to push them further. Yet no targeted financial support has been announced to provide unpaid carers with the modest additional support they might need to continue to care. This comes on top of the failure to honour previous promises, for example to provide Carer’s Leave. This is wrong – and it weakens the very foundations of the entire system.

Instead, the Autumn Statement has made one message very clear: adult social care needs funding not in its own right, but to relieve the NHS. A significant proportion of the additional funding has been set aside to accelerate discharge into community settings and help free up hospital beds. While, of course, we support faster and smoother discharge from hospital, we believe that this should not be the single perspective. Nor is it the right strategy to adopt for future reform. Improving adult social care should be seen not only as an investment that we make in the NHS, but also in ourselves as a resilient and caring society.

### More clarity is needed

With the exception of the investment that is specifically dedicated to accelerating discharge from hospital, no information has been shared to explain what use will be made of the additional funding set out in the Autumn Statement. For example, there does not seem to be any commitment to achieving the promises made by the Government in the *People at the Heart of Care* White Paper, including a £1.7 billion investment in improving social care.<sup>687</sup>

In his speech as Chancellor of the Exchequer, Mr Hunt said that the increased funding will enable the social care system to help deliver an estimated 200,000 more care packages over the next 2 years. But without a better definition of what constitutes a care package, without knowing what size these packages will have, how this number compares to the number of care packages currently delivered, or to the estimated number that is needed, this is an empty promise.

The Autumn Statement leaves many questions unanswered, both in terms of the breakdown of the funding that has been made available, and in terms of the Government’s strategy and vision for adult social care. We ask, therefore, the following questions:

- (1) What is the exact breakdown of the additional £4.7 billion that has been made available for adult social care in 2024/25?
- (2) What assurances can be given that the planned additional funding, for example raised through increases to the Council Tax, will be ringfenced for adult social care?
- (3) What provisions, if any, have been made to provide targeted support for unpaid carers?

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<sup>687</sup> Department of Health and Social Care, *People at the Heart of Care: Adult Social Care Reform White Paper*, CP 560, December 2021: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf)

- (4) What provisions, if any, have been made to protect the £1.7 billion investment in social care pledged by the Government in the *People at the Heart of Care* White Paper?
- (5) What assessments have been made of the impact of this additional funding for adult social care? Have these assessments accounted for inflationary pressures?
- (6) What does the Government mean when it says that 200,000 more care packages will be delivered in the next two years? What is the size and nature of a care package? How does this number compare to the number of care packages that are currently delivered, and to the number of care packages that are needed?
- (7) How will the impact of this additional funding be monitored?

We look forward to receiving your response as soon as possible.

28 November 2022