

Research report October 2022

Falling short

How far have we come in
improving support for unpaid
carers in England?

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nuffieldtrust

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Contents

	Key messages	2
1	Why does support for unpaid carers matter?	4
2	Our approach	6
3	What is the policy vision to better support unpaid carers?	8
4	To what extent has the policy vision been achieved?	13
5	Why has the policy vision not been achieved?	28
6	How far does £25 million for unpaid carers go?	37
7	What actions are needed?	39
	Appendix A: Data sources for this report	42
	Appendix B: Policy commitments outlined in the 2008 Carers Strategy	44
	Appendix C: The policy context (commitments and initiatives)	47
	Appendix D: Detailed policy analysis – what does the evidence tell us?	50
	Appendix E: Sources of data on unpaid carers	68
	References	70

Key messages

- Unpaid carers play a crucial role in providing essential care for people who need help because of ill-health, frailty, disability, a mental health condition or an addiction. This care, provided by both adults and children and worth billions of pounds a year – is often not visible but has become an essential part of the health and care system, bridging gaps in state-funded support.
- Over the past decade and a half there has been a strong policy focus on improving the support available to unpaid carers in England. Bold commitments detailed in policy documents such as the 2008 Carers Strategy (*Carers at the Heart of 21st-Century Families and Communities*)¹ and the 2018–20 Carers Action Plan² set out to better support carers, recognise their value and improve services for carers. This report seeks to assess the extent to which these policy commitments have been realised.
- Despite the laudable policy statements in support of carers, and the additional pressure put on unpaid carers during the Covid-19 pandemic, this report shows that the reality for unpaid carers has been one of diminishing help over time: evidence reveals an 11% drop between 2015/16 and 2020/21 in the numbers of carers in receipt of ‘direct support’, meaning that at the end of this six-year period 13,000 fewer carers were being given the choice and personalisation that this type of support is designed to offer. Access to breaks for carers – funding for ‘carer support involving the cared-for person’ – also declined during this period, by 42%.
- At the same time local authority gross expenditure on services for carers has also reduced: the latest data detail an 11% drop in 2020/21 compared with 2015/16. This has translated into a reduction in the support offer available to carers, with local authorities providing fewer direct support payments and directing 36,000 more carers to information and advice only. Carers report finding it harder to access adequate advice and support, and satisfaction with carer support services is declining.

- Key to explaining this mismatch between the promises of better support for carers and the reality for the rising number of unpaid carers are:
 - a lack of accountability and agreement on who is responsible for policy success and failure
 - a lack of clarity on who is responsible for what within local systems
 - a failure to set out how policy success might be measured
 - a false assumption that legislation alone can secure change
 - the invisibility of carers in wider policy decision-making
 - funding pressures and budgetary constraints
 - a lack of data needed to support service commissioning, and to evaluate policy success.
- To tackle this, we make a series of recommendations aimed at parliamentarians, policy-makers, local commissioners and data organisations. These include improving accountability within government for achieving success in better supporting carers; committing to ensuring that councils and organisations delivering support to carers are adequately funded; requiring all integrated care boards to develop an action plan to support carers and to include carers in health inequalities impact assessments at a local level; and having an explicit focus on unpaid carers within data policy to drive better-quality data at national and local levels.

1 Why does support for unpaid carers matter?

Unpaid carers play a crucial role in supporting vulnerable adults and children by providing essential care worth more than £132 billion a year before the pandemic,³ and up to £193 billion a year in 2020 during the Covid-19 pandemic.⁴ It is clear that without the provision of appropriate support services for carers, the reliance of the health and social care system on unpaid carers will become increasingly unstable.⁵

Yet despite a clear policy vision and legislative changes aimed at better supporting carers, unpaid carers feel they are ignored⁶ and evidence shows that many are still struggling without adequate recognition or support.^{7,8}

Further, the picture for many providing care remains bleak. Carers report poorer health than their non-caring peers⁹ and are at increased risk of illness and long-term health conditions.¹⁰

Years of very significant financial pressures for local authorities, which were required to make £7.7 billion of savings to adult social care budgets between 2010 and 2020,¹¹ have taken a toll and it is hardly surprising to see that some of the knock-on effects of these budgetary pressures have been cuts to services for carers. This has been combined with increasingly tight eligibility criteria that restrict access to services for people who need social care – effectively placing even more of the work of caring onto unpaid carers.

The impacts of the Covid-19 pandemic – which saw a 13% decrease in the number of carers' assessments in 2020/21 in England compared with the previous year, and access to respite and day services significantly reduced¹¹ – have made things even worse for many carers. This has left two in three unpaid carers (66%) finding it difficult to take time away from caring,¹² with one in six carers taking on an additional 40 hours or more of caring a week during the pandemic according to work by the Carers Trust.¹³

These pressures are being compounded at present: many carers are now facing a combination of low fixed income, energy price hikes and rapid increases in the cost of living. Compared with adults earning more than £50,000 a year, those with a personal income of less than £10,000 – which includes all of the 1.3 million¹⁴ unpaid carers receiving a Carer’s Allowance of £69.70 a week – are eight times more likely to struggle with rising energy and food prices, according to analysis by the Office for National Statistics.¹⁵

Figure 1: Key facts

Who is an unpaid carer?

An unpaid carer is a child, young person or adult who looks after a family member, partner or friend who needs help because of ill-health, frailty, disability, a mental health condition or an addiction.¹⁶ The care they give is unpaid.

How much is this care worth?

During the Covid-19 pandemic in 2020, unpaid carers in the UK provided care worth £193 billion a year.⁴

Juggling work and caring

More than half of all adult carers (53%) are in paid employment, and more than a third (36%) are working full time.¹⁷ An estimated 2.6 million adults in the UK give up work to care.¹⁸

What are the financial costs of caring?

Over half (55%) of carers in England receive no help or support and almost 1 in 5 (19%) experience financial difficulties due to their caring responsibility.¹⁹ Estimates show that 1.2 million carers in the UK are living in poverty.²⁰

2 Our approach

This report measures progress made against a policy vision and commitment to better support unpaid carers in England. Our policy analysis explores what the evidence shows and seeks to explain the progress (or lack of) in this endeavour. Within the analysis we sought to identify key lessons that can help to explain what actions are needed to make policy implementation more successful in the future.

To assess what progress has been made against the policy vision, we looked at the evidence using as a framework for analysis and synthesis the five strategic themes first set out in the 2008 national Carers Strategy,¹ and reaffirmed the 2018–20 Carers Action Plan.²

- services and systems that work for carers
- recognising and supporting carers
- building research and evidence to improve outcomes for carers
- employment and financial wellbeing
- supporting young carers

We reviewed policy documents published and in the public domain describing the policy vision, including those identifying policy priorities and specific commitments or initiatives, and legislation related to carers – taking the national Carers Strategy (2008) as our starting point. Our focus within this report is primarily on policy commitments to better support carers and implementation progress in England.

To support this policy analysis and to understand the extent and nature of both policy ‘success’ and policy ‘failure’, we also analysed data from a variety of sources (see Appendix A for further details, including the potential limitations and widely-acknowledged challenges of data quality in this area). These included: Short and Long Term (SALT) services data and data from the Adult Social Care Finance Return (ASC-FR)²¹ – both of which are part of a national dataset of social care activity that local councils report on; and the national Survey of Adult Carers in England (SACE).²² Additionally, to estimate

the number of carers in England we used data from a range of government sources including the 2011 Census for England²³; 2019 Health Survey for England¹⁹; 2020–21 Family Resources Survey¹⁷; and the 2022 General Practice Patient Survey.²⁴

Having identified a gap between the policy vision and commitments made to better support carers, and the progress made to date, we then go on to explain why this policy–implementation gap exists. By identifying some of the most salient contributing factors, our analysis starts to unpack how we got to this point, and what might be done differently to avoid failure and improve the chances of policy success in the future.

We used a red/amber/green (RAG) rating system to broadly categorise the evidence for implementation progress, testing our conclusions, which are derived from the evidence and policy analysis with a wide range of stakeholders. We used this process to generate and refine our recommendations, while ensuring relevance and applicability from a range of perspectives.

3 What is the policy vision to better support unpaid carers?

Over the past decade and a half, there has been a strong policy focus on improving the support available to unpaid carers in England, underpinned by cross-government commitment to action. In this chapter we provide a brief summary of this policy context and the vision it sets out for improving support for unpaid carers.

The starting point for much of this work was the publication in 2008 of a national Carers Strategy for England,¹ which outlined a programme of actions to better support unpaid carers.

The 2008 Carers Strategy, *Carers at the Heart of 21st-Century Families and Communities*¹ (see Appendix B for key policy commitments outlined in the strategy), set out a 10-year vision for what support for carers should look like. It stated that, by 2018, carers will be ‘universally recognised and valued as being fundamental to strong families and stable communities. Support will be based on individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring.’ The Carers Strategy also provided a framework for this policy vision based on five core elements:

- services and systems that work for carers
- recognising and supporting carers
- research to improve outcomes for carers
- employment and financial wellbeing
- supporting young carers.

Recognised, Valued and Supported: Next steps for the Carers Strategy was published in 2010²⁵ – a cross-government document that set out actions over four years to better support carers. Priority areas included:

- supporting those with caring responsibilities to identify themselves as carers at an early stage
- recognising the value of carers’ contribution in designing local care provision and planning individual care packages
- enabling carers to fulfil their educational and employment potential
- providing personalised support for carers to enable them to have a family and community life
- supporting carers to remain mentally and physically well.

In 2014, the Department of Health published ***Carers Strategy: Second national action plan 2014–2016***,²⁶ which built on the 2008 Carers Strategy and the 2010 ‘next steps’ document.²⁵ It retained the 2008 vision for recognising, valuing and supporting carers, and focused on four priority areas identified in the 2010 document:

- identification and recognition
- realising and releasing potential
- a life alongside caring
- supporting carers to stay healthy.

The action plan identified key actions for the following two years.

Several key legislative changes aimed at better supporting unpaid carers followed the 2014 Carers Strategy. Most notably, the **Care Act 2014** gave carers in England the legal right to recognition and entitlement to support (see Box 1). This included:

- a right to a carer’s assessment to identify support needs
- a right for eligible needs to be met
- a duty on local councils to provide information and advice about the support services available for carers
- a duty on NHS bodies to cooperate with local authorities in delivering the Care Act.

This law came into effect in April 2015, to replace most previous laws regarding carers and people being cared for.

Although the Care Act does not deal with the assessment of people under the age of 18 who care for others, the **Children and Families Act 2014** gave young carers and young adult carers a right to a carer’s assessment and to have their needs met, that is, similar rights to assessment as other carers have under the Care Act.²⁷

Box 1: What is the Care Act 2014 and what did it do?

The Care Act 2014 outlined new rights for carers, which put them on the same footing as the people they care for (‘parity of esteem’). It also:

- introduced national care and support eligibility criteria for both carers and the person being cared for
- placed new legal duties and responsibilities on local authorities to assess carers’ needs, and to provide support to those who meet eligibility criteria
- put more emphasis on existing personal budgets, which give people the power to spend allocated money on tailored care that suits their individual needs as part of their support plan
- provided rights for carers to request a direct payment
- aimed to make the law fair, more consistent and easier for carers to understand how the system works and how decisions about them are made.

In 2016, the government launched a **consultation on an updated carers strategy**.²⁸ However, in 2018, it was confirmed that a revised strategy would no longer be published and instead the updated information would be included in the forthcoming social care Green Paper.

In place of a new carers strategy, in 2018, the government published *Carers Action Plan 2018–2020: Supporting carers today*, a **two-year cross-government action plan**² to build on the existing Carers Strategy’s focus on recognising, valuing and supporting carers. The programme of work aimed to support carers in England and to bridge the gap while waiting for the

social care Green Paper to be published. The action plan covered the five key priority areas:

- services and systems that work for carers
- recognising and supporting carers in the wider community and society
- building evidence and research to improve outcomes for carers
- employment and financial wellbeing
- supporting young carers.

A review of progress against the actions was published in 2019.²⁹

Improving the recognition of and support for carers has also been an area of strategic focus across the NHS – as evident in the 2019 NHS *Five Year Forward View*³⁰ and *The NHS Long Term Plan*.³¹

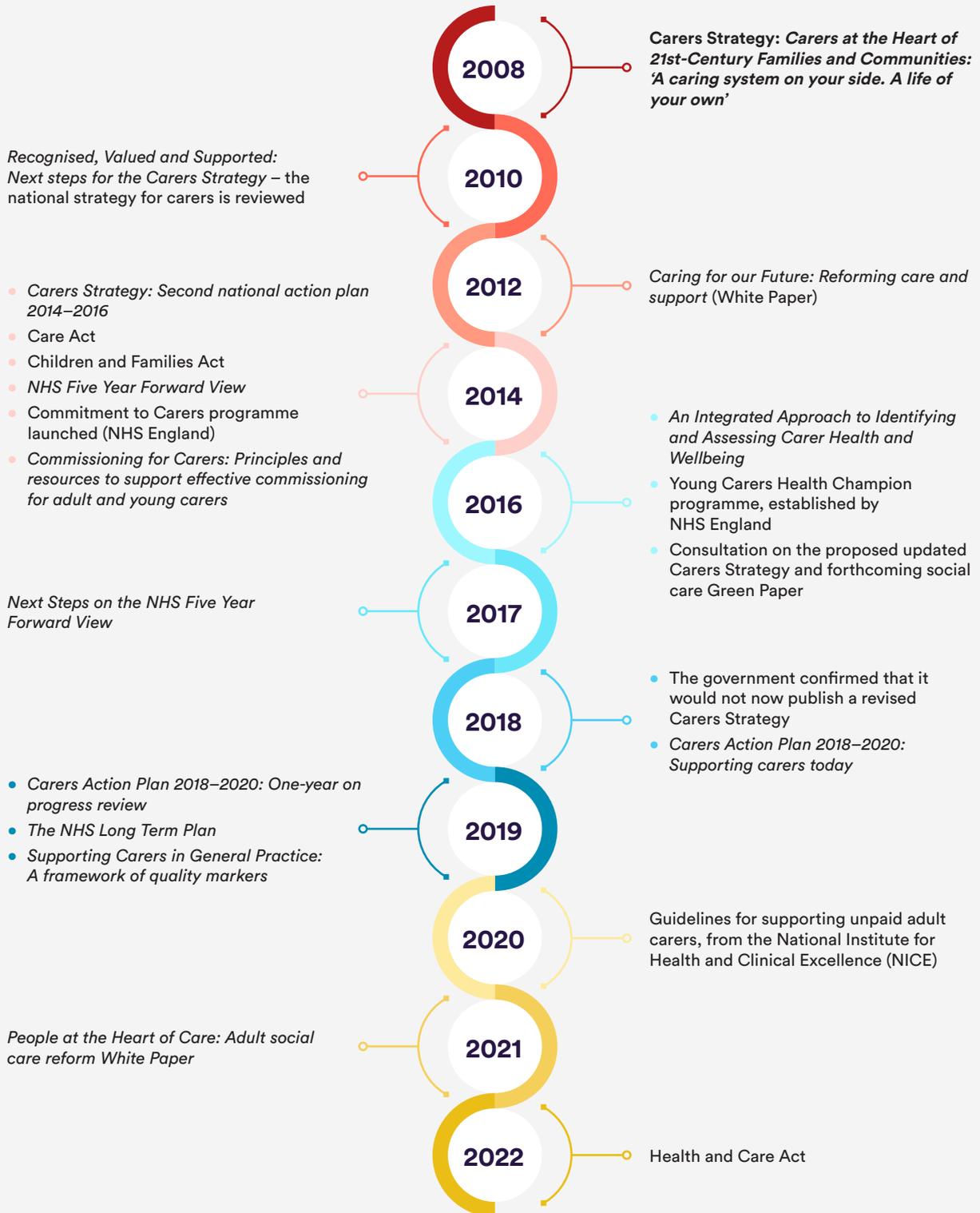
Some three years later than originally planned, the adult social care reform White Paper, *People at the Heart of Care*,³² was published in December 2021 and sets out a 10-year vision for adult social care. The White Paper outlines several policies aimed at better supporting unpaid carers. Priorities include:

- empowering carers to find user-friendly information and advice on health, care and housing
- enabling carers to know their rights
- helping carers to understand the local service landscape to maintain their own health needs
- personalised/tailored information and advice.

The White Paper also sets out £25 million in funding for carers. However, it does not outline a clear plan for how this should be spent to deliver on the plan to better support carers.

The policy timeline outlined in Figure 2 uses the 2008 Carers Strategy¹ as a starting point and presents key policy priorities and commitments, including legislation and initiatives, relevant to unpaid carers up to the present day.

Figure 2: Policy timeline



* Further details of the initiatives and policy commitments are provided in Appendix C.

4 To what extent has the policy vision been achieved?

To evaluate policy success, we looked at a range of data sources to quantify progress against the policy vision described in the previous chapter, using policy objectives set out in the 2008 Carers Strategy and the 2018–20 Carers Action Plan as a framework for analysis.

What do the data show?

The number of unpaid carers is increasing but we lack robust up-to-date data.

There currently is no up-to-date definitive source for the number of unpaid carers in England. The most accurate source of high-quality population data on the prevalence of unpaid carers is the Census³³, which asks respondents if they look after or give any help or support to anyone because of long-term physical or mental health conditions or illnesses, or problems related to old age. The relevant data from the 2021 Census is expected to be published in early 2023.

The previous Census (2011) identified 5.4 million unpaid carers in England, an increase of 552,956 or 11% since the 2001 census.^{23,34} The largest growth was among carers providing fifty or more hours of care per week.³⁵ If we assume a similar level of increase in the decade following the 2011 census, this would imply there currently are around 6 million unpaid carers in England. There is evidence to suggest that during the Covid-19 pandemic numbers of unpaid carers may have increased significantly above this, with Carers UK estimating up to 13.6 million unpaid carers across the UK.¹²

Other estimates for the numbers of unpaid carers exist with a wide range between them (and varying definitions of caring): the 2021 Family Resources Survey (UK-wide)¹⁴ suggests 6% of people are providing unpaid care; the 2019 Health Survey for England¹⁹ suggests that 17% of adults over 16 are unpaid carers; the 2022 General Practice Patient survey²⁴ suggests that 19% of adults over the age of 16 registered at GP practices in England are providing unpaid care.

Until the 2021 census data are published it is not possible to say definitively how many unpaid carers there are in England. Variability in the percentages from different sources described above in part reflects differences in survey methods, while highlighting the paucity of robust up-to-date data on carers. What we can say with some certainty is that the number of carers has been increasing over the past decade, and it is likely that there are around 6 million unpaid carers in England today.

Local authority assessments for carers have not kept up with the growth in the numbers of people providing unpaid care.

Carers' assessments are important because they are the route to support for carers. Without a local authority assessment, no help is offered to the carer. We used aggregate data that approximately 151 councils with adult social services responsibilities (CASSRs) in England submitted to NHS Digital over a six-year period from 2015/16 to 2020/21 to look in detail at assessments for carers.

Our analysis of SALT data shows that the total number of carers that local councils in England assessed for support across the six years increased from 386,605 in 2015/16 to 388,730 in 2020/21 – 2,125 extra assessments by 2020/21 compared with six years previously, representing an increase of less than 1% over this period.

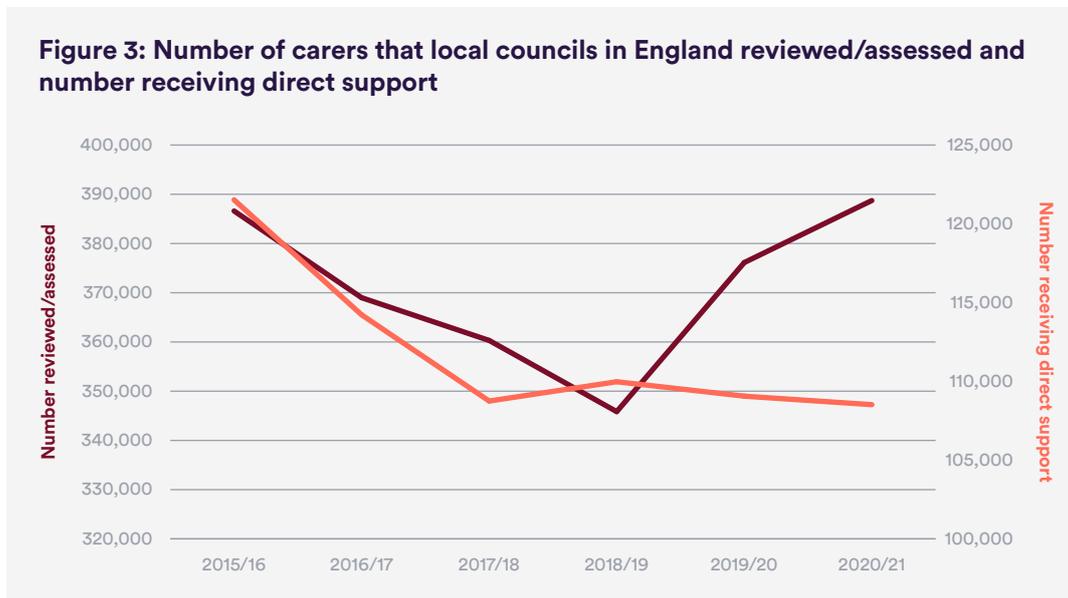
This increase is very much less than what would be expected given the growth in the number of unpaid carers over time evident, for example, in the 11 percent increase in carers shown between the 2001 and 2011 English census, and in the increase in unpaid caring during the Covid-19 pandemic.¹²

Even among those who do get a carer's assessment, approximately one in eight will not be eligible for any support, according to our analysis of SALT data.

Within the six-year time period, we also saw unexpected fluctuations in the numbers of carers’ assessments (see Figure 3). It is difficult to explain why the number of carers that local councils in England assessed dropped by 11% between 2015/16 and 2018/19 – from 386,605 to 345,850 – although it is somewhat reassuring to see a recovery in the subsequent two years, with local councils assessing a total of 388,730 carers in 2020/21.

Among those who have had a carer’s assessment, substantially fewer are now receiving ‘direct support’ from their council – an increasing number of carers are getting only ‘advice and guidance’.

Analysis of SALT data shows a significant drop in the number of carers who receive ‘direct support’ – in the form of direct payments/part direct payments, local authority managed personal budgets or local authority commissioned support – as the outcome from a carer’s assessment. Our analysis reveals that there were 13,000 fewer carers getting direct support in 2020/21 than there were six years previously in 2015/16 (see Figure 3).



Note: In calculating the number of carers receiving direct support, we included those in receipt of direct payments and part direct payments, local authority managed personal budgets or local authority commissioned support. We excluded those who were given information, advice and other universal services/signposting.

Source: Nuffield Trust analysis of SALT data.

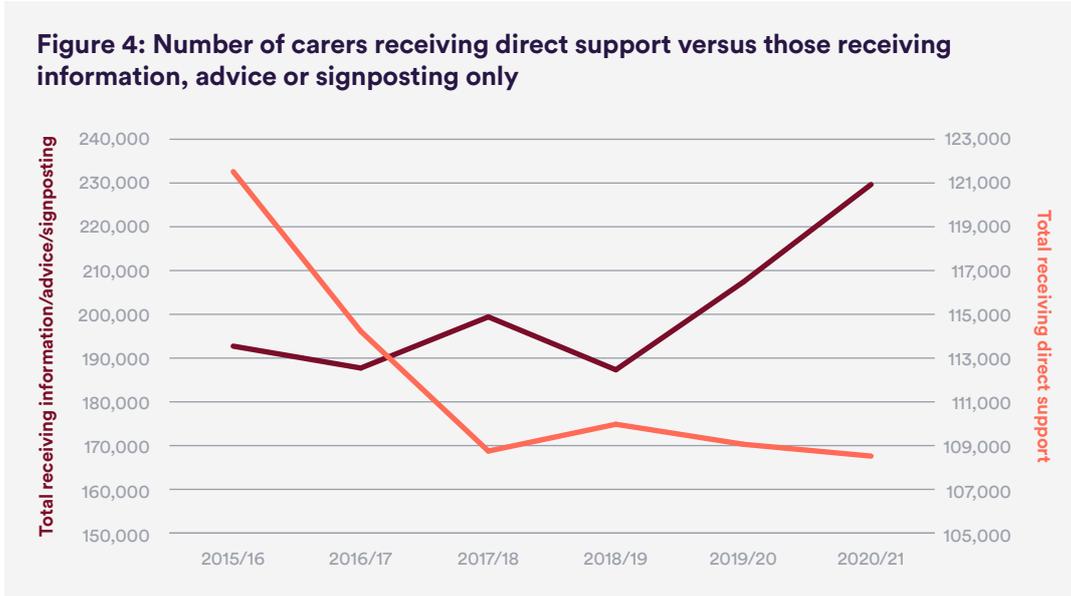
This drop is important because direct support is crucial to giving carers more choice over the care and support they receive and more control over their lives.²⁷ The Care Act 2014 states that councils need to assign a personal budget to everyone who is eligible for support so they can have more control over that support. With a personal budget, a carer can ask their local authority for a direct payment. Personal budgets have been included in the law as they are important for making care and support personalised, and direct payments are an essential part of this because they are designed to give carers more choice and more say in arranging their own care and support.

The trend towards lower levels of direct support – an 11% drop from 121,520 in 2015/16 to 108,520 in 2020/21 – means fewer carers are now being given the choice and personalisation that direct payments were designed to offer.

What is even more worrying to see is a new emerging data trend over the two years from 2018/19 to 2020/21 showing a fall in the *proportion* of carers who got direct support as the outcome from their carer’s assessment. Despite an increase in the number of carers’ assessments being undertaken in England in those two years, for every 100 carers’ assessments done in England in 2015/16, 31 resulted in support in the form of a direct support payment to the carer; but by 2020/21 this had reduced to 28 in every 100 carers’ assessments.

We cannot be sure exactly why the number of unpaid carers being offered direct support is declining, particularly when the number being assessed for support is going up. But one possible explanation is that narrowing eligibility criteria are making it more difficult for carers to access the direct support they need.

Analysis of SALT data shows that the number of unpaid carers getting only information, advice or signposting to other services after a carer’s assessment has grown substantially in recent years. It reveals that the number of carers accessing information, advice or signposting increased by more than 36,000 between 2015/16 and 2020/21. Taken together with the reduction in those getting direct support, this trend suggests that councils are responding to carers increasingly with the provision of advice and information rather than financial or other support, as shown in Figure 4.



Source: Nuffield Trust analysis of SALT data.

While some people will want and benefit from information, advice and signposting to other services, an increasing emphasis in recent policy on a support offer for carers that consists mainly of these elements could effectively result in a reduced support offer for carers and may explain the trend in the data showing a decline in the number of carers receiving direct support.

Satisfaction with support is low and has been getting worse. Despite a strong policy focus on providing advice, guidance and signposting, carers report that they are still finding it difficult to access clear information.

We analysed data from the Survey of Adult Carers in England (SACE),²² a national postal survey sent every two years to approximately 136,000 adults caring for a person aged 18 or over, to look at how easy it is for carers to find information and support, and how satisfied carers are with the support they are given.

The data show that carer satisfaction with the support they receive remains low, and has been declining. In 2021/22, 36% of carers reported being extremely or very satisfied with the services and support they received, compared with 41% in 2014/15 – a five percentage-point decrease in satisfaction over the eight-year period (see Figure 5).

Figure 5: Percentage of carers who reported they were very satisfied or extremely satisfied with the support services they received



Source: Nuffield Trust analysis of SACE data.

The proportion of carers who report finding it easy to find information about support has not improved over time, despite being a major area of policy focus, dropping from 66% in 2014/15 to 58% in 2021/22 – an eight percentage-point decrease over an eight-year period (see Figure 6). This is particularly concerning because most carers only receive advice, guidance and signposting to other services as the outcome of their carer’s assessment.

Figure 6: Proportion of carers who reported that it was easy to find information about support



Source: Nuffield Trust analysis of SACE data.

Access to breaks for carers is declining.

Breaks from caring are essential to protect carers' physical health, and also their mental wellbeing. Analysis of SALT data shows a worrying decline in funding that is used to support breaks for carers.

Breaks for carers – which make up the vast majority of instances where carers are receiving 'support involving the cared-for person' – can take many different forms and include:³⁶

- residential or nursing home care – where the person being cared for has a short stay in a residential or nursing home
- day-sitting services – where the carer is enabled to take a break to go shopping, meet up with friends or have time to themselves
- night-sitting services – where someone goes into the carer's home to enable the carer to have a proper night's sleep
- day care – where the person being cared for goes to a day centre or takes part in activities away from home, enabling the carer to have a break from caring.

According to our analysis, there were 24,000 fewer carers receiving support involving the cared-for person in 2020/21 compared with 2015/16 – a decline of 42% (see Figure 7).

Figure 7: Number of carers receiving support involving the cared-for person between 2015/16 and 2020/21



Note: Support for the carer involving the cared-for person is predominantly comprised of respite care and day care services.

Source: Nuffield Trust analysis of SALT data.

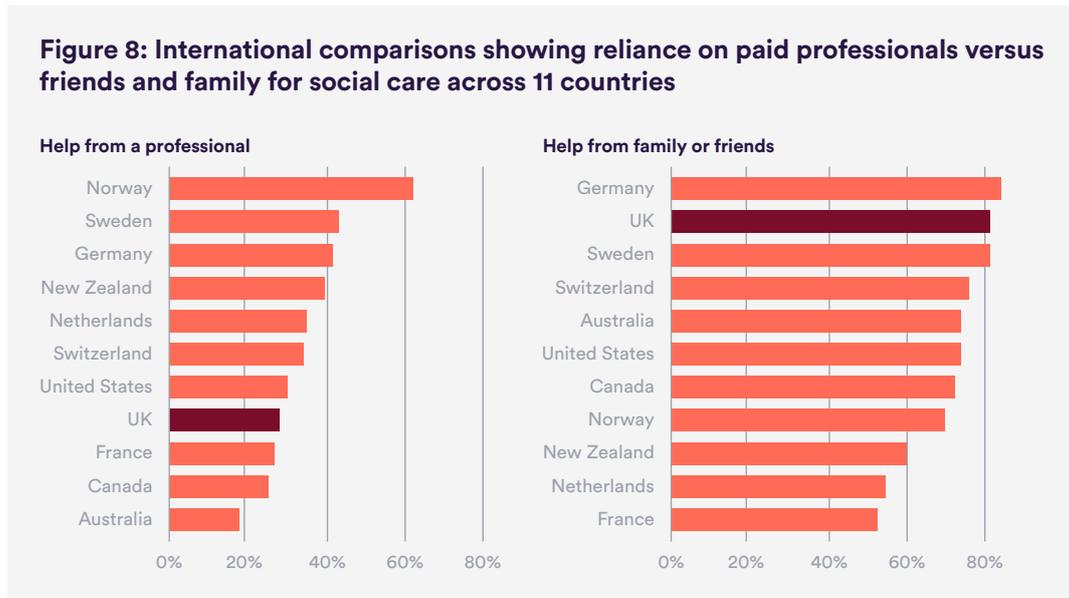
The Covid-19 pandemic has exacerbated this problem significantly: between February 2020 (just before the coronavirus hit the UK) and April 2021, the provision of day services decreased by 47%, community support schemes also decreased by 47% and home-based respite services decreased by 15%.¹¹

International evidence suggests that the UK relies more heavily on unpaid carers than many other countries do.

This lack of support for carers is particularly interesting in light of international evidence that suggests the UK relies more heavily on unpaid carers to provide social care than many other countries do.³⁸ Taken together with the other evidence set out here, this suggests that unpaid carers in the UK do more, but very few are visible to their local council and only a small proportion get any support.

Data show that people in the UK needing help at home – for example with day-to-day activities such as dressing and bathing – have a higher reliance on informal social care compared with peers in other countries. Analysis of survey data from 11 countries by The Commonwealth Fund³⁸ as part of its 2021 International Health Policy survey (including 1,876 people in the UK)

shows that, in comparison with other countries and with the exception of Germany – whose system explicitly encourages and facilitates family-based care through direct cash payments – older adults in the UK receive comparatively less help from paid professionals (that is, from social care services) and instead rely more heavily on unpaid carers (see Figure 8).



Source: The Commonwealth Fund, International Health Policy Survey of Older Adult. Results from the UK were significantly different from the Netherlands, Sweden and Switzerland for the question on help from a professional. The UK was significantly different from Canada, France, Germany, the Netherlands, Norway and the US for help from family or friends. Both questions only included respondents who reported having someone who helps them with their activities.

Funding for carer support services has been declining over time.

Evidence shows that local authorities’ real-term gross expenditure on carer support services has decreased since 2015/16.

Data from the Adult Social Care Finance Return (ASC-FR) collection³⁹ – which collates information from local authorities on commissioned support for carers – show that gross expenditure on carer services was 11% lower in 2020/21 (£156 million) than in 2015/16 (£176 million). These data also show that for three of the six years in the period (2016/17, 2017/18 and 2020/21), local authorities’ gross expenditure on carers decreased by more than 5% in comparison with the level of expenditure the previous year (see Figure 9).

With the Covid-19 pandemic further magnifying the levels of unmet need confronting local authorities,^{40,41} it is hardly surprising to find that, in 2020/21, only 4% of directors of adult social care services were fully confident that their budget would be sufficient to meet their statutory duties for the year ahead.

Figure 9: Percentage change in gross expenditure on support for carers that local authorities reported compared with the previous year, using 2015/16 as a starting point



Source: Nuffield Trust analysis of SALT data. All percentages have been rounded to whole numbers.

Conclusion

In summary, our analysis of national data shows that progress has been very limited, when this is measured against the policy vision set out in the 2008 Carers Strategy,¹ the Care Act 2014 and ambitions to better support unpaid carers laid out in the 2014–16 and 2018–20 Carers Action Plans.^{2,26}

It is difficult to reconcile these data with the picture emerging from the adult social care reform White Paper, *People at the Heart of Care* (2021),³² which states that ‘good progress’ has been made in some areas since the publication of the 2018–20 Carers Action Plan in 2018.² While there has been a lot of activity in this area, as reported in the White Paper, we have seen much less focus on measuring the impact of policies on carers directly, including outcomes such as the provision of direct payments or access to respite care.

How much progress has been made in implementing the policy vision to better support unpaid carers?

In this section we assess the overall progress made in policy implementation, using as a framework for analysis and synthesis the five strategic themes set out in the 2008 Carers Strategy and the 2018–20 Carers Action Plan (see Chapter 2).

Services and systems that work for carers

Despite policy promises to the contrary, we continue to have services and systems that do not work for carers.

We see evidence of this, for example, in the fewer and fewer numbers of unpaid carers being given the choice and personalisation that direct support payments were designed to offer – with our analysis showing an 11% drop in these payments between 2015/16 and 2020/21. This sits in direct opposition to the policy ambition laid out in the 2008 Carers Strategy to see ‘direct payments utilised by increasing numbers of people’ (page 153),¹ and the view of the previous Secretary of State for Health and Social Care on health and social care policy reform – that it is ‘especially ambitious about personalised care and personal budgets’.⁴²

Together with evidence showing the increasing difficulty that carers experience in accessing respite care – a drop of 42% in the provision of ‘support for the cared-for person’ over the same period, as we detail in this report – what this means for carers is less control over how care is organised, less personalised support and fewer breaks from caring.

At the same time, we are seeing evidence of another worrying policy shift in the wrong direction. In England, an increasing number of people who have a carer’s assessment are getting only the very lowest levels of support available: that is, advice, guidance and signposting to other services. In the two years between 2018/19 and 2020/21, this went up by 23%.

Taken together with data showing a drop in direct support payments, the trend towards more advice, guidance and signposting suggests that the offer of support for carers in England has been steadily diminishing in recent years, rather than better support being provided.

It is hardly surprising, then, to find that the data we present in our report also show high levels of dissatisfaction with support services among carers.

Recognising and supporting carers, including young carers, and research to improve outcomes for carers

One area where there has been positive progress is legislative change to better recognise carers' rights, and to provide clarity about their entitlement to support, together with a legal duty to meet eligible needs. The Care Act 2014, which put the rights of carers on a par with those of the people they care for, was a significant legislative step forward.

Yet it is not entirely clear that this *legislative* progress has led to better *practical* outcomes for carers. Despite legislative change to provide parity of esteem for carers, evidence suggests that carers' needs are still not always considered in policy decision-making or in assessments of policy impact – indeed they can be overlooked entirely or considered only as an afterthought. One recent example of this is the policy of 'discharge to assess', where the negative impacts on unpaid carers of rapid hospital discharges, measurable in terms of costs to carers' physical and mental health, have been largely brushed under the table – with 53%³⁷ of carers reporting that their caring responsibilities were not considered, they were not kept informed and they lacked information about how to support their relative after discharge.

Although clear ambitions were set out in the 2008 Carers Strategy¹ and the updated Carers Action Plans^{2,26} to build research capacity and to improve health outcomes for carers, here again we see very limited evidence of policy success. Progress on better use of data and research to improve outcomes for carers has been slow.

Data on unpaid carers remain problematic, with concerns about both data quality and notable limitations in the scope of national data. This includes a lack of:

- robust data on expenditure on unpaid carers
- data on objective health outcomes for carers and health and social service use
- data on unmet need.

While a shift within local authorities from aggregate data use to the use of pseudonymised individual-level data is needed, this has yet to be implemented at scale.

Carers are not a homogenous group and too often diversity among carers is not well recognised. In part this is because data on the different needs of different types of carers are missing. For example, local authorities provide data on carers' assessments, and on the support provided to carers, as part of the Short and Long Term (SALT) returns, but these data need to be broken down further, for example by age, gender, ethnicity and Index of Multiple Deprivation score (which can be derived from the carer's postcode). This would make it possible to investigate potential differences in the provision of carers' assessments, and in support, for different groups of carers.

Better data are needed both to tackle inequity in health outcomes for carers, and to ensure that a strong evidence base informs future strategies. Despite a firm commitment in the 2018–20 Carers Action Plan² to making real improvements to data quality and the use of data, it is still not possible to do basic data linkage – for example, linking data that carers provide in the national Survey for Adult Carers in England²² to NHS records in primary care or hospitals.

It is important to recognise that some good progress has been made towards better identifying young carers in schools.⁴³ However, local authorities do not carry out an assessment of many young carers' needs and almost two-thirds (64%) receive no support, whether formal or informal. Data on objective health outcomes and health trajectories over time for young carers are largely non-existent and this is an important knowledge gap.

Employment and financial wellbeing

Improving the financial wellbeing of carers and ensuring that they 'have access to financial support when they need it' is identified as a priority

policy goal in the 2018–20 Carers Action Plan.² Although some progress has been made to protect carers’ state pensions, and a Bill to provide carers with the right to five days (unpaid) leave a year is currently before the House of Commons,⁴⁴ a comprehensive plan for improving the financial wellbeing of carers and better supporting working carers has yet to emerge.

Despite some notable initiatives to better support working carers – including the Carer Passport scheme,⁴⁵ the Carer Confident benchmarking scheme⁴⁶ and the Working for Carers project – many carers continue to struggle combining paid work and caring responsibilities and find that carers’ assessments do not adequately take into account their need to combine employment and caring, with more than one in three (38%) giving up work as a result.⁴⁷

Right now, many carers are facing a combination of low fixed income, rapid increases in the cost of living and energy price hikes. For the 1.3 million UK adults receiving a Carer’s Allowance – of £69.70 a week in England – it is hard to overstate the magnitude of the financial challenge they face or its impact on their wellbeing, including their ability to save for their own future. Compared with adults earning more than £50,000 a year, those with an income of less than £10,000 are eight times more likely to struggle with rising energy and food prices, according to analysis by the Office for National Statistics.¹⁵

Although it is clear that unpaid carers and the people they care for are among those hardest hit by the cost-of-living increases,⁴⁸ policy-makers in England have been slow to recognise and respond to the impacts of these increases on benefit recipients, including carers.

Summary and conclusion

Figure 10 presents a summary of the evidence on progress in policy implementation, with the full detailed policy analysis available in Appendix C. This analysis of policy impact should be read alongside data from our own Nuffield Trust analysis in the previous section. We conclude from this evidence that policy success in delivering on the ambition to better support unpaid carers has been very limited. It shows that despite some positive steps, the overall picture remains one of diminishing support for carers in England.

Figure 10: Evidence of progress in policy implementation

Policy goal	Examples of evidence of implementation progress
<p>Services and systems that work for carers</p> <p>▲</p>	<ul style="list-style-type: none"> ● Closer linking between local authorities and local carer services, and some progress in joint working between health services and local authorities. ● Waiting times for carers to access support services remain substantial. Carers wait an average of 57 days from requesting support to getting the support they need.⁴⁹ ● The number of carers accessing information and advice increased by more than 36,000 between 2015/16 and 2020/21. However, the proportion who report finding it easy to get information about support has not improved over time – reducing from 66% in 2014/15 to 58% in 2021/22 (Nuffield Trust analysis of SACE data).
<p>Recognising and supporting carers</p> <p>▲</p>	<ul style="list-style-type: none"> ● The number of carers’ assessments in England declined substantially between 2015/16 and 2018/19 (by 40,775), although there has since been an uptick of 12% in the past two years (Nuffield Trust analysis of SALT data³⁹). It is unlikely, however, that carers’ assessments are keeping pace with the increase in the number of carers in England. ● The number of carers getting support has decreased over time. There were 13,000 fewer carers getting ‘direct support’ in 2020/21 than there were six years previously in 2015/16. Access to breaks for carers is also declining, with a drop of 42% in carer support involving the cared-for person over the same period (Nuffield Trust analysis of SALT data³⁹). This means that the number of carers able to access respite care decreased by more than 24,000 between 2015/16 and 2020/21. ● Real-term funding for carer services has reduced, with gross expenditure on carer services being 11% lower in 2020/21 than in 2015/16 (Nuffield Trust analysis of ASC-FR data³⁹).
<p>Research to improve outcomes for carers</p> <p>▲</p>	<ul style="list-style-type: none"> ● There is a lack of data on carers’ health outcomes and health service use due to a lack of linking of routine health data with local authority data or other carer-specific datasets. In particular, there is a lack of data on the health trajectories of young carers. ● Some data are available at the local authority level to understand regional differences in support service provision, but data quality is often poor and more robust data are needed on waiting times, voluntary sector support, unmet need and service demand.
<p>Employment and financial wellbeing</p> <p>▲</p>	<ul style="list-style-type: none"> ● More than four in 10 working carers (44%) report struggling to combine paid employment with caring responsibilities, 18% of carers report having reduced their hours of work to care and 38% report having given up work to care.^{47,50} ● Support services are not doing enough to consider the needs of working carers or to help them to balance their caring role with employment (for example, services lack flexibility and reliability). Only one in four carers (25%) report that their need to combine employment and caring was adequately considered in their carer’s assessment.⁴⁷ ● Financial support for carers is not enough and significant numbers are not eligible to receive such support: Carer’s Allowance is only £69.70 a week, and carers are not eligible for it if they are providing fewer than 35 hours of care a week or if they earn more than £132 a week after tax and national insurance deductions.⁵¹
<p>Supporting young carers</p> <p>▲</p>	<ul style="list-style-type: none"> ● Schools have made progress in identifying young carers. A 2019 report found that 96% of young carer services were receiving referrals from schools and more than half (51%) had dedicated school workers.⁴³ ● Adult social services’ and health services’ identification of young carers remains inadequate, and linking across services and organisations is inconsistent. A 2019 report found that only six in 10 young carer services received referrals from adult services.⁴³ ● A significant number of young carers are still not receiving appropriate support or having their needs assessed. Fewer than one in five parents of young carers (19%) reported that the local authority had made an assessment of their child’s needs and nearly two-thirds of young carers (64%) were receiving no support, whether formal or informal.

Key: Against the policy ambition to better support carers: ● Good progress has been made ● Some progress is evident but this has been limited ● Evidence shows that little or no progress has been made

5 Why has the policy vision not been achieved?

In this chapter we seek to explain why, in the context of a policy vision to better support unpaid carers, and despite some progress, we continue to see a persistent gap between the policy vision and implementation. While recognising there will be many contributing factors, here we highlight eight important issues.

Lack of accountability and agreement on who is responsible for policy success and failure

While there is a well-articulated policy vision for better supporting unpaid carers, it is not clear who is responsible for its delivery – in part because support for unpaid carers straddles different policy areas across government and a variety of ministerial appointments.

This means that it is not clear who is responsible for ensuring progress, or who should be held accountable if the measures of success – which should be set out from the start – are not met and if policy fails. This lack of clear lines of responsibility and accountability also means that lessons that could helpfully inform policy choices are not being learned.

Much stronger partnership working across stakeholders within government is needed as current arrangements are fragmented and they lack the coordinated approach required to deliver more effectively on the policy vision to improve support for unpaid carers.

Lack of clarity on who is responsible for what within local systems

A lack of clarity on who is responsible for what is also an issue within local-level systems. NHS staff, education providers and local authorities are not always fully aware of their role and responsibilities in terms of the implementation of policy goals or legislation.

For example, stakeholders have considered that some of the duties set out in the Care Act 2014 are ambiguous and this lack of clarity extends to health services – primary care staff have shown a lack of awareness of their duties associated with carer legislation, for example in identifying carers and signposting them to support services.⁵² Where there is a lack of clarity on the duties and responsibilities of different parts of the health and social care system, or confusion about how services should be delivered, the policy vision to better support carers starts to fall over.

Too often, there is no clear leadership and accountability for supporting carers within local health systems – with stakeholders we spoke to describing the carers agenda within integrated care systems as being something that is frequently passed from pillar to post.

Without clear accountability, partnership working across services will be ineffective and the learning from successful local schemes and initiatives will be limited. A lack of clear responsibility and vision for who should be carrying projects forward, as well as an absence of a clear funding route, have meant that previous and successful initiatives, such as local pilot schemes that have shown promising results, are often not scaled up or implemented more widely. Many of the valuable insights from such work are therefore often being lost due to the lack of clarity on who is responsible for this work and an ineffective learning culture.

While Public Health England recognises unpaid caring as a social determinant of health,¹⁰ much more needs to be done to embed this knowledge into local health system planning. The shift towards integrated care systems provides a good opportunity to get things right for the future, ensuring that carers are visible in local systems and that caring is seen as an important determinant of health and inequity in health outcomes.

As part of place-based commissioning, for example, integrated care boards should recognise carers as a group for whom there is clear evidence of poorer health outcomes.^{9,10} Carers should be included in health inequality impact assessments, and integrated care boards should be required to develop a ‘plan on a page’, identifying actions to support carers, with clearly identified indicators of success. Although local pockets of excellent practice in developing an action plan to support carers are emerging, these are not yet widespread and greater effort is needed to share and embed best practice.

The Core20Plus5⁵³ approach advocated by NHS England and NHS Improvement to support integrated health systems in tackling health inequalities specifically calls for population health data to identify ‘ICS-determined population groups experiencing poorer than average health access, experience and/or outcomes, but not captured in the ‘Core20’ alone.’ Unpaid carers are not currently included in the listed exemplar groups. It is clear that, based on evidence of poorer health outcomes among carers, ICS population health data should include data on unpaid carers’ health outcomes and care experiences, and the Core20Plus5 should explicitly include carers as part of tackling health inequalities at a local level.

Failure to set out how policy success might be measured

While the 2008 Carers Strategy¹ demonstrated a vision for what success in supporting carers should look like, it did not go far enough in setting out how success should be measured or give detail on how progress against this vision would be monitored over time. Similarly, the recently published social care White Paper, *People at the Heart of Care*,³² describes policy progress in terms of activity and initiatives that have been implemented, but it does not focus on directly measuring the impact of such initiatives on carers.

At a national level, the obfuscation of policy success and failure is more likely where measures of policy success are based on actions and descriptions of what has been done, alone, rather than on actions together with clear measurement of the *impact* of the changes on outcomes that matter to carers – for example, measures of policy success that quantify access to practical

help such as flexible respite care for working carers; a reduction in long waits for carers' assessments; and a reversal of the decline in carers' satisfaction with support services.

In the future, policy-makers must be clearer about how policy success should be measured. Metrics that describe what policy success looks like must be set out at the same time as the policy vision.

Legislation alone is not enough to secure change

As we have seen in other areas, such as integrated care,⁵⁴ legislation alone is often not enough to secure change and to ensure collaborative working across service providers and stakeholders.

Achieving effective collaboration across service providers and organisations continues to be a significant challenge. Despite some improvements in multi-agency working in delivering carer services, which the Care Act 2014 has facilitated, such as closer linking between local authorities, the voluntary sector and health services, inconsistency remains. There is still considerable regional variability in the joining up of services to deliver support services for carers. One example of this is difficulties in the identification of young carers due to inadequate and inconsistent data sharing across adult and child social services.⁵⁵

Despite legislation to provide parity of esteem for carers (the Care Act 2014), carers' needs are still not always being properly considered. One example is the policy shift towards 'discharge to assess'.⁵⁶ In response to the Covid-19 pandemic, NHS policy moved to discharge people from hospital more rapidly to free up hospital beds. This led to a sudden increase in the numbers of patients discharged with unmet care needs and a subsequent increase in pressure on unpaid carers, who felt their caring responsibilities were not adequately considered within the discharge decision-making process.³⁷

Failure to actively consider carers in wider policy decision-making

The example above also illustrates a more fundamental policy problem: a failure to actively consider carers needs in wider policy discussion. Too often, unpaid carers are not visible in wider policy decision-making, and in the assessment of policy impact the consequences for carers are not considered upfront. While a policy of rapid discharge may benefit hospital efficiency,⁵⁶ patients who are discharged from hospital without an at-home support service in place still need to be cared for. Here, the negative impacts of rapid hospital discharges on unpaid carers, measurable in terms of potential costs to carers' physical and mental health, have been largely brushed under table. This is, somewhat belatedly, now being addressed in policy: one positive feature of the Health and Care Act 2022 (part 1, section 91) is that it explicitly requires NHS trusts to involve carers in the discharge of hospital patients with care and support needs.

A second example of the invisibility of carers in wider policy decision-making is the impacts of food and energy price hikes. Unpaid carers are one of the groups that the cost-of-living crisis hits the hardest,⁴⁸ something that has been recognised in Wales⁵⁷ through an additional £500 payment for unpaid carers. Policy-makers in England meanwhile have been slow to take on board, and respond to, the financial impacts of cost-of-living increases on carers – the most notable feature of the policy response so far has been its absence.

Funding pressures and budgetary constraints

The social care system is over-stretched and under-resourced, with the past decade seeing £7.7 billion in cuts from local authority social care budgets.¹¹ As we document in this report, between 2015/16 and 2020/21, for three of those years (2016/17, 2017/18 and 2020/21), local authorities' gross expenditure on carers decreased by more than 5% in comparison with the level of expenditure the previous year.

The Covid-19 pandemic has further magnified the resource challenges facing local authorities, with increasing levels of unmet need. For example, spending on adult care was £61 million over budget (all local authorities) in 2020/21, and directors of adult social care services were expected to collectively find £601 million in savings in 2021/22, representing an average 3.7% of budgets.¹¹ These financial pressures and budget cuts directly impact service provision. Work by Fernandez and others⁵⁸ and Yeandle⁵⁹ has shown that financial pressures impact the success of local authorities in effectively implementing the Care Act as they constrain local council resources. Certain groups – and specifically carers – are more likely to ‘lose out’ when decisions about cuts to social care services are made.

The declining trend in local authorities’ provision of support to carers is intertwined with, and compounded by, a narrowing of support provided to people who need social care. This means that many carers are hit with a ‘double whammy’ of:

- cuts to services for carers and narrowing eligibility criteria, which translate into less support available for themselves as a carer
- less support available for the person they care for.

This creates a toxic combination of both less support, and more work, for carers. It is hardly surprising, then, to see that 52% of unpaid carers report that providing care has an impact on their health, for example that it leads to physical strain, stress or exacerbates an existing health condition.⁶⁰ However, this link between budgetary cuts to social care services and services for carers, and poorer health among carers, is too often glossed over.

It is not only local authorities facing significant financial constraints, but also health services such as primary care. In particular, a lack of resources and time pressures on staff in GP practices might explain the challenges evident in the identification of and support offered to carers.⁵²

Lack of data needed to support service commissioning and to evaluate policy success

Local services should be built and planned around unmet need and what matters most to carers. For this we need much better data. Local assessment of need is important as a starting point, but many local authorities still do not have a clear understanding of who is providing unpaid care in their area.⁴⁹ Without a clear idea about local carer need, it is difficult to design and plan support services. In addition, it is often not feasible to evaluate the impact of initiatives or programmes to support carers given the available data, particularly at a local level, due to problems with data quality and the lack of capacity for data linkage.

A lack of data also hampers efforts to evaluate policy success. Data on metrics of key policy interest – how many carers give up work because flexible respite care is not available, for example – are not available.

Tackling poor health outcomes among carers and creating parity of health for carers require investment in research linking health and social care data, including data on unmet need, objective health outcomes and service experiences. Robust local data on health outcomes and service experiences for carers is essential to support integrated care systems in discharging their responsibilities to use data in tackling health inequalities, as part of the Core20PLUS5 approach advocated by NHS England and NHS Improvement.⁵³ Better data are also needed to tackle inequity in access to support among different groups of carers. This includes data to help understand the needs of different types of carers, and to support the commissioning of services that meet these needs in appropriate ways.

As part of this, we need a much stronger focus on understanding how different patient characteristics may combine or interact with each other ('intersectionality') to exacerbate inequalities for some groups of carers. One of the key barriers to better understanding inequalities between different groups of carers is a lack of appropriate data. Local authorities provide data on carers' assessments, and on support provided to carers, as part of the

Short and Long Term (SALT) returns. In the implementation of the White Paper on adult social care reform, the government should require that these data are broken down further, for example by age, gender, ethnicity and Index of Multiple Deprivation score (which can be derived from the carer's postcode). This would make it possible to investigate potential differences in the provision of carers' assessments and in support for carers – for example, across ethnic groups or inequalities based on a combination of factors such as ethnicity, socioeconomic disadvantage and age – in a way that cannot be done using SALT data at present.

Limited accountability for local authorities

Legislation – such as the Care Act 2014 and the Children and Families Act 2014 – places statutory duties on local authorities to assess carer needs and provide appropriate support services. However, there is little to no accountability for local authorities regarding the implementation of this legislation. The fact that many local authorities are unable to provide figures on waiting times for carers accessing local support services from the time of the initial approach is evidence of this.

In particular, carers find it difficult to identify who they should contact when they have a concern about services they should be provided with under the duties of the Care Act. It is not clear to carers who has responsibility for responding to and resolving complaints from carers, for example when services they are entitled to and have been receiving are cut or reduced. Clarity is needed on how duties are fulfilled and complaints procedures are handled within local systems – and how and when these should be escalated to the national regulator, the Care Quality Commission.

This fits with the recent policy focus on the importance of a stronger feedback culture in social care,³² which requires organisations to improve routes for feedback and local authorities to assess how they are meeting the needs of unpaid carers; and with the recently published adult social care White Paper,³² which emphasised the importance of the oversight and accountability of information and advice services.

Figure 11 illustrates the eight key factors we have highlighted in this chapter that explain why there is a policy–implementation gap in support for unpaid carers.

Figure 11: Eight key factors that explain why the policy vision to better support unpaid carers has not been achieved



6 How far does £25 million for unpaid carers go?

In the 2021 adult social care reform White Paper,³² the Department of Health and Social Care put forward an offer of £25 million for unpaid carers over three years. In Figure 12, we illustrate what this can buy in terms of services to support carers. Our analysis is based on costings that the Personal Social Services Research Unit⁶¹ has calculated.

Figure 12: What £25 million buys for unpaid carers



* Local authority own-provision social services day care for adults requiring mental health support (aged 18–64): £33 per session.⁶¹

** Local authority own-provision day care for adults requiring learning disability support (aged 18–64): £63 per session.⁶¹

The adult social care reform White Paper sets out a 10-year vision for adult social care, and promises £5.4 billion in funding to support reform. Although the £25 million earmarked to support unpaid carers may sound impressive, it is in fact less than 1 percent of the £5.4 billion total funding promised for adult social care reform: this shows the relative lack of prioritisation of unpaid carers in wider government policy and decision-making, including policy on social care reform, and more broadly illustrates the position accorded to unpaid carers' within the current political agenda.

In reality the £25 million promised to support carers does not stretch far at all.

One option would be to use this £25 million to support better access to respite breaks for carers, something recognised in the social care reform White Paper as an area of 'particular concern'.³² However, as Figure 12 shows, this funding is not enough to buy 800,000 carers – including young carers – needing a break from caring for an adult with mental health problems even one 3.5-hour day care session to provide respite for the carer.

Alternatively, this funding could be used to provide a direct support payment to carers. Even if this funding were only used to support carers in England who are providing more than 50 hours of care each week – of which there are at least 1.4 million⁷ – £25 million is only enough to provide a one-off direct support payment of £17.85 as Figure 12 shows. And this would still leave approximately 4.2 million of the six million unpaid carers in England with no additional support at all. To put this in some context, in 2022 more than 57,000 unpaid carers in Wales received a £500 payment – part of an investment of £29 million in unpaid carers by the Welsh Government in recognition of the 'pivotal role' they have played during the pandemic and recognising the financial and emotional hardship many have experienced.⁵⁷

It is difficult to reconcile a policy ambition which sets out to 'kick-start a change in the services provided to support unpaid carers'³² with the funding offer of £25 million for unpaid carers in England. This sum is clearly inadequate to address the level of unmet need experienced by so many individual carers, and will not be enough to deliver the improvements to services for carers and commitment to better support carers that have been promised.

7 What actions are needed?

In this chapter we outline key recommendations for parliamentarians, policy-makers, local commissioners, service providers, research organisations and other stakeholders for whom the findings of this report are relevant, at national and local levels.

Key recommendations: parliamentarians and policy decision-makers

Support for carers is falling short and ministers need to understand why policy commitments to provide better support for carers have failed and identify what actions are needed to turn this around. **Parliamentarians and policy decision-makers must take on board lessons from history and avoid repeating them.** Responsibility for delivering on policy commitments made to improve support for carers must be much more clearly defined.

Stronger partnership working across government stakeholders – for example within the Department for Work and Pensions, the Department of Health and Social Care, and NHS England – is needed to deliver more effectively on the policy vision to improve support for carers. Current arrangements are fragmented and lack a coordinated approach.

Action 1 Identify clearly who is accountable at a ministerial level for achieving success in better supporting unpaid carers and what action from parliamentarians is needed to reverse the erosion of support for carers, and to ensure carers are much more visible in policy decision-making in the future.

Action 2 Appoint a senior policy lead for carers within the Department of Health and Social Care, at director level, who is responsible for joining up thinking across relevant stakeholders within government and delivering on policy objectives to better support carers, and defining upfront how ‘success’ will be measured.

Action 3 Commitment by government to reversing the trend that saw 13,000 fewer carers receiving ‘direct support’ in 2020/21 than six years previously.

Key recommendations: local commissioners and service providers

Carers must not be left out of the ‘levelling up’ policy agenda. Integrated care boards must recognise the health disparities for carers and include carers in population-based commissioning of services to address health inequalities. Integrated care systems must establish clear leadership and accountability for supporting carers within local health systems identifying actions to support carers that are **aligned to strategic objectives including, for example, reducing inequalities in health and improving discharge processes.** Carers must know who they should contact if they have a concern about services and support for carers, with clarity of accountability for carers if services they are entitled to are cut or reduced.

Local authorities must work to **ensure access to support on an equal footing** for all carers – avoiding a ‘postcode’ lottery and actively tackling the potential impacts of intersectionality (how different patient characteristics may combine or interact with each other) and geographical inequalities in support.

The following two actions are for integrated care boards:

Action 4 As part of place-based commissioning, recognise carers as a group for whom there is clear evidence of poorer health outcomes. Include carers in health inequalities impact assessments, and explicitly include data on carers’ health outcomes and care experiences as part of the Core20Plus5 approach.

Action 5 Develop a succinct plan identifying actions to support carers, with clearly identified indicators of success, and clarity on responsibilities for delivering this.

Key recommendations: research organisations and data leads at local and national levels

Tackling poor health outcomes and creating parity of health for carers require **investment in research linking health and social care data**, including data on unmet need, objective health outcomes and service experiences. Commissioning of health research with a specific focus on **young carers should be identified as a high priority**.

In **implementation of the White Paper on adult social care reform**, the government should require that improvements are made to the **quality and completeness of data**, to understand local demand and help with service planning, and to better measure the impact and success of policy initiatives.

- Action 6**
- (a) Make better use of local data to understand local need, and to commission services to meet this need.
 - (b) Provide better national data on metrics of key policy interest, for example:
 - the number of carers’ assessments that include a request for support to allow the carer to continue working – and, of these, how many such requests are declined
 - how many carers give up work because flexible respite care is not available.

Action 7 Focus explicitly on unpaid carers within data policy to shift local authorities from using aggregate data to using pseudonymised individual-level data, and make better use of NHS numbers to support data linkage between health and social care, including data that GP practices and hospitals hold.

Appendix A: Data sources for this report

Short and Long Term (SALT) services data and Adult Social Care Finance Return (ASC-FR) data

This report contains aggregate information that approximately 151 councils with adult social services responsibilities in England submitted to NHS Digital, to provide insights into adult social care activity (Short and Long Term – SALT – services data) and expenditure (Adult Social Care Finance Return – ASC-FR – data) at national and local levels. NHS Digital publishes these data each year, based on data for a 12-month period (1 April to 31 March).

To explore funding for carer support services, we analysed ASC-FR data on gross current expenditure on other (not long- or short-term) social care, by primary support reason between 2015/16 and 2020/21, with a focus on data coded as ‘social support: support to carer’.

To assess support that councils provided to carers, we analysed SALT data (by year) from 2015 to 2021. This included data on:

- direct support
 - direct payments
 - part direct payments
 - local authority managed personal budgets
- information, advice and other universal services/signposting
- those who were assessed but received no direct support
- support involving the cared-for person (in practice this is most usually respite services and day care).
- A number of considerations should be acknowledged when interpreting SALT and ASC-FR data, including:

- Data completeness and quality can vary. For example, when carer services are outsourced to a third party, local authorities are not able to quality-check data. SALT data may not fully capture activity commissioned at local population level (not individual-level) by local authorities for services that could be used by some carers, including generic information or local support services.
- The data capture only a very small proportion of carers in England (fewer than 400,000) which is substantially below recent estimates of the number of carers provided in this report. This raises issues relating to how representative the SALT data are and their generalisability.
- The data may contain some coding ambiguities. For example, respite services may be recorded in ‘support involving the cared-for person’ and may also be covered by direct payments (depending how they are funded).
- At a local level, some local authorities map carers to the cared-for individual (one to one) and can therefore over- or under-estimate the number of carers (that is, if several carers care for one person or one carer cares for several people).
- The data are only on those caring for an adult – they exclude carers who are caring for someone under 18 years of age.

Survey of Adult Carers in England

The Survey of Adult Carers in England (SACE)²² is a national postal survey that takes place every other year. Councils with adult social services responsibilities conduct the survey and NHS Digital collects the data. The questionnaire is sent to a random selection of carers aged 18 or over, who are caring for a person aged 18 or over, and asks about:

- their quality of life
- their overall satisfaction with social services
- whether they have been included or consulted in discussions about the person they care for
- whether they find it easy to get information about support.

We analysed SACE data trends between 2014/15 and 2020/21. The 2020/21 survey was postponed due to the Covid-19 pandemic and therefore took place over the autumn of 2021.

Appendix B: Policy commitments outlined in the 2008 Carers Strategy

Services and systems that work for carers

Workforce. ‘Training professionals across the board, from health to housing, to provide better services and support for carers.’

Third sector. ‘Ensure that third sector support for carers is available throughout the country to a larger proportion of carers than is currently reached.’

Services. ‘Carers able to access specialist carers’ services in every community.’

Expanded NHS services.

- ‘Pilots to look at how the NHS can better support carers in their caring role through developing models of best practice and enabling more collaborative service provision between the NHS, local authorities and the third sector’.
- ‘Pilots to improve the support offered by GPs for carers’.
- ‘Piloting annual health checks for carers’.
- ‘Disseminate models of best practice to primary care trusts (PCTs) on how to provide better support for carers’.
- ‘Develop a full training package for all GPs, dependent on the results of the pilots’.
- ‘Consider providing carers across the country with annual health checks’.
- ‘Consider providing replacement care for carers to attend hospital appointments and screenings’.

- ‘Discuss with GPs and other health professionals the measures that can be taken that will provide a sharper focus on the distinct needs of carers.’

Annual Carers Grant. ‘In the context of community empowerment and the reform of the care and support system, we will consider how the relationship between local authorities and the third sector and carer-led organisations can be developed to make better use of the expertise of these organisations and to provide carers with greater choice and control over the way in which services are provided to them. As part of this we will also examine how best to use the Carers Grant to the benefit of carers.’

Recognising and supporting carers

Information and advice. ‘Providing every carer with the opportunity to access comprehensive information when they need to. The information will be easily accessible for all groups of carers, and specific to their locality.’

Emotional support. ‘Improving the emotional support offered by central [and] local government and the third sector to carers.’

Personalisation agenda. ‘Consider extending flexibility in the way personal budgets and direct payments can be used.’

Easy-to-access support. ‘Where appropriate, carers offered a lead professional to help access services and ensure early intervention when circumstances change.’

New break provision.

- ‘Consider further increases to break provision taking account of evidence about quality and outcomes.’
- ‘Disseminate models of best practice on quality and innovative approaches to break provision based on the evidence garnered in the pilots.’

Expert partners in care. ‘Work to establish the legislative or other requirements needed to enable carers to receive appropriate information, especially in cases where mental capacity is an issue.’

Building research and evidence to improve outcomes for carers

Information about carers.

- ‘Provide vital data about carers to aid commissioners and policy-makers at a local and national level in providing better support for carers.’
- ‘Establishing a standard definition of carers across government.’
- ‘Review the national indicator set to ensure that carers’ experience of services is measured.’

Employment and financial wellbeing

Employment and skills. ‘Up to £38 million to enable carers to be better able to combine paid employment with their caring role and re-enter the job market after their caring role has ended through encouraging flexible working opportunities and increased training provision.’

Income. ‘Review the structure of the benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system.’

Young carers

- ‘Over £6 million to ensure young carers are protected from inappropriate caring and receive the broader support they need. Through:
 - strengthening support from universal and targeted services;
 - strengthening the quality and join-up of support around families so children are better protected from inappropriate caring.’
- ‘Ensure protections for young carers are fully embedded: further measures to be considered in the light of research findings over the next two years.’

Appendix C: The policy context (commitments and initiatives)

Since the 2008 Carers Strategy, alongside the key legislative changes aimed at better supporting unpaid carers, there have been various other initiatives and commitments to improve support. Some of these are outlined in Table C1.

Table C1: Overview of initiatives and commitments for better supporting carers

Initiative or commitment	Details
<i>The NHS Five Year Forward View</i> , published in 2014 ³⁰	<p>This set out commitments to:</p> <ul style="list-style-type: none"> • find new ways to support unpaid carers • build on the new rights established in the Care Act 2014 by improving both the identification of carers and the support offered • support the most vulnerable carers • better work with voluntary organisations and local communities • introduce more flexible working to NHS staff with caring responsibilities.
The Commitment to Carers programme, launched in 2014 ⁶²	<p>Launched by NHS England, this programme outlined eight priority areas:</p> <ul style="list-style-type: none"> • raising the profile of carers • education, training and information • service development • person-centred, coordinated care • primary care • commissioning support • partnership links • NHS England as an employer.
<i>Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers</i> , published in 2014 ⁶³	<p>NHS England published this document to help clinical commissioning groups better identify carers and help them to stay well.</p>
The Young Carers Health Champion programme, launched in 2015	<p>Launched by NHS England, this programme aimed to improve health literacy, promote health and wellbeing and develop young carers' capacity to participate in the development of carer-friendly services.</p>

Initiative or commitment	Details
<p><i>An Integrated Approach to Identifying and Assessing Carer Health and Wellbeing</i>, published in 2016⁶⁴</p>	<p>NHS England published this document to help promote collaborative working between adult social care services, NHS commissioners and providers, and voluntary services to develop an integrated approach to the identification, assessment and support of carers.</p>
<p><i>Next Steps on the NHS Five Year Forward View</i>, published in 2017⁶⁵</p>	<p>Built on the initial priorities of the <i>NHS Five Year Forward View</i>, this document committed to further action to identify and support carers, including:</p> <ul style="list-style-type: none"> • the development of quality markers for carer-friendly GP practices to help with carer identification, health checks, flu jabs and signposting to advice and support • helping health organisations to support carers, including young carers • increasing the role of carers alongside patients in decision-making • improving communications and support for bereaved carers.
<p><i>The NHS Long Term Plan</i>, published in 2019³¹</p>	<p>This outlined a commitment to continue to improve how carers are identified and supported to address their own health needs. Actions included:</p> <ul style="list-style-type: none"> • the use of carer-friendly GP practice quality markers • encouraging the national adoption of Carer Passports • improved recording of carer status in health records • promoting crisis out-of-hours support for carers, and approaches to contingency planning with carers • top tips for general practice to support young carers, including promoting access to preventative health and social prescribing services • timely referral to local support services.
<p><i>Supporting Carers in General Practice: A framework of quality markers</i>, published in 2019⁶⁶</p>	<p>NHS England and NHS Improvement published this document to improve how general practice identifies and supports carers, through:</p> <ul style="list-style-type: none"> • improving carers' health and promoting positive wellbeing • reducing carer crisis and family breakdown • reducing unwarranted variations in carer support • meeting needs more appropriately.
<p>Guideline for supporting unpaid adult carers, published in 2020⁶⁷</p>	<p>Published by the National Institute for Health and Clinical Excellence (NICE), this guideline set out responsibilities for local authorities and NHS organisations to identify, support and involve carers when assessing and planning services. The guidance aims to help health and social care practitioners to identify people who are caring, and provide the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for providing end-of-life care.</p>
<p><i>People at the Heart of Care: Adult social care reform White Paper</i>, published in 2021³²</p>	<p>Published in December 2021 (some three years later than originally planned), this White Paper set out a 10-year vision for adult social care. It outlined several policies for better supporting unpaid carers, including:</p> <ul style="list-style-type: none"> • empowering carers to find user-friendly information and advice, care and housing • enabling carers to know their rights • helping carers to understand the local service landscape • giving personalised information and advice. <p>The White Paper also set out £25 million in funding for carers.</p>

Initiative or commitment	Details
Health and Care Act 2022 ⁶⁸	<p>The Health and Care Act 2022 outlines several duties relevant to unpaid carers, including:</p> <ul style="list-style-type: none">• a duty of integrated care boards to promote the involvement of carers in decisions relating to prevention, diagnosis, treatment or care in relation to patients• a duty of integrated care boards to promote the involvement of carers in commissioning arrangements, the manner in which services are delivered and the range of health services available• a duty to involve carers in decisions and planning when discharging patients from hospital with care and support needs.

Appendix D: Detailed policy analysis – what does the evidence tell us?

In the following sections, we discuss the evidence relating to the implementation of the policy goals across each of the five key themes in more detail, to assess how it stacks up.

Policy goal 1: Services and systems that work for carers ▲

There has been some progress in improving services and systems for carers, for example:

- NHS England’s development of GP practice quality markers
- NHS England providing a framework to better identify and support carers
- Health Education England’s development of carer learning resources
- the publication of best practice guidance on commissioning short breaks for carers.⁶⁷

However, the evidence indicates that many services and systems are still not working for carers. Services for carers are often not appropriate to their needs, often not providing flexible or personalised support. Carers’ assessments are the route by which carers can access services, but many perceive these as a ‘tick box’ exercise that their local authority undergoes, during which their individual needs are not considered properly, particularly if they work alongside their caring role.⁴⁷ Many carers do not understand the services available to them, what they are entitled to and how to access support. A

2018 report by the Work Foundation⁵ found that support for unpaid carers – including financial support, employment support, respite care, education and training, and emotional and social support – was generally considered to be inadequate. Many carers reported difficulty in understanding how to access and use services.

Collaborative working across services ▲

Some progress has been made towards more collaborative working across services and greater involvement of the voluntary sector.

Some progress has been made through implementation of the *NHS Five Year Forward View*,³⁰ which set out objectives to better work with voluntary organisations and local communities to support carers and to provide links between services through integrated care systems. A 2020 report by Fernandez and others⁵⁸ found more collaborative working between local authorities and the voluntary sector. They found that the Care Act 2014 had facilitated collaboration between services – many local authorities responded to the expected increase in service demand by strengthening partnerships with local voluntary sector organisations, leading to a much greater involvement of the local voluntary sector in the delivery of carer support and even carrying out carers’ assessments in some areas. The report also highlighted instances of successful collaborative working between the NHS and local authorities, but to a lesser extent.

Insufficient support from health services ▲

Despite duties that the Care Act imposed, the objectives that the *NHS Five Year Forward View*³⁰ (and ‘next steps’⁶⁵) and the 2019 *NHS Long Term Plan*³¹ set to find new ways to support unpaid carers, as well as several carer-focused initiatives, such as the development of quality markers for carer-friendly GP practices, there is still some way to go for health services in better supporting carers.

Health services are still not doing enough to support carers – services are not adequately proactive in identifying and supporting carers to meet their needs. The 2019 General Practice Patient Survey found around eight in 10 carers (81%) had a very or fairly good experience at their GP practice.⁶⁹ Only 8% of carers reported a poor experience. However, evidence suggests that health

services are still not doing enough for carers. Work by Peters and others⁵² found that primary care services have made little progress in identifying and supporting carers, with many not being proactive enough and that more could be done to address carer needs in collaboration with other health and care services to limit the demands on primary care.

A 2021 Carers UK survey⁷⁰ found that two-thirds of carers (66%) reported wanting more support to look after their own health and 52% wanted better recognition from the NHS. Survey research⁷¹ during the Covid-19 pandemic found that many carers were unable to access health services, 90% had their treatments postponed or cancelled, 80% did not get a hospital inpatient service they needed and half could not get an outpatient service.

Many carers are still not registering as a carer with their GP practice and those who do report that it makes little difference to the care they receive.

The Care Act 2014 set out an expectation that registered carers would experience several benefits from their GP practice such as appointments at convenient times, a designated carers' champion, signposting to information and advice, and free annual health checks.⁷² However, a 2019 Healthwatch report⁷³ on unpaid carer experiences of GP services in Cheshire found that only two out of three had registered as a carer at their GP practice, with a quarter not aware that they could register as a carer and many unaware of the benefits on offer to them. Of those carers who registered, most felt that it had not benefited them and many believed there was a lack of staff awareness of carers' rights. A Healthwatch survey published in 2021⁷⁴ found only 65% of carers to be registered as a carer with their GP, and only 54% of carers reported that their GP had been helpful. Similarly, a 2021 Carers UK survey⁷⁰ found that only 75% of carers reported that their GP knew they were a carer. The 2021 General Practice Patient Survey⁶⁹ found carers to report lower levels of overall satisfaction with their GP service compared with the non-caring population; 9% rated their experience to be poor or very poor compared with 6% of non-carers.

Carers are more likely to report unmet health needs.

Carers are more likely than non-carers to report that their health needs are not being met and are less likely to be satisfied with the GP appointment times that are offered to them.¹⁰ Cartagena Farias and Brimblecombe's work⁷⁵ examining the health trajectories of unpaid carers in the UK found that the deterioration in physical health over time was greater for carers compared with non-carers.

Carers UK⁷⁶ found that of those caring for 50 or more hours a week, most reported that their GP knew about their responsibilities but did not do anything differently, few had a GP who gave regular carer health checks or provided home or telephone appointments and for more than half of carers, their GP had not told them about how to access support. Of those carers who did not receive health checks from their GP or signposting to other services, more than half let a health problem go untreated. This corresponds with the findings of the 2019 General Practice Patient Survey,⁶⁹ in which some carers reported that the services that their GP practice offered were difficult to access. Six per cent of carers declined the appointment offered to them, with the most common reason being that there were no appointments on the preferred day or at the preferred time. Of the carers declining an appointment, around one in four (26%) did not see or speak to anyone subsequently to arrange another appointment.

The Covid-19 pandemic has widened health outcome and service use gaps – unpaid carers reported more impact on their health compared with non-carers (16% versus 13%) and more unpaid carers reported that access to health care for non-Covid-19 issues was impacted (30% versus 20%). A 2021 Carers UK report⁷⁰ found that 69% of carers reported that their mental health and 64% reported their physical health had worsened during the pandemic – with 25% of carers reporting their physical health to be bad or very bad and 30% reporting their mental health as bad or very bad.

Accessing information and advice ▲

The number of unpaid carers accessing information and advice has increased over recent years.

Nuffield Trust analysis of SALT data³⁹ indicates that the number of carers accessing information, advice and other universal services/signposting

increased by more than 36,000 between 2015/16 and 2020/21. Despite this, the proportion of carers who reported finding it easy to find information about support reduced – from 66% in 2014/15 to 58% in 2021/22 – indicating that carers have found it increasingly difficult to access information and advice.

There is regional variation in the extent and accessibility of information. Navigating the system is often not easy. Work reviewing local authority websites found that almost all were compliant with the Care Act 2014.⁵⁸ However, there was substantial variation in the organisation and content of information relating to carer support and some local authorities failed to provide enough essential information for carers to receive appropriate support. In qualitative work, carers reported that information about the support available was scattered.⁷⁷

Substantial waiting times for carers to access support services ▲

Waiting times for carers to access the support they need remain substantial – many wait weeks or even months.

Many carers have to wait a long time for assessments and services, even if they have an urgent need.⁴⁹ Carers have to wait an average of 28 days for an assessment and 29 days for support after an assessment (so 57 days from requesting support to getting the support they need).

Policy goal 2: Recognising and supporting carers ▲

There has been some progress since the publication of the *NHS Five Year Forward View*³⁰ in better identifying and supporting carers. Integrated care systems have helped to identify carers and provide access to support services (for example, breaks). And through implementation of NHS England's Commitment to Carers programme, some NHS trusts have developed Carer Passports to facilitate recognition and support, while NHS England quality markers for primary care have helped to establish best practice in identifying and supporting carers. Despite this, evidence indicates that implementation of the Care Act 2014 and the Children and Families Act 2014 across England has been inconsistent. A 2022 Carers Trust report⁷⁸ found that 86% of unpaid

carers agreed that ‘successive governments have ignored the needs of unpaid carers for a long time’.

Many carers are still not being assessed ▲

A 2020 Carers Trust report⁷⁹ found that around six in 10 carers (59%) reported not having had a carer’s assessment since the Care Act 2014 and nine in 10 (90%) had not had an assessment after their circumstances changed. Similarly, a 2021 Carers UK report⁷⁰ found that only 24% of carers in England reported having had an assessment or review in the previous 12 months, representing a decrease from 27% in 2019 and 31% in 2016.⁴⁷ Of those carers who reported receiving an assessment, 19% waited longer than six months and the majority reported that their needs were not given sufficient consideration; for example, only 24% felt that their need to have regular breaks from caring was thoroughly considered.

The Covid-19 pandemic saw a 13% reduction in the number of requests to local authorities for carers’ assessments; however, there was considerable variation across regions – some local authorities reported a trebling of assessments, whereas others reported a substantial decline.¹¹ It is thought that the decline in assessments in some regions may in part be due to reduced contact with referral routes (for example, GPs and social workers). A Healthwatch survey published in 2021⁷⁴ found that 45% of carers were not able to get a carer’s assessment during the pandemic. And a 2022 Carers Trust survey⁷⁸ found that only 25% of carers had received an assessment or re-assessment in the previous year, with the main reasons for not getting one being that it was not offered or they did not know they could get one.

However, Nuffield Trust analysis of SALT data (see page 15) shows that the total number of carers being assessed for support each year by local councils in England increased from 386,605 in 2015/16 to 388,730 in 2020/21 – representing an increase of less than 1% over six years. Evidence in this report shows clearly that carers’ assessments are not keeping pace with the increase in the number of carers in England.

Declining access to support services ▲

Declining numbers of carers are accessing support services.

Nuffield Trust analysis of SALT data (see page 15, Figure 3) shows a drop in the number of carers who are receiving ‘direct support’ as a result of a carer’s assessment. It reveals that there were 13,000 fewer carers getting this support in 2020/21 than there were in 2015/16.

Likewise, a Carers UK survey⁴⁷ found a general decline in support from social services. Carers were asked about changes to care and support services over the preceding year. Around three in 10 (32%) reported a change in the amount of services received and, of those, around one in four (26%) reported a reduction in the amount of support that social services arranged and one in 10 (10%) reported support service closure with no replacement. Overall, one in eight carers (12%) reported that they or those they support received less care or support during the previous year due to a reduction in the amount of support from social services.

Qualitative work¹³ reinforces these trends – carers report the social care system to be complicated, often being unable to access support. Qualitative work by Future Care Capital⁷⁷ found that just less than half of carers had not received any support at all, due to a lack of knowledge about where to go for support and eligibility requirements, and approximately three in four (74%) felt that some additional support would be useful. The 2019 Health Survey for England⁶⁰ reported that 55% of adult unpaid carers were providing care without receiving any support. A 2018 Healthwatch report⁴⁹ found that carers are not always accessing the support they need. Similarly, a Carers Trust survey published in 2022⁷⁸ found that only 7% of unpaid carers reported receiving enough support, 15% reported having received a personal budget and for 55% of carers this did not meet their needs, and 22% of carers reported having been told that they would not be able to get the support they were entitled to.

Evidence suggests that the Covid-19 pandemic has led to a further decline in support services: between February 2020 and March 2021, community support schemes saw a 47% reduction in capacity, day centres also a 47% decrease and other day services a 5% drop.¹¹ However, requests for carer support decreased by 7% in 2020/21 compared with 2019/20, whereas carers

seeking support due to breakdown, sickness or unavailability increased.¹¹ In a 2021 Carers UK survey,⁷⁰ many carers reported that services had not returned to pre-pandemic levels: 35% reported reduced access to day services (20% of services had closed), 24% reported reduced access to respite (15% of services had closed), 28% reported that services were not meeting their needs and 61% felt uncertain about what practical support they might be able to access in the next 12 months.

Low carer satisfaction with support services ▲

Not many carers are satisfied with support services.

Nuffield Trust analysis of SACE data (see page 18, Figure 5) shows that carer satisfaction with the support they receive remains low. In 2021/22, 36% of carers reported being extremely or very satisfied with the services and support they received compared with 41% in 2014/15.

Declining funding for carer support services ▲

Funding for carer support services has been declining over time.

Evidence shows that local authorities' real-term gross expenditure on carer support services has decreased since 2015/16. Nuffield Trust analysis of ASC-FR data (see page 21) shows that gross expenditure on carer services was 11% lower in 2020/21 than in 2015/16. It also shows that for three of the six years from 2015/16 to 2020/21 (2016/17, 2017/18 and 2020/21), local authorities' gross expenditure on carers decreased by more than 5% in comparison with the level of expenditure the previous year (see page 22, Figure 9). The Covid-19 pandemic has magnified levels of unmet need confronting local authorities.⁴⁰ In 2020/21, only 4% of directors of adult social care services were fully confident that their budget would be sufficient to meet their statutory duties for the year ahead.

Declining access to breaks/respite care ▲

The number of carers able to access breaks has declined in recent years.

According to Nuffield Trust analysis of SALT data (page 20, Figure 7) there were 24,000 fewer carers receiving 'support involving the cared-for person' in 2020/21 compared with six years before that – a decline of 42% between 2015/16 and 2020/21.

Carers UK⁸⁰ carried out analysis and found that fewer than one in 10 carers (8%) reported that they had been able to take sufficient breaks. Around four in 10 (39%) had taken a break but would have liked to have taken more. And just under half (46%) had not been able to take any breaks even though they would have liked to.

The Covid-19 pandemic has led to a further decrease in access to breaks and respite care: between February 2020 and April 2021, day services and community support schemes both decreased by 47%, as noted earlier, and home-based respite services decreased by 15%.¹¹ A Healthwatch survey⁷⁴ during the pandemic found that 90% of carers reported not being able to access day or respite services and 59% were not able to take a break from their caring responsibilities.

Policy goal 3: Building research and evidence to improve outcomes for carers ▲

Recent progress in building research capacity and data to improve outcomes for unpaid carers includes the addition of questions about providing care to the Health Survey for England and the establishment of the Carer Research and Knowledge Exchange Network.

While there are several datasets at national and local levels providing data on unpaid carers (see Appendix E), there are some notable gaps and limitations with the available data. For example, there are known data quality issues for much of the data at the local level due to inconsistent and incomplete reporting across local councils and voluntary organisations. There is also a reliance on data collected from samples that are not necessarily representative of the caring population, as well as variation in defining unpaid carers across sources, making linking across datasets challenging.

Where are the data gaps?

Carer health outcomes and health service use

There is a lack of opportunity for data linkage across health and social care services. It is not possible to link local authority data or carer-specific datasets

to routine health data or data on health service use (for example, primary care or hospital records). This makes it difficult to evaluate the need for and use of health services or health care experiences.

The health trajectories of young carers

Despite the unique challenges facing young carers, data (at a national level) relating specifically to this cohort are minimal – particularly objective measures of health.

Support service provision at a local level (for example, local authority data)

Data offer limited insights into regional activity, which is crucial given the variation in practices and service provision across localities. The support that voluntary sector services provide to unpaid carers at a local level is often not captured in the data and few local authorities hold data on waiting times for accessing assessments and support services. A 2018 Healthwatch report⁴⁹ found that only one in four local authorities was able to provide these data.

The need or demand for services

Estimates of the number of people with caring responsibilities in England vary substantially – ranging from 6.5 million to 13.6 million.^{12,76} Even today, the 2011 Census figure for the number of unpaid carers is still referenced in many reports (approximately 5.8 million unpaid carers in England and Wales), despite other sources indicating that the number of carers may be substantially higher. The same challenge exists at a local level – just under half of local authorities (48%) do not know how many carers are in their area, which makes it difficult to understand the demand for services or interpret trends.⁴⁹

Policy goal 4: Employment and wellbeing ▲

Since the 2008 Carers Strategy, several key initiatives have aimed to support carers so that they can better balance caring responsibilities and employment, including:

- the Carer Passport scheme
- the Carer Confident benchmarking scheme
- the Working for Carers project⁸¹

- the Timewise Foundation's Flexible Jobs Hub
- a number of employer-led initiatives.

The Department for Work and Pensions has published two reports: *Fuller Working Lives*,⁸² which announced a cross-government strategy to support carers to remain in and re-enter employment; and *Informal Carers and Employment*, a systematic review of the strategies to keep carers in employment.⁸³ The Government Equalities Office has published best practice guidance⁸⁴ and a toolkit for employers to provide opportunities for those who have been out of work due to caring responsibilities. However, evidence indicates that many carers are still struggling to balance employment and their caring role.

Insufficient support to balance caring responsibilities and employment ▲

Working carers are still struggling to balance caring responsibilities and employment. Many are left with no option but to reduce their working hours or give up work altogether.

It has been estimated that there are 3.7 million working carers in England and Wales, with about 2.6 million (72%) working full time and 32% providing 30 or more hours of care a week.⁵⁰ A survey of working carers in England and Wales⁵⁰ found that more than four in 10 (44%) were struggling to combine paid employment with caring responsibilities, and that carers employed in the voluntary or third sector were more likely to find it difficult to combine work and care than those in the private sector. In the 12 months before the survey, 46% reported having used their annual leave to provide care, 24% reported having worked in the evening to make up for hours spent caring, 23% had worked weekends and 15% had taken sick leave to care.

Analysis that the Work Foundation⁵ undertook found that providing care has a substantial impact on employment outcomes. A Carers UK survey⁴⁷ found that around one in five carers (18%) had reduced the number of working hours to care and around two in five (38%) had given up work altogether. The same report also found that about one in 10 carers (12%) reported taking a less qualified role or not taking a promotion due to their caring responsibilities and more than half reported the adverse impact of caring on their work to be one of the biggest challenges they faced.

Work by the Office for National Statistics found no substantial difference between the number of unpaid carers (61%) and the number of non-carers (64%) who reported being in work (that is, with a paid job either as an employee or self-employed, casual work or unpaid voluntary work in the previous week). However, as care hours increased, unpaid carers were less likely to work. For example, for those providing 50 or more hours of care a week, more than two-thirds (68%) were not working, and this dropped to 37% for those providing 20–34 hours a week. If in employment, unpaid carers were more likely than non-carers to work part time (31% versus 25%).

Fernandez and others, in their qualitative work,⁵⁸ found that many carers were having to leave employment due to a lack of flexible working options, their health getting worse or increasing caring responsibilities. Similar work by Future Care Capital⁷⁷ found that more than two in five carers (42%) reported that their caring responsibilities impacted their work life, with around one in five (18%) having to give up work altogether and one in 10 reducing their working hours or performance. A survey of working carers⁵⁰ found that half reported that caring affected their job, with most experiencing difficulty concentrating, more a third (36%) had refused a job offer or promotion due to caring, three in 10 (30%) had reduced their hours of work due to caring, 29% were considering reducing their working hours and 24% were thinking about giving up their job. Similarly, a Carers Trust survey published in 2022⁷⁸ found that almost half of carers (48%) had to give up work or study and 15% had to reduce their hours of work.

Support services are not tailored to the needs of working carers.

Carers UK found that half of carers reported challenges accessing support services – such as inflexibility, unreliability or services unable to meet their needs – as reasons for giving up work or reducing their hours of work.⁷⁶ Analysis by Carers UK⁴⁷ found that many support services were failing to give sufficient consideration to carers’ employment – only one in four carers (25%) reported that their need to combine employment and caring was adequately considered in their carer’s assessment. Work by the Department for Work and Pensions⁸³ reported that a lack of flexibility and an inability to find appropriate formal care services can act as triggers for leaving employment. A survey of employers⁸⁵ found that two-thirds wanted more practical assistance and flexible services available outside normal working hours to ensure carers are supported to stay in work. In a 2021 Carers UK survey,⁷⁰ 20% of working

carers reported that if they did not receive affordable and accessible care to support them, they would need to reduce their working hours or give up work altogether, and 21% reported that if care services that were closed or cut back during the pandemic did not return, they would need to reduce their working hours or give up work entirely.

Employers aren't doing enough to support carers.

There have been several key initiatives aimed at better supporting carers to remain in employment. Legislation has also been introduced: in the UK, employers are legally obliged to give unpaid carers time off during an emergency, carers have the right to request flexible working⁵⁹ and a Bill to provide carers with the right to five days (unpaid) leave a year is currently before the House of Commons. Despite this, much of the support provided still remains at the discretion of employers, and many carers lack awareness of these rights and show a reluctance to request support.⁸⁶

Workplace support that employers offer is not sufficient and there is significant variation across employers. In a survey of working carers,⁵⁰ most reported that their employer was only aware of their caring role in an 'unofficial capacity', only around one in 10 (9%) was entitled to paid care leave, only one in four (25%) was entitled to flexitime and four in 10 carers (40%) reported their employer to be carer-friendly. The survey also found fewer than four in 10 carers (39%) felt supported by their employer when caring impacted their work, almost half of carers (46%) had used their annual leave to provide care, fewer than one in four (24%) had worked evenings to make up hours spent caring and 15% had taken sick leave to provide care.

A survey of employers⁸⁵ found only around six in 10 (61%) provided unpaid special leave arrangements, half of employers (51%) provided paid leave and around one in four (27%) provided carers' leave separate from special leave.

Financial support is inadequate ▲

Financial support for carers remains inadequate – many are struggling to cope. In a Carers UK report, more than half of carers (53%) reported the financial impact of care as one of the biggest challenges they face.¹² This corresponds with the 53% of carers reporting financial difficulties as a result of caring in the Survey of Adult Carers in England.⁸⁷ Just over three in 10 unpaid carers

(31%) reported that they were struggling to make ends meet when describing their financial situation. Similarly, a Future Care Capital report⁷⁷ found that more than two in five carers (44%) reported that caring had an impact on their financial situation. Financial difficulties are associated with reduced work/income and increased caring-related spending.⁸⁸

Carers UK⁷⁶ estimated that 70% of carers are more than £10,000 worse off due to reduced hours and earnings, and 1.2 million carers in the UK live in poverty. In addition, in 2021, Carers UK⁷⁰ found that 18% of carers reported being in debt, 6% were unable to afford utility bills and of those carers struggling to make ends meet:

- 63% were spending their own money on care or support services or products for the person they cared for
- 52% felt anxious or stressed when thinking about their financial situation
- 21% did not feel confident they would be able to manage financially over the next year
- 13% reported having cut back on food/heating
- 12% had borrowed money from friends and family.

The financial impact of caring extends to younger carers – a National Institute for Health Research report⁸⁹ found that young carers were twice as likely to have left employment and were £160 a month worse off than their non-carer peers.

The new rate of Carer’s Allowance from April 2022 means that, since 2010, it will have increased from £53.90 to £69.70 a week. Carer’s Allowance is the main financial support for carers; however, it remains one of the lowest welfare benefits, is not aligned with the national living wage and is widely considered ineffective in preventing financial hardship.⁸⁸ There have been calls from carer organisations for the level of financial support for carers to be increased, particularly that Carer’s Allowance should be raised in line with the national living wage.⁴⁷ Not only is the level of financial support falling short for many carers, but many are not eligible to receive any monetary support. The threshold for Carer’s Allowance means that only those carers providing the most intense levels of support are eligible. Carers are not eligible for the allowance if they are providing fewer than 35 hours of care a week or if they earn more than £132 a week (after tax and National Insurance).

Making comparisons across the nations of the UK further highlights the lack of progress that England has been made in relation to financial support. It lags behind Scotland in the support it offers – unpaid carers living in Scotland are provided with an extra allowance supplement of £230.10, paid twice a year – and in Wales, unpaid carers have access to a £300 support grant to help them with the cost of living crisis and the Welsh Government has committed a further £500 each for unpaid carers in recognition of the pivotal role they have played during the pandemic.⁵⁷

Carers have continued to struggle throughout the Covid-19 pandemic. Survey analysis⁹⁰ found that carers had lower financial wellbeing than non-carers; 22% of carers experienced some degree of financial strain, 2% reported that their household had used a foodbank in the previous month and carers were more likely to report that their household experienced hunger (4%).

The cost-of-living crisis has further added to the challenging financial situation that many carers face. A 2022 Carers UK survey⁹¹ found that:

- 67% say they are currently unable to meet their monthly expenses
- 64% are cutting back on heating
- 58% are worried that they will have to use food banks
- 35% are spending more on supplies (e.g. continence pads)
- 33% have already fallen behind with their utility bills
- 24% are using foodbanks
- 20% are spending more on equipment such as adaptations or medical devices.

Similarly, a Carers Trust survey published in 2022⁷⁸ found that of those receiving Carer's Allowance, 87% said it was not sufficient to meet their needs as an unpaid carer, 47% reported struggling to make ends meet, 45% had used the allowance to pay for things essential for caring, 31% had cut back on food and 22% were behind on bill payments.

Policy goal 5: Young carers ▲

Legislative changes aimed at improving the identification of and support for young carers includes the Children and Families Act 2014, which extended the right to a needs assessment to all young carers regardless of the type of care they provide or who they provide care for, and to have their needs met. The Care Act 2014 set out how assessments of adults must cover the needs of the whole family to ensure that both child and adult services are triggered as appropriate, and it placed a duty on local authorities to take ‘reasonable’ steps to identify young carers, including requesting information from schools and young carer services, and a duty of cooperation on education providers to work with local authorities.

Recent initiatives aimed at better supporting young carers have included the Young Carers in Schools programme, the Young Carers Health Champion programme, which NHS England established to support health literacy and promote wellbeing, and a scheme that NHS England launched to encourage GP practices to identify and support young people providing care. Meanwhile the Next Steps on the *NHS Five Year Forward View*⁵⁴ set out priorities relating to young carers such as helping health services to support carers.

Schools have got better at identifying young carers ▲

The identification of young carers in schools has improved and most are managing to balance their caring role with education.

A 2019 Carers Trust and National Centre for Social Research report⁴³ found that most young carer services (96%) were receiving referrals from schools, more than half (51%) had dedicated school workers and only 2% of young carer services were not doing any work with schools. The report acknowledged that good practice in the identification of young carers in schools in England has been growing due to national and local programmes.

Work by the Department for Education⁵⁵ found that most children and young people were managing to combine their caring role with their education, but they were more at risk of being absent and falling asleep in school than their non-carer peers. However, a 2022 Carers Trust report⁹² found that only 34% of young carers and 36% of young adult carers agreed that their school, college

or university understood about them being a young carer, 27% of young carers and 51% of young adult carers reported struggling to balance caring with school, college or university work, and 52% of young carers and young adult carers reported that they never or did not often receive help from their school, college or university to balance their school, college or university work. A UK survey of 15- to 17-year-olds with caring responsibilities found that 37% reported a negative impact of their caring on school performance.⁹³ Similarly, the Children’s Society⁹⁴ reported that 27% of young carers (aged 11–15) missed school due to caring and 39% reported that their school was unaware of their caring responsibilities.

Some services are still failing to identify of young carers ▲

Local authorities and the NHS often do not identify young carers and, despite some instances of effective linking across organisations, inconsistencies remain. The 2019 Carers Trust and National Centre for Social Research report⁴³ found that services often did not identify young carers or only identified them if they had been caring for a long time, and that there was a lack of awareness of who young carers are. While local authorities, particularly children’s services, have been making progress to better identify young carers – 24 out of the 26 local authorities (that responded) reported improvements since 2014 – adult social services are less effective in identifying young carers through engagement with families. Almost all young carer services (98%) received referrals from children’s social services; however, only six in 10 received them from adult services.

The same report found that in some areas there is effective linking across organisations such as social care, education and voluntary services, allowing young carers to be identified early on, but good practice is inconsistent across regions. In particular, information sharing between local authorities and the local voluntary sector was described as needing improvement, and less than half of the local authorities (nine out of 24 respondents) had a protocol in place linking adult and child services. Similarly, the Me-We Project⁹⁵ found that the implementation of the whole family approach was not working effectively due to the gaps between children and adult services.

For health services, linking between GP practices and voluntary sector services for young carers remains inconsistent,⁴³ there is a lack of data sharing

across organisations, such as GP practices and schools, and GP practice staff rarely identify young carers.⁹⁶ In addition, NHS duties in relation to the identification of young carers are vague, with many staff having limited awareness of their responsibilities.⁴³

Inadequate support service provision for young carers ▲

Young carers are still not receiving appropriate support or having their needs assessed.

A Me-We Project report highlighted that many young carers and their families are still not receiving the support they need.⁹⁵ This parallels Department for Education work,⁵⁵ which found that fewer than one in five parents of young carers (19%) reported that their local authority had assessed their child's needs. Nearly two-thirds (64%) were receiving no support, whether formal or informal.

A National Institute for Health Research report⁸⁹ found that young people who provide care (aged 16–25 years) had poorer physical and mental health when compared with those not providing care. Around half of the young people (52%) reported that more services were needed for the person they support and, for some young carers, service provision had not responded to changing needs or circumstances. Some young carers reported that accessing services could be lengthy, time-consuming and stressful, and that more could be done to involve young people in discussions about service provision and to consider their needs when planning care. Longitudinal analysis found that young carers were less likely to be in employment and with lower earnings than their peers.

In a Carers Trust survey published in 2022,⁹² young carers reported wanting access to breaks and respite, help from services that understand them and better support for the person they care for. The same survey found that 42% of young carers felt stressed and 36% were worried, and that the Covid-19 pandemic had increased pressure on young carers, with 53% reporting the number of hours of caring to have increased in the previous year. Meanwhile in a survey of 15- to 17-year-olds with caring responsibilities in the UK, 57% reported mental health problems and 30% reported physical health problems.⁹³

Appendix E: Sources of data on unpaid carers

Several of the datasets that provide data on unpaid carers are outlined in table E1 (below). The table outlines the data source, frequency of data collection/publication, and the level of data (whether at a national and/or regional level).

Table E1: Mapping of data sources for carers

Data	Source	Date	Level of data (national or local)
Survey of Carers in Households ¹	NHS Digital (commissioned by the Department of Health and Social Care)	Survey conducted in 2009–10 (single time point)	National survey (England)
UK Census ²	Office for National Statistics	Last published data 2011, awaiting 2021 data (every 10 years)	National survey (England and Wales)
General Practice Patient Survey ³	Ipsos MORI (commissioned by NHS England)	Yearly	National survey (UK)
Health Survey for England ⁴	NHS Digital	Yearly	National survey (England)
Adult Social Care Outcomes Framework (ASCOF) ⁵ Short and Long Term (SALT) services data Adult Social Care Activity and Finance Return (ASC-FR)	NHS Digital	Yearly	National and regional – local authority reported (England)
Adult Social Care Outcomes Framework (ASCOF) ⁵ Personal Social Services Survey of Adult Carers in England (SACE)	NHS Digital	Every other year	National and regional – local authority reported (England)

Data	Source	Date	Level of data (national or local)
Family Resources Survey ⁶	Department for Work and Pensions	Yearly	National survey (UK)
UK Household Longitudinal Study ⁷	Understanding Society (University of Essex and Institute for Social and Economic Research)	Yearly (longitudinal study – data collected in waves)	National survey (UK)
Our Future study (young carers) ⁸	Funded by the Department for Education	Yearly	National longitudinal survey (England)
Labour Force Survey ⁹	Office for National Statistics	Yearly	National interviews/survey (UK)
English Longitudinal Study of Ageing ¹⁰	Collaboration of University College London, the Institute for Fiscal Studies, the University of Manchester, NatCen and the University of East Anglia (funded by the National Institute on Aging and Government)	Every two years	National interviews/survey (England, aged 50 and over)
Next Steps (previously known as the Longitudinal Study of Young People in England; LSYPE) ¹¹	UCL Centre for Longitudinal Studies (funded by the Economic and Social Research Council [ESRC] and previously by the Department for Education)	In waves (varies)	National survey (England)

- 1 NHS Digital (2010) ‘Survey of carers in households – England, 2009–10’. <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/survey-of-carers-in-households-england-2009-10>.
- 2 Office for National Statistics, ‘Census 2021’. <https://census.gov.uk>.
- 3 NHS, ‘GP Patient Survey’. www.gp-patient.co.uk.
- 4 NHS Digital, ‘Health Survey for England’. <https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england>.
- 5 NHS Digital, ‘Measures from the Adult Social Care Outcomes Framework’. <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof>.
- 6 Department for Work and Pensions, ‘Family Resources Survey’. www.gov.uk/government/collections/family-resources-survey--2.
- 7 Understanding Society, ‘UK Household Longitudinal Study’. www.understandingsociety.ac.uk/about.
- 8 Department for Education, ‘Our Future’. www.ourfuturestudy.co.uk.
- 9 Office for National Statistics, ‘Labour Force Survey’. www.ons.gov.uk/surveys/informationforhouseholdsandindividuals/householdandindividualsurveys/labourforcesurvey.
- 10 ELSA, ‘English Longitudinal Study of Ageing’. www.elsa-project.ac.uk.
- 11 Centre for Longitudinal Studies, ‘Next Steps’. <https://cls.ucl.ac.uk/cls-studies/next-steps>.

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