

# Caring in a complex world

Perspectives from unpaid carers  
and the organisations that  
support them

Deborah Fenney  
Clair Thorstensen-Woll  
Simon Bottery

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# About this report

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# Key messages

- Unpaid carers contribute the equivalent of 4 million paid care workers to the social care system. Without them, the system would collapse.
- Carers are not always able to access the support they need. There can be a disconnect between what professionals in the statutory sector are aiming to deliver, and unpaid carers' experiences of support and services.
- Access to good health and social care for the person they are caring for is a vital issue affecting quality of life for many carers.
- Carers play a vital role in co-ordinating the care that is received. To reduce the burden on them, it is important for health and social care systems to be as integrated as possible.
- The impact of wider health and care issues on carers cannot be ignored. The impacts of ongoing funding issues and the health and social care workforce crises on carers and local support services were highlighted multiple times in our research. Workforce shortages in particular are directly impacting on carers' health and wellbeing because they are the ones left to fill in the gaps.
- Despite much research on interventions to support unpaid carers, existing meta, systematic and scoping reviews of the literature suggest that much of the evidence lacks robustness, there is limited cost-effectiveness data, and there is a clear need for more research.
- To better support unpaid carers locally, commissioners and services need to develop and maintain a good understanding of their populations. This can be facilitated by supporting local professionals to identify carers and signpost them to available services, meaningfully measuring the impact of support, and engaging with local carers. Local support offers should be built on this understanding.



- Commissioners and providers of services for unpaid carers need to actively raise awareness of their local support offers among unpaid carers, while at the same time ensuring that support is appropriate and accessible, as well as inclusive of diverse populations. Carers are a hugely diverse group – both in terms of who they are and who they care for – but policy and services do not always reflect this diversity.
- Awareness of carers and their needs should be embedded in strategic-level and commissioning decisions. Professionals who ‘get it’ and advocate consistently are vital. But the work cannot just rely on a few committed individuals; system-level carers’ partnerships and strategies have a key role in advocating for and embedding the carers’ agenda.
- Integrated care systems (ICSs) are key emerging forces in supporting unpaid carers. Carer support directly involves health as well as social care, so there are opportunities to align approaches to supporting unpaid carers at ICS as well as place level. This will need leaders who understand the value of carers to the working of the wider system.



# 1 Introduction

People who support a family member or someone close to them do not always identify as carers. But unpaid carers – that is, anyone who provides care, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support – play a key role in the health and care system. Unpaid carers contribute the equivalent of 4 million paid care workers (7.9 billion hours) to the social care system; without them, ‘the system would collapse’ ([Bottery and Mallorie 2023](#)). Caring can be a big commitment and carers themselves also need support with their own health and wellbeing. Yet, as the findings from this project and other research (eg, [Fernandez et al 2021](#)) show, carers are not always able to access the support they need.

This report sets out findings from work by The King’s Fund, commissioned by the Department of Health and Social Care, to understand the current picture of local support available for unpaid carers in England. We were asked to look at what evidence is available for different types of interventions, what kinds of support are prioritised by the carers and professionals involved in commissioning and delivering services for carers, and what factors act as barriers to or facilitators of access to different types of support.

We took a two-phase approach to this work. In phase one, we reviewed existing literature, research and national datasets, and talked to key stakeholders – including organisations that support and work with unpaid carers. We gathered insights into what is happening in local authorities in relation to the types of services provided for carers, any different models or variations in these types of services, and examples of good practice.

Based on the insights from phase one, we chose four local authority areas that were identified as having approaches that others could learn from in their support for unpaid carers (phase two). In each area, we spoke to local authority and voluntary sector professionals involved in commissioning and delivering this support. We wanted to explore the reasons for local service patterns and commissioners’ and service providers’ priorities, and identify evidence of impact and any transferable learning. We also worked with local carers’ organisations to convene focus groups



to hear from people who have lived experience of providing informal care to family or friends. We asked about the support available for carers in their area, what is important to them, and what the barriers or facilitators are to getting support. (For a detailed account of the methodology, see Appendix: Methodology.)

In this report, we combine the insights from these two phases of work to present some key facts and figures around who is doing unpaid care, the policy context of support for unpaid carers, a taxonomy of types of support, and examples (including what we heard about from the local authority sites). We then present four key insights, based on our findings, about what is important to carers and those commissioning and providing support, and the barriers to or facilitators of unpaid carers getting support.

Throughout this project, we have tried to ensure that carers' voices are central. Our research team included people with direct or indirect experience of caring, and we convened an external group of people with lived experience of caring to advise the project at key stages. We also spoke to unpaid carers living in each of the four local authority sites. Several of the stakeholders and professionals working at those sites also shared their own experiences of caring. Given how diverse unpaid carers are, it is important to acknowledge all of these different perspectives that have fed into the project.





## 2 Facts and figures

Unpaid carers are critical to the health and social care fabric of our society. The government's recent social care White Paper, *People at the heart of care* ([Department of Health and Social Care 2021](#)), recognises that 'We rely on the crucial contribution of those who provide care to a family member, friend or neighbour, either in part or totality' and goes on to say that 'We will continue to celebrate and support the amazing work they do'.

However, who exactly are we celebrating and what sort of support is currently provided to unpaid carers? In this section, we set out some basic definitions of unpaid carers, set out who provides unpaid care and how many people fall into this population, how much time they spend on caring, and the kinds of support for which they are currently eligible.

### Who is providing unpaid care?

#### Definitions of 'carer'

There is no standard definition of an unpaid carer. In this report, we draw on two main sources of data on carers, both with different definitions.

The 2021 Census\* asked whether people over the age of 5 'look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age'.

The Health Survey for England 2019 asked adults aged 16 and over whether they had 'personally provided help or support to anyone in the last month because they had long-term physical or mental ill-health problems, a disability or problems relating to old age'.

\* The Census was undertaken during the Covid-19 pandemic, which the Office for National Statistics (ONS) notes 'may have influenced how people perceived and undertook their provision of unpaid care and therefore may have affected how people chose to respond'.



Differences in how ‘carer’ is defined (see box on page 7) may affect the number of people who identify as carers.

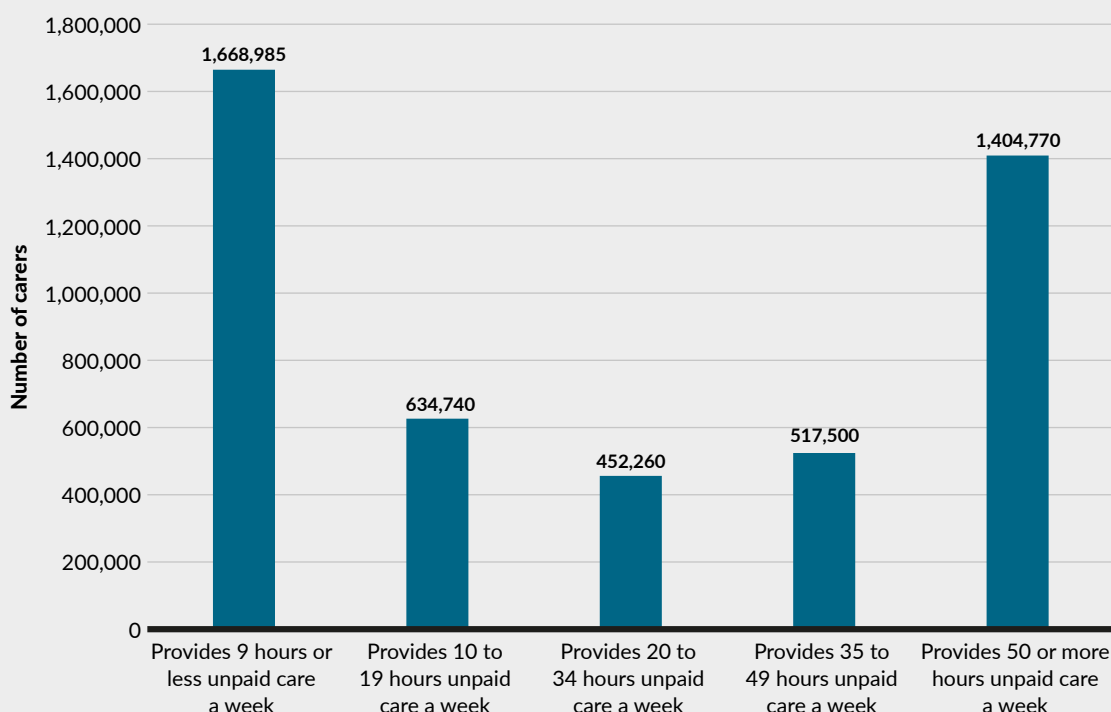
- The 2021 Census found that an estimated 4.7 million people over the age of 5 years in England provided unpaid care in 2021, equivalent to 8.9 per cent of the population (ONS 2021).\*
- The Health Survey for England 2019 found that 17 per cent of adults reported providing unpaid help or support to at least one person (NHS Digital 2020).

These estimates are also affected by the defined carer age group: the Census includes all those over 5 years old while the Health Survey for England includes only those aged over 16.

**Figure 1 Unpaid carers in England**



The 2021 Census found that of 4.7 million carers, around 1.7 million provide less than 9 hours of care a week, but around 1.4 million provide 50 or more hours a week.



Source: ONS 2021

\* We use the commonly reported age-standardised percentage for simplicity. The non-age standardised percentage is 8.8.



Carers are a hugely diverse group (see box on page 10), but gender, age, ethnicity, geography and deprivation all have an impact on likelihood of caring.

### **Gender**

The 2021 Census found that 10.3 per cent of females in England provided unpaid care compared with 7.6 per cent of males. Similarly, the Health Survey for England 2019 found that women (20 per cent) were more likely to have provided unpaid care than men (14 per cent).

### **Age**

The Health Survey for England also found that the proportions of men and women providing care increased with age and were highest among men aged 65–74 (19 per cent) and women aged 55–64 (34 per cent), and lower among older age groups.

### **Ethnicity**

Analysis by the London School of Economics and Political Science ([Brimblecombe and Burchardt 2021](#)) shows that carers from minority ethnic backgrounds typically provide more hours of care than white carers.

### **Geography**

The 2021 Census found that the north-east of England had the largest proportion of people who provided any amount of unpaid care in 2021 (10.1 per cent) and was also the region with the largest proportion of people providing 50 or more hours of unpaid care a week (3.4 per cent). The region with the smallest proportion of people who provided any amount of unpaid care was London (7.8 per cent).

### **Deprivation**

The Census found that a higher percentage of people provide unpaid care in the most deprived areas of England (10.1 per cent) than in the least deprived areas (8.1 per cent). This contrasts with the 2011 Census, which found a lower percentage of unpaid care in the most deprived areas.



### Carers are a very diverse group

The figures can sometimes obscure the real people they describe. Therefore, we have included descriptions of some of the carers we spoke to in our research, to indicate the diversity of carers. A carer might be:

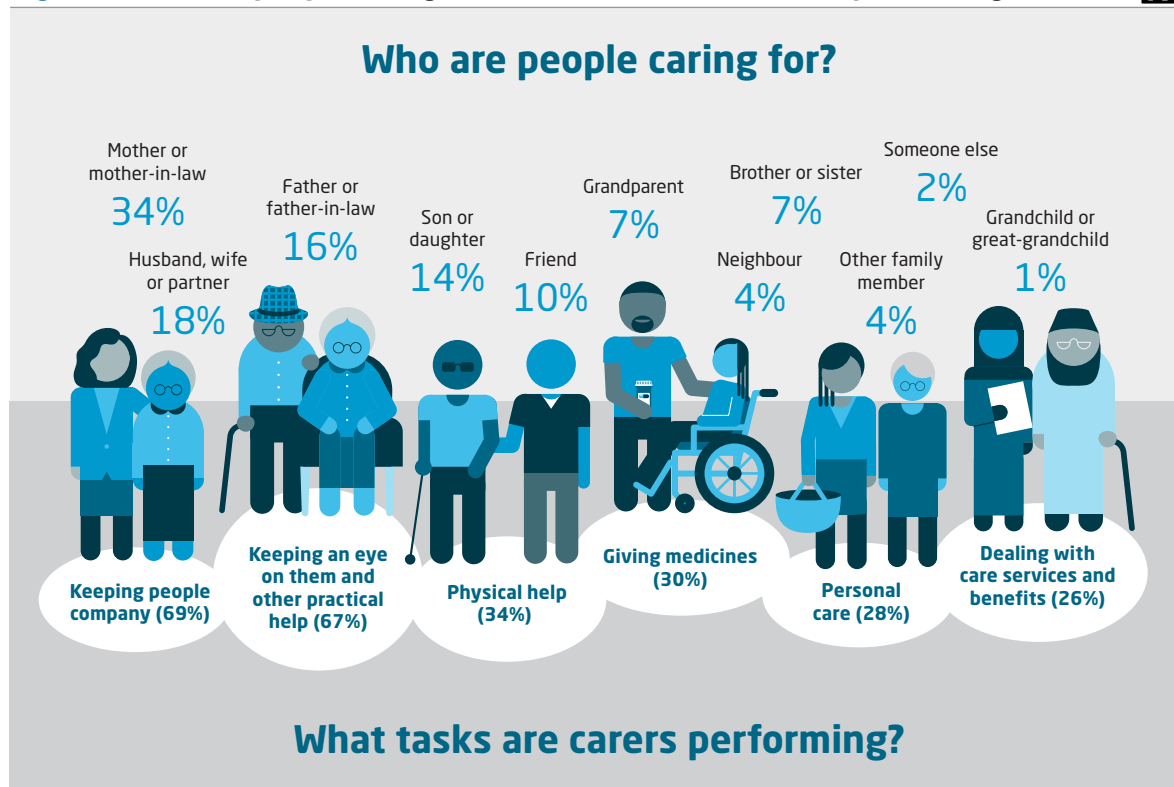
- A person caring for a spouse with a rare condition, who find themselves locked out of support because due to its rarity they do not meet the usual criteria for support.
- A person caring for an adult son with mental health issues and chronic substance use.
- A person caring for their same-sex partner, who also received support from that partner when they themselves had a serious illness.
- A person caring for two adult siblings, both with high support needs.
- A person caring for parents, one who lives independently, the other who lives in a nursing home.
- A person caring for a son with autism and a parent with dementia, all of whom live together.
- A person caring for a teenage son with high-level physical support needs, and some older family members with dementia.
- A person supporting an adult son with autism, and a neighbour with dementia.

### Who are unpaid carers providing care for?

The Health Survey for England 2019 found that most unpaid carers were caring for family members. More than a third were providing care for their mother or mother-in-law (34 per cent), and 16 per cent were caring for their father or father-in-law. One in six (18 per cent) were caring for a husband, wife or partner, while 14 per cent were caring for a son or daughter. One in ten carers (10 per cent) were providing unpaid care to a friend.

Support was most likely to be provided for tasks such as keeping people company (69 per cent), keeping an eye on them (67 per cent) and other practical help (67 per cent) (see Figure 2). Help was least likely to be provided for tasks such as helping to deal with care services and benefits (26 per cent), personal care (28 per cent), giving medicines (30 per cent) and physical help (34 per cent).

**Figure 2 Who are people caring for, and what tasks are carers performing?** **K**



The Health Survey for England also found a relationship between caring responsibilities and individuals' health, with 52 per cent of carers reporting some impact. More than a third of adults (36 per cent) reported feeling tired as a result of their caring responsibilities, 32 per cent reported a general feeling of stress, and 26 per cent reported having disturbed sleep. The impact increased according to the number of hours spent caring: 80 per cent of adults providing twenty or more hours of care reported at least one health impact, compared with 38 per cent of those who provided less than one hour of care.

The Personal Social Services Survey of Adult Carers, which covers carers who are in contact with local authorities in England, also found that carers reported a range of health conditions relating to their caring duties (NHS Digital 2022a). Many reported feelings of tiredness, stress, disturbed sleep and depression, while nearly half also reported financial difficulties due to their caring role.



The adult carers survey found that almost half of carers (49.9 per cent) care for someone with a physical disability, 38.5 per cent care for someone with a longstanding illness, and 35.4 per cent care for someone with dementia. Other common reasons for caring for someone include sight or hearing loss, mental health condition and learning disability.

### Support for carers

Around 1.4 million unpaid carers in England are entitled to Carer's Allowance as they satisfy the criteria for this nationally administered state benefit, which is only available to unpaid carers providing more than 35 hours of care a week. However, because of overlapping benefit rules, only around 1 million people receive Carer's Allowance.

In 2021/22, around 314,000 carers in England received direct support from their local authority, which has a statutory duty under the Care Act 2014 to carry out assessments of unpaid carers and, where there is a risk to the carer's wellbeing, provide services to support them (on a similar basis to their duties to meet the needs of those needing care and support directly). Local authorities can charge for these services but, according to Carers UK, most do not. The Act also includes a legal duty on NHS organisations to co-operate in fulfilling these duties.

In 2014, NHS England produced a 'Commitment to carers', which aimed to 'help promote working together between Adult social care services, NHS commissioners and providers, and third sector organisations that support Carers' ([NHS England 2014](#)). Under the Health and Care Act 2022, NHS England and integrated care boards (ICBs) are required to promote the involvement of carers as part of developing services and strategies. There is also a duty on ICBs to promote the involvement of carers in decisions about prevention, diagnosis or treatment of illness.

Support for carers is therefore a wider responsibility than just being the remit of local authorities. This recognises the fact that carers who receive support such as Carer's Allowance or from local authorities comprise a relatively small percentage of the 4.7 million unpaid carers in England identified by the 2021 Census.

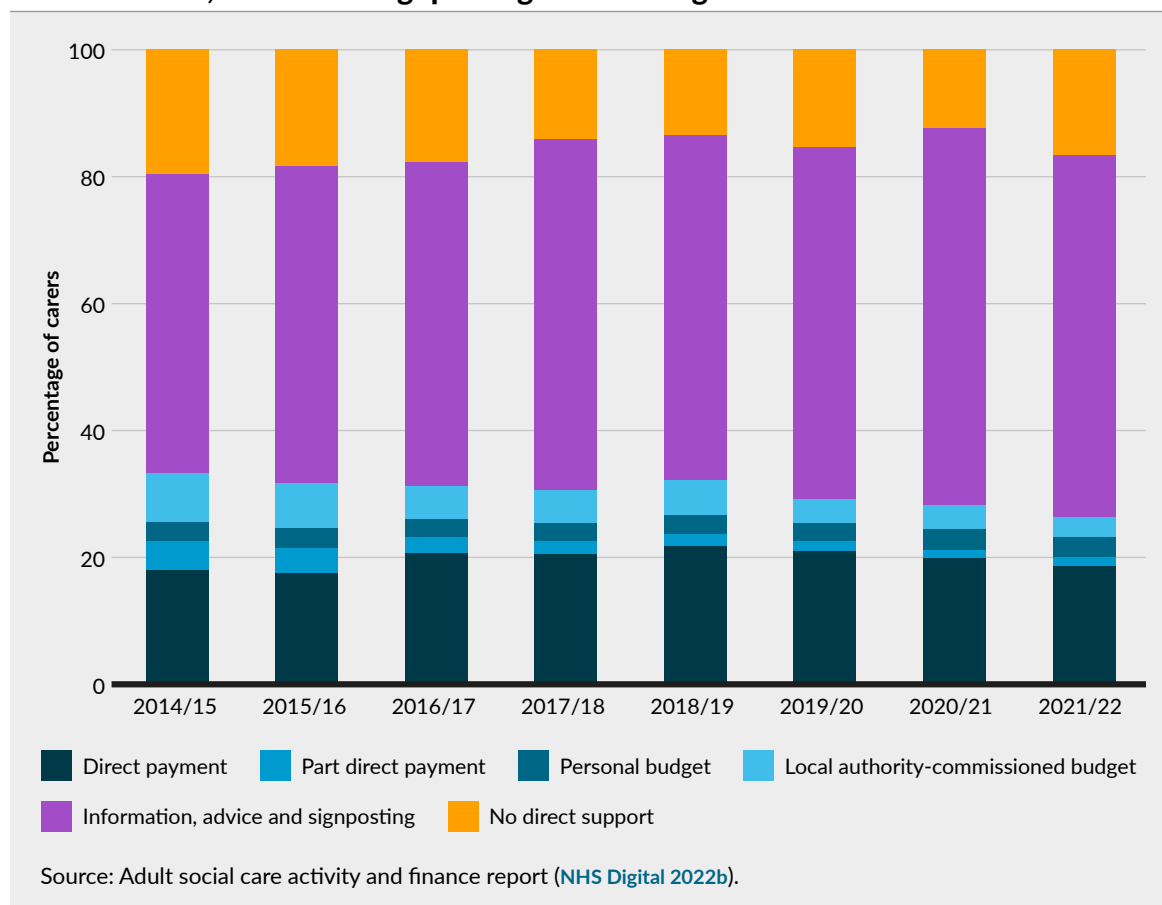


## Trends in local authority support

The number of carers receiving direct support from local authorities was the same in 2021/22 as it was in 2015/16, at 314,000. However, there has been a shift in the type of support they receive (see Figure 3). Fewer carers now receive paid support such as direct payments, personal budgets and commissioned support (27 per cent compared with 31 per cent in 2015/16) and more receive advice, information and signposting (56 per cent compared with 50 per cent in 2015/16).

The number of people provided with respite care delivered to support their carers has fallen from 57,000 in 2015/16 to 33,000 in 2021/22.

**Figure 3** The proportion of carers in England receiving either no support, or information, advice and signposting is increasing





In addition to this local authority expenditure on carers, in 2021/22, £285.7 million of funding was earmarked for support to unpaid carers through the Better Care Fund, which pools NHS and local authority budgets to encourage integration of health and social care.

## National datasets

As demonstrated in this section, there is good national data about carer demographics and activity, and about the issues facing carers, which may give some indications as to the types of support that are needed most. National carer charities also conduct their own surveys, which highlight the issues that are most important to carers (see, for example, [Carers UK 2022b](#)).

The data collected by local authorities on carer support (and reported in annual returns) has value for tracking long-term national trends ([NHS Digital 2022b](#)). However, there are concerns about data quality, such that many of our stakeholders in phase one were dubious about how well the data represented what actually happened in practice. This is supported by our own assessment of the difficulties of 'ranking' local authorities based on available data. It is problematic to use the data to identify 'best' (and 'worst') performers, even if there were agreed measures of performance.

At a fundamental level, there is an issue even with the question of how many carers there are in England. As noted above, the Health Survey for England identifies 17 per cent (of adults over 16) while the 2021 Census finds 8.9 per cent (of over-5s). This difference may relate to self-identification as a 'carer' – a consistent theme of the literature about carers and also an issue we encountered in this research.

However, we also heard concerns about the accuracy and quality of the Adult Social Care Finance Return (ASC-FR) data collected by local authorities about the carers to whom they provide services. For example, we were told (though were not able to corroborate) that assessments or services by third-party (usually voluntary) organisations might not be counted in the carer numbers that a local authority submits in its ASC-FR data. When we explored ASC-FR data, we also found very wide differences between the four local authorities in our study.





It is possible that some of these differences reflect genuine differences in the approach and strategy adopted by individual local authorities to providing support to carers. For example, the percentage of carers supported with advice and information varied from less than 20 per cent in one of our sites to more than 80 per cent in another. It is possible that this is a strategic choice. More difficult to explain is the specific reported spend on carer support in our four areas: on 'social support – support to carer', the highest-spending local authority reported expenditure 50 times that of the lowest-spending local authority. Even accounting for differences in local authority size and spending on adult social care overall, this is surprising.



## 3 A taxonomy of support

In our phase one analysis, we developed a taxonomy of support for unpaid carers. We reviewed a wide range of literature (see Appendix: Methodology) and spoke to key stakeholders to understand the breadth of types of support available. We grouped these into three broad categories.

- Support to carer – interventions that are solely delivered to the carer.
- Support to carer and the person they care for – interventions that might be delivered to the carer and/or the person they care for, but still provide support to the carer.
- Wider interventions – other aspects we noted from the literature of the wider context of support for unpaid carers, but not necessarily delivered directly to carers.

Examples of what these three categories include are set out briefly in Table 1 below. It was not straightforward to find a way to group the different types of support available beyond simply a list of interventions; but these three categories were reviewed and refined with a broad set of stakeholders (see Appendix: Methodology).

**Table 1 A taxonomy of support**

### Support to carer

1. Identification (including carers' passports)
  - People identifying themselves as carers.
  - Statutory/voluntary and community sector (VCS) services identifying people as carers.

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2. Assessment
  - Formal (statutory duty) and informal assessments of need.
3. Training
  - Wide variety of training interventions, including:
    - short/one-off interventions
    - courses on a range of topics (eg, specific courses for carers of people with particular conditions such as dementia, or particular needs such as medication management, on how to manage their own health)
    - delivered in a range of formats (eg, online, face-to-face, groups)

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4. Employment support
  - For those currently employed – a diverse range of interventions, including flexible working, carer's leave, workplace support and networks, carer-specific policies, carer champions.
  - For those seeking work – support (eg, around CV/interview/application; work placements, confidence-building).

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5. Group support
  - Social/activity/interest groups (eg, singing).
  - Peer groups (eg, for carers of people with dementia).
  - Online and in person.

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6. Individual support
  - Professional psychological support/interventions.
  - Befriending.
  - 1-to-1 peer support.
  - Online self-help.
  - Health services to the carer.

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7. Financial support
  - Direct payments/personal budgets and grants (Carer's Allowance was not covered in this work).

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**Table 1 A taxonomy of support *continued***

### Support to carer AND person they care for

#### 8. Information and advice, including advocacy

- Information and advice to the carer about:
  - entitlements and support
  - services
- Advocacy.

#### 9. Respite and breaks

- Rest for the carer is the key outcome rather than specific service delivery. This may be taking a break with the person they are caring for, or without that person – and both may be important (eg, holiday and family time that does not involve caring, as well as time for oneself). Several different types of break were described in the literature, including:
  - non-residential activities for the person they are caring for, delivered outside the home (eg, day centres, activity groups)
  - short breaks away from home for the carer or the person they are caring for
  - holidays for the carer and the person they are caring for, but with support so that the carer is not caring
  - replacement care delivered at home, including palliative care

#### 10. Support in hospital/discharge support

- Support to carer when the person they are caring for is in hospital, being discharged or dies in hospital.

#### 11. Technology (including digital)

- Includes both generally available tech as well as specialised tech.
- Already available include:
  - using the internet for things such as shopping, keeping in touch with people, banking, NHS services (eg, booking appointments, requesting prescriptions, accessing patient records, health consultations)
  - smartphones and tablets
  - apps, videos, televideo
- More specialised include:
  - remote monitoring devices/telemonitoring
  - devices assisting independent living
  - remote comms with health care professionals
  - sensors – pressure, motion, etc.
  - pendant alarms
  - activity pattern recognition sensors
  - artificial intelligence (AI)

*continued on next page*



**Table 1 A taxonomy of support** *continued*

**Wider interventions**

1. Housing
  - Role of specialist housing types (eg, ExtraCare), as well as adaptations and equipment (eg, through Disabled Facilities Grants).

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2. Health and social care services provided to the person being cared for
  - Including diagnostics, health checks, as well as social care, etc.

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3. Support from family, friends and neighbours

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4. Involvement of carers in design and planning of services
  - Meaningful involvement, and also with support provided, so that the person can attend while the person they are caring for is being supported.

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5. Support to professionals
  - Initiatives to increase awareness, skills and confidence in identifying and supporting unpaid carers.

In developing the taxonomy in phase one, we examined the strength of the evidence and drew several insights.

1. The overall sense from existing meta, systematic and scoping reviews of the literature was that much of the evidence lacks robustness, there is limited data on cost-effectiveness, and there is a need for more research. There were, however, a few exceptions.
  - The National Institute for Health and Care Excellence (NICE) highlighted good evidence that training can support carers to improve their skills, confidence and understanding of needs (NICE 2020).
  - Group support appeared relatively well-researched, and there is good evidence of effectiveness for carers of people with dementia and people with cancer (NICE 2020; Henwood *et al* 2018; Thomas *et al* 2017; Huis In Het Veld *et al* 2015).
  - There is good evidence for effectiveness of individual support for several groups of carers – for people with dementia, cancer and stroke (Livingston *et al* 2020; NICE 2020; Knapp *et al* 2019; Henwood *et al* 2018; Thomas *et al* 2017).



2. Overall, support for carers of people with dementia seemed to be the most frequently researched group. This is consistent with dementia being one of the main conditions affecting people who are receiving support from unpaid carers.
3. There are multiple types of support offered to carers, and it was difficult to 'boundary' some of these types of support. There are many interdependencies – for example, carer identification (a cornerstone of ensuring that carers can access support) involves both support to professionals (to enable them to identify carers) and information and advice to potential carers, enabling them to self-identify. There is limited evidence about which services are most valued or cost-effective, though some (for example, respite and breaks – broadly defined) are considered essential to carers.
4. The literature reviewed, and the stakeholders we spoke to during both phases of the research, frequently highlighted that none of this should be considered 'one size fits all'. Diverse carers have diverse needs – based on who they are caring for, other care and support in place for that person, who they are themselves, and the stage they are at in the caring journey (for example, whether they are a new carer or providing end-of-life care). Carers value personalised approaches that do not simply see them as an extension of the person they are caring for.
5. Interventions should give adequate attention to the carer and the person they are caring for, as perspectives, needs and preferences can differ. The carer/cared-for person 'dyad' was discussed in the literature, but it was clear from our workshops and focus groups that even this can be simplistic. Often a whole family may be involved in caring for a family member, or one carer may be supporting multiple people (for instance, a parent and a spouse or child). Our brief carer descriptions (see box on page 10), based on some of the people who attended our focus groups, demonstrate some of this diversity.

In phase two, we asked the four local authority sites about the services they provide for unpaid carers. The sites offered all of the support to the carer/cared-for person set out in the taxonomy (Table 1 on page 17) in some form. For example, sites commissioned a range of types of training through their carers' organisations:

- practical skills (for example, manual handling, digital literacy)
- specialist knowledge (for example, understanding power of attorney)
- targeted training (for example, to carers of people with dementia).



Carers' organisations also provided the bulk of information and advice, one-to-one and emotional support, and peer groups, either related to a characteristic of the carer (for instance, from a minority ethnic background, or parent carers), a characteristic of the person being cared for (for example, for carers supporting people with dementia), or more general peer support around the experience of caring. One commissioner highlighted the role of voluntary and community sector (VCS) organisations in delivering emotional and peer support – describing it as the 'soft stuff' that the rest of the system may value but does not have time for.

In two sites, we also heard about peer groups facilitated by the local authority (for carers of people using specific services they provided). In one site the carers' organisation gave an example of a peer group they had facilitated in response to a request from male carers, which they had subsequently found funding for and enabled those in the group to design and run their own activities.

Personal budgets were a focus for all sites, and three talked about trying to use them 'creatively' to enable carers to have a meaningful break. In two sites, carers' organisations were additionally commissioned to provide small grants to carers through a less formal process than the personal budget. In one site, however, a commissioner described personal budgets as 'used often when basically there isn't any other option for the carer to receive respite or a break of some kind'. We also heard about sites reviewing or shifting away from traditional forms of commissioned respite (for example, residential beds), acknowledging the difficulties of making these suitably flexible for carers while also affordable to the local authority. Who pays was also a theme of discussion – whether a service is chargeable depending on who is considered the recipient of the service.

Three of the four sites discussed health support to carers (for example, health checks, vaccinations) and in-hospital support (for example, with planning for discharge or enabling carers to stay on the ward after hours). The site that did not talk about health support was also the site that described challenges in their relationship with the health system (discussed later on), so this may be due to a lack of communication rather than a lack of provision.



## 4 Support for unpaid carers: four insights

We identified four local authority areas that had emerged from the insights in phase one of our research as potentially having approaches to supporting unpaid carers that other areas could learn from. These areas varied in terms of size, population and geography, ranging from a small metropolitan council to a larger county council with a population of more than 1 million. While representativeness was not the aim in choosing sites – rather, their approach to supporting carers – the sites were relatively well spread across England, with a mix of urban and rural geography. Table 2 shows some of the variation and similarities between the four sites.

**Table 2** Examples of key similarities and differences between the four local authority areas

	Site A	Site B	Site C	Site D
Adult carers' assessments delivered in house	Yes	No	Yes	Mixed
Dedicated carers' strategy/document	Yes	No – but a priority theme in broader documents	Yes	Yes
Cross-sector carers' partnership	No (separate council and NHS carers' strategy groups)	No	Yes	Yes
GP incentive to identify carers	No	No	Yes	Yes

This project was not an evaluation of support services for carers. Our phase one research showed that it is not possible – from existing datasets – to reliably identify good or poor practice. Our fieldwork confirmed that consistent data collection and resource to understand and monitor meaningful outcomes for carers is a work in progress. Therefore, what we present here are four insights based on what local





people – professionals and carers – told us was important to them in terms of supporting unpaid carers locally. It should be noted that because these were four areas that had been identified as potentially high performing, or having approaches other places could learn from, the barriers identified here may not describe the full range of issues other local areas might face. However, we hope they indicate some potential ways forward to improve support for unpaid carers.

These four insights were:

- develop and maintain a strong understanding of your population
- build your local support offer according to this understanding
- embed awareness of carers in strategic-level and commissioning decisions
- pay attention to the impact of wider health and care issues on carers.

### **Develop and maintain a strong understanding of your population**

Across the four sites, it was clear that the particular context – the demography and geography of the place, and the history of relationships and organisations – influenced their approach to local support for unpaid carers. Understanding this local context is essential. However, even within that, there were several shared priorities or ways of working that sites could point to in developing a strong understanding of their local populations.

#### **Identifying carers is vital – and is an ongoing need**

Because people move in and out of caring relationships, and may not self-identify as carers ([Carers UK 2022b](#)), identification is an ongoing task. All of our sites acknowledged carer identification as an ongoing priority, and this was probably the issue that was highlighted most by professionals across all four sites. While primary care contacts were seen as ‘the holy grail’ of identifying carers, commissioners described triangulating these with several different data sources: census data, national datasets, carers’ assessments, and intelligence from local carer support organisations.

Professionals were also optimistic about improvements in their processes due to developments in increasing awareness of carers among local professionals. However, it was clear from the focus groups that carers were still experiencing



issues in this regard. We found many further examples of this gap between strategic ambition and how carers experienced service and support, which we discuss further in section 5.

*We'd probably been looking after our son, like all parents, all our lives we look after our kids, and nobody in none of the years that passed has anybody mentioned carers, carers' centre. We never saw ourselves as carers. We were his parents and loved him and did everything we could, like you would do with your kids.*

(Focus group participant)

### **Professionals need support to be aware of and know how to signpost carers**

Because many people do not identify themselves as carers, it is important that professionals know how to identify a carer, and what to do once they have (NICE 2020). Professionals and carers across our four sites highlighted the significant role that GPs, social workers and other 'frontline' staff could play in identifying and signposting carers to support, by ensuring that any contact with a professional could be an opportunity to identify a carer.

*At the minute I think we largely do promote our work through other professionals that we think will be coming into contact with carers or the people that they care for.*

(Carers' organisation lead)

Relationships between different voluntary sector partners were another key aspect of carer identification. In three sites, voluntary sector professionals talked about the importance of spreading wider awareness of support for carers across different organisations, rather than one having 'ownership' of carers. However, we also heard about difficulties of competition for funding in the voluntary and community sector due to the way that local services are commissioned. In one example, these concerns had meant that an organisation was reluctant to refer clients to a 'competing' organisation, even if they might also be able to support the person.

Initiatives in the four sites to improve awareness included providing training and support for GPs and primary care staff, social workers, social prescribers and employers. Some training was delivered in house, and some was delivered by the



local carers' organisation. We heard about several 'champion schemes' to promote awareness, including one in which GP practices were encouraged to identify a 'champion' to co-ordinate work within their team and link into other work to support carers in the system (for example, receiving training and support from the local carers' organisation). This scheme was financially incentivised by health commissioners (initially from the clinical commissioning group and now the ICB), which had been set up in response to learning during Covid-19 that local GPs had poor records or a lack of understanding about carers.

*The GP surgeries had their carers registers, which came in years ago with the strategy. But actually when we collectively did a letter from all three organisations that went out to everybody who was on the GP registers and from the carers' centre to say, 'we can support you to get your vaccination', they were so out of date, the GP ones. So we had carers ringing us whose partner or the person they cared for had died years ago and the records hadn't been updated. So although they'd updated the record for the person cared for, they hadn't then updated the carer's record... But from that, it allowed us to get to a starting point for the GP award scheme to know that those registers were up to date.*

(Carers' organisation lead)

The Covid-19 pandemic highlighted several issues as well as opportunities to find and support carers. In one site, the local carers' organisation was tasked with calling to check on carers during the early part of the pandemic as the local authority did not have the capacity to do this. In two areas, carers' organisations supported the vaccination effort in relation to carers. These types of joint working highlighted where formal contact records were out of date, and encouraged people to identify themselves as carers where they might previously not have done so.

Finally, we heard in phase one about the potential for integrated digital architecture to enable joined-up data and identification of carers. But our fieldwork indicated that a lack of joined-up recording systems was not the only barrier related to electronic records. For example, where staff were not fully trained on how to use their local adult social care recording systems, this meant that carers were inconsistently flagged or followed up. Staff capacity also impacted on this, and staff turnover created risks to maintaining knowledge of local services and availability.



### **Need for meaningful measurement of impact, but this is still in development**

Measuring the quality and impact of support services is important and needs to take into account process, experience and outcomes. Process is often easier to measure but insufficient on its own. Professionals in our sites discussed recognising and trying to shift towards an approach to measurement that was meaningful and looked at outcomes, not simply a process-focused, 'numbers-based' approach. As noted earlier, it is important to involve carers meaningfully, and this includes in measures of outcomes and impact. However, all of this was still an ongoing development issue, because outcomes were harder to measure, with capacity and resource being key barriers.

Voluntary sector organisations also encountered some of these barriers, but in one of the sites, the carers' organisation had focused specifically on ensuring that it could justify its worth and have clear evidence for impact. However, even that organisation highlighted that it was still difficult to measure impact in terms of prevention.

Relationships between organisations were one way to ensure that the impact of services was not just numbers based and enabled some narrative as well as more formal reporting. However, in one site, competition within the voluntary and community sector was described as a block to sharing learning.

### **Engaging with carers is important to identify priorities**

Meaningful involvement is essential to planning and delivering quality services to unpaid carers, and even more so in the absence of robust measures of carer satisfaction and measurement of outcomes. In phase one, we heard (and some of the literature highlighted this) that there is a need for more attention to involving carers, and to hear carers' views alongside those of professionals and the people being cared for. We also heard that including outcomes for carers in an evaluation of support for cared-for individuals – a whole-family approach – could improve the quality of data. Respondents in all four sites discussed the role of co-production in identifying their priorities, and described examples of engagement, but this was more developed in some areas than others.

Again, we saw different approaches – for example, one site had a dedicated carers' co-production group while another included carers on the local strategic partnership group. One of the local carers' organisations had been commissioned to provide a



'speaking-up function' to facilitate carers' involvement. Carers we spoke to in these areas described positive stories of having been involved in shaping or responding to service development.

*My job is around getting the carers together to find out what it is that they want, and I do that with the relevant staff here, and then talking to our local MPs [Members of Parliament], talking to the council, health authority.*

(Carers' organisation lead)

In another area, carers' voices were represented by the head of the local carers' organisation. Although there was a strong relationship and examples of influence, this also risked (indeed, there was an example of) the carers' agenda not being represented when this one person was absent. In the focus group for that site, carers also expressed a wish to be more regularly involved.

Professionals consistently told us that recognising the value of carers was central to developing awareness of carers' needs and progressing the carers' agenda. We heard from professionals and unpaid carers that this was not always the case, and carers might either not be recognised, or not seen as separate from the person they care for, with their own needs and concerns. A key aspect of this was 'mainstreaming' data and awareness of carers, so that more services can support carers properly – not just carer-specific services.

### **Build your local support offer according to this understanding**

Across the four sites, it was clear that unpaid carers wanted the offer of support to be aligned with their needs and the context of their experience as carers. Although people who attended the focus groups in each area had a diverse range of experiences, their priorities across the sites were consistent. They wanted information and advice to be easily available; timely support for themselves and the person they care for; and, above all else, advocacy and co-ordination support.

*There's a lot of support out there but what is very difficult to find is anyone that you can go to who will say 'right, this is what you need, this is the help that's available, this is who to contact'. You know, there doesn't seem to be any sort of central point that can support you on this, which is a great pity.*

(Focus group participant)



## Commissioners and providers need to actively develop awareness of the support offer

The information, advice and support that carers described in the focus groups were mainly accessed from their local carers' organisations. As the carers attending the focus groups were recruited from local carers' organisations, this is somewhat expected, and does not provide a representative experience of all unpaid carers. These carers described their local carers' organisations as being their initial contact into receiving support. The organisations were highly praised, being described as 'invaluable' and seen as a 'life-saver', acting as a one-stop shop where carers can go for information and signposting, as well as a place to be listened to.

*I like the fact that [carers' organisation] actually care for you when you come in so they're very welcoming, they offer you drinks and make sure that you're alright, you know. You know when you care for someone, you want... eventually, you want someone to care for you, you know? Because you haven't got the energy or time to do anything for yourself.*

(Focus group participant)

Group support – whether delivered through or outside of formal services – was described as instrumental for carers signposting one another to services they have found helpful, circulating information and advice, as well as providing peer support and emotional wellbeing. Some carers described using what they had learnt to support other carers who might not have known what was available for them. In some cases, carers have not only signposted other carers to services but helped them fill out forms and applied for support on their behalf. These peer networks were therefore valuable to carers who might not identify as such but still needed support.

Although the carers we spoke with were aware of and accessing some of the support offered, particularly through the voluntary sector, they recounted the difficulty they had with finding different forms of support. Many had not initially accessed support as they did not know what was available, what they were entitled to, or did not even acknowledge that they were a carer. Participants spoke about their early experiences of supporting the person they were caring for, where at first, they did not see themselves as a carer: 'I don't call myself a carer. I'm a mum' (focus group participant). Many found that at the start of this journey, they did not know where to begin to look for information and support, or what support they might need. But their role as a carer evolved over time, as did their support needs.



*That's where we come adrift as carers, where do we start? Because the world is such a complex place, how can we possibly know where to go, who is going to help with this stuff?*

(Focus group participant)

Similarly, some carers spoke about not having the right 'language' to ask for support and self-refer to services. They found that unless they used specific 'trigger words' while in contact with formal services, they were assumed to be managing. Some carers described reaching out to services without knowing what they needed, and being left to navigate their own carers' support without a roadmap.

*She rang the advice line to be asked the question, how can we help you? Well, she didn't actually know how they could help her because she was asking for help but she didn't know what help was available... You can't say, 'well, this is what I want' because you don't know what you want because you're in that situation where you've just got this whole scenario that you weren't expecting to have to deal with and you really don't know where to start with it.*

(Focus group participant)

### **The role of assessments in facilitating support**

While statutory carers' assessments were a key pillar of the Care Act 2014, in all sites we heard about initiatives to increase people's access to support without having to undertake a statutory assessment. These included less formal initial conversations that could still lead to support, or support (for example, small-scale carers' breaks) that could be offered regardless of assessment. There were several reasons for this: a lack of resource to deliver full, detailed statutory assessments, leading to delays in access; a concern about unnecessarily burdening people; and a view from some professionals that some people do not want (or are afraid of) assessments. This also reflected what we heard during phase one, from stakeholders and in the literature, about the stress/intrusion of a formal assessment and a sense of futility when support was not available afterwards ([Carers UK 2021b](#)), as well as significant backlogs/lack of reviews due to the pandemic.

*I think the quality of the assessment, the quality of the time that they're given, it's really excellent. You can read it in their assessments how the cared-for person has been given that time, that one-to-one, the focus. It makes it all about them.*

(Carer assessment team manager)



Professionals described the quality of their assessments positively, because they felt these were now much more holistic and focused on the carer's needs. However, there were still ongoing issues: we also heard that not all sites had capacity to review their assessments and follow up on what support had meant to carers; and even where that review was available, this was not always clear to local carers. There was also a concern from professionals and unpaid carers in different sites that social workers conducting a social care assessment might not consistently identify the need for someone in that person's life to have their own carers' assessment. We also heard that the presence of a carer might lead to a social worker deprioritising the needs of the person being cared for – with little acknowledgement of the carer's own needs.

*I can see it for a social worker, she'll go into somewhere to do an assessment and there's a family member there, then that person's got more support than a person living on their own. So, when you've got to ration a service, your definition of somebody in crisis, often having a carer or a family member or a friend in, providing support, means that they're maybe not always top of your list.*

(Service lead)

### **Support needs to be appropriate and accessible**

Across the four sites, unpaid carers told us they wanted support that is appropriate and accessible. This support should be tailored to their situation, and should not create extra work for the carer to be able to attend events or take a break. In many cases, carers have more than one responsibility, and care for someone in a wider context of supporting other family members and friends. It is important to consider this wider context to develop services that are appropriate both for the carer's needs and the needs of the person or people they care for.

*I think the interesting thing I've found is that you need to work out what the right support is. There's lots of people saying there's help and support, but ultimately, when you start going down the route, you find it's not really appropriate.*

(Focus group participant)

Although some carers found value in activities such as coffee mornings or craft sessions, they also talked about the time and energy costs of attending them. For example, some spoke about events specifically aimed at carers being held at





times that overlap, or held in a location too far away to be practically accessible for the carer to attend. Others found that some activities intended for carers to have a break did not include provision for the people they were caring for, and so the carer themselves would need to arrange replacement care. Although carers acknowledged that they valued the time to have a break from their caring responsibilities, they also wanted the option to include the person they were caring for – for them to be able to participate in the carer’s life – as well as not having to organise for paid carers to step in.

*Support groups, I would like more access to. Apart from that, try and get some more places that will be quality of time for both mum and myself, and not just sending her to a day centre where maybe it’s not compatible for her needs there and she’s only doing it for me. So support groups, definitely more for me if possible in the future, and better quality places for both me and mum for quality time.*

(Focus group participant)

The Covid-19 pandemic also impacted how carers could access support. For some, the switch to online support had been very helpful, and had allowed providers to show the benefit of remote support provision more quickly. However, we encountered one carer in our research who still did not use video-calling software, and so we supported her to take part via a telephone interview. Although digital services are increasingly becoming the default form of communication across health and care, it is important to consider the various levels of digital literacy and access to technology among different groups, including carers and the people they are caring for ([Mistry and Jabbal 2023](#)).

### **Support needs to be inclusive of diverse populations**

In phase one we heard that increasing strategic integration brings with it opportunities to ensure that diversity considerations are addressed in commissioning and procurement. Beyond simply identifying the number of carers locally, it is also vital to understand who these carers are – the different communities and contexts they live in, and which services might be most useful to them. The data analysed in phase one is part of this, as are local carers’ surveys and data from service providers. To better understand and predict carers’ needs, one site was developing a dashboard of data drawn from different local services. Another site was looking at expected versus actual service use to improve targeting of its offer.



Our focus group participants reflected some of this diversity, and talked about having support available to them that meets their needs and considers their lives as a whole, not just their role as a carer. For example, we heard in one site how the local carers' organisation had created a safe and welcoming environment for carers from the LGBTQ community – something the carer said was not always the case in mainstream services.

For others, an important and often overlooked consideration was having information available in different languages. A carer who often relays information about available support to their peer network suggested that not having information in different languages relevant to the local area, as well as differing cultural expectations about responsibility for caring for someone, prevents some carers from accessing support.

*I think the other thing is, language wise, when you can read and write, you can speak that language, that helps 100 per cent... Otherwise they struggle. They just struggle, they just get on with it, like I did...*

(Focus group participant)

We also heard from professionals how experiences during the Covid-19 pandemic had highlighted the need to address inequalities faced by carers from minority ethnic groups. In some sites, bespoke services for carers from Black and minority ethnic groups have been developed to better support local communities. Professionals described working with different voluntary and community sector organisations to understand the barriers different communities face in accessing support and to develop solutions to overcome those barriers. For example, a health and wellbeing hub for carers from minority ethnic communities had been set up in the heart of the community and has become more popular, particularly during the pandemic. However, the importance of tackling the inequalities experienced by carers was also acknowledged as an area that could be improved on. This also links back to the ongoing need to identify carers, and to understand the particular needs of a local population.



## Getting a proper break

Many carers we spoke to clearly appreciated and enjoyed the activities run by their local carers' organisations, though often expressed a preference for more practical support that would make meaningful change in their life and the life of the person they were caring for. Taking a break from work, regardless of sector, is important to maintain health and wellbeing (Carers UK 2022a). Carers appreciated it when services arranged respite and carers' breaks, which enabled them to rest and take a break from their caring responsibilities.

Carers UK (2021a) raised the issue of carers using their breaks not for their own health and wellbeing, but for necessities like sleep. Reflecting this, in our focus groups we heard about carers using their breaks to care for another person they support, or to simply catch up on some sleep.

Without proper cover for this time, we were told that they would be unable and unwilling to take a break as it would cause additional stress for themselves and the person (or people) they were caring for.

Having alternative care in place for the person they are caring for was vital for carers to be able to step away for a break. Carers stressed how important it is that any alternative care arranged is appropriate for the person they are caring for, and that carers' breaks are arranged regularly, not only in an emergency. This also has implications for how a break or respite service is evaluated – carers may need time to get used to and trust a service before they can fully benefit from a break.

*I mean, he was only away for one night or maybe two nights, and in that time, it was just catching up on your paperwork or catching up on some sleep, but it would have been really useful to have a big block of respite to just recharge and spend time with the other kids and go away somewhere, rather than just snatching a day here or there.*

(Focus group participant)



## The importance of timely support

*If I rang 999 asking for the fire brigade and I went through all the hoops and the miscommunication [that I've experienced in seeking support as a carer], the place would have burned down three months ago. These are family crises of the same magnitude but just seem to be... It's like a labyrinth, going through some malfunctioning computer game.*

(Focus group participant)

As well as prioritising identifying carers locally, professionals in all four sites highlighted the importance of prevention in relation to supporting carers, linked to statutory duties. This was described in terms of reaching people early and preventing carer breakdown, including through the use of social prescribing and informal community support, but also of facilitating carers' wellbeing further upstream, in terms of things like employment and education. One way this preventive support was targeted was through local voluntary and community sector commissioning. Despite its importance to professionals, however, the unpaid carers we spoke to were more likely to characterise their experiences of support as reactive or only receiving help in the midst of a crisis.

There was a general sense that if the people they care for are well supported, then carers themselves are better supported. Not receiving timely support for the health and wellbeing of the person being cared for was described as a significant barrier for carers themselves to access support.

*[There's] stress before you even do anything because you're just expecting another battle.*

(Focus group participant)

The role unpaid carers take on is not limited just to providing care. Carers told us about an array of roles within their lives and those of the person they are caring for, including assuming the role of care co-ordinator. Communicating and liaising between many organisations across the health and care sector was described as the minimum to simply get the support that was needed by the person they were caring for. They spoke about the time and energy they spend chasing referrals, arranging appointments and sourcing information.



*We want to go and talk to people, we want somebody who can sit down and say 'we know exactly what you're going through, we're experiencing this, what you need is support from X, Y and Z, and we'll pull that together and people will give you your rights.'*

(Focus group participant)

A carer who supported their father, who lived independently, described a series of delays in getting him referred, diagnosed and supported for several conditions. These delays meant that some of the support offered became irrelevant, as his needs had passed the point when it would have been useful.

*It was all these things that would have been really great for him had I got them at the time he needed them, but it was always just too late... I'm not trying to blame anyone because I know all the services are so short of personnel and money and they're all working really hard... But you sometimes feel, why bother? Because if you're not going to get it when you need it, there's no point in them bothering... To be honest, if I hadn't had to be chasing all these things up, my stress level would have been so much less and I wouldn't have needed to have support.*

(Focus group participant)

### **Embed awareness of carers in strategic-level and commissioning decisions**

*But I think we've just got that ability to maybe think about seeing a caring role as 'everybody has one' to some certain degree, and some people will need some support around their own kind of wellbeing. And wellbeing in its broadest sense of not just physical or mental health but employment, training, education, living. You know, so thinking broad, and those opportunities – particularly through some of the big changes in health and how we're delivering things is that real opportunity.*

(Commissioner)

As well as developing a strong understanding of the local carer population and designing the local support offer around this, we heard that a key aspect of ensuring consistent support for carers locally was embedding awareness at a strategic level across local health and care services.



### **Professionals who ‘get it’ and advocate consistently are vital**

For carers and professionals alike, staff who understand the particular issues carers face and can support them appropriately was key. As well as providing unpaid carers with good support, those in more strategic-facing roles consistently advocate for and help to embed the ‘philosophy’ across organisations. However, we heard how staff turnover meant it was important to pay attention to this work and to ensure that staff awareness is an ongoing effort. Carer champion schemes were one example of this.

### **System-level carers’ partnerships and strategies have a key role in advocating for and embedding the carers’ agenda**

All four sites had either a dedicated local carers’ strategy or action plan, or had identified carers as a specific priority group in a wider strategy. Two areas described explicitly developing these through, or linking them into, multi-agency processes to develop wider buy-in across their local area.

Two of the four sites also described how they had developed strategic, multi-agency groups that focused on advocating for and developing support for unpaid carers. These were both several years into their work, but had secured representation and buy-in from senior colleagues across the local health and care system. This had enabled them to embed the carers’ agenda into wider governance structures and thus spread it into other aspects of work. Both had ensured that their partnership was either chaired or co-chaired by a health commissioner to strengthen health partners’ investment in the work, and had seen a positive impact in both recognition of and investment in carer support locally. Carer representation on these boards was also important (*see section 2, ‘Re-engaging carers’*).

Participants emphasised the need to attend to the interpersonal relationships in these partnerships and not to take them for granted, to ensure that they were as effective as possible. They also discussed the continuous development of these partnerships, and the role of wider organisations such as local businesses in progressing carer awareness. Despite this work, however, one area highlighted how funding cuts were a barrier to keeping carers on the agenda locally.



### Commissioning arrangements varied significantly

The four sites had very different commissioning arrangements, reflecting the history of service provision and local progress toward integration. While all had a 'main' voluntary sector carers' organisation that was commissioned, in two sites this was through an integrated commissioning process between the local authority and integrated care board (ICB), while the others had these as separate strands (in effect meaning that the carers' organisation was holding separate contracts with the ICB and the local authority). Sites with joint commissioning arrangements were also those that described the strongest integrated care system (ICS) arrangements and relationships with their voluntary sector organisations.

Carer services were provided via a complex mix of in-house and commissioned-out services. To give a flavour, this included:

- carer groups facilitated by local authority-run social care facilities for the carers of those using their services, as well as more general carer groups run by the local voluntary and community sector (VCS)
- private and VCS organisations commissioned to provide carer support
- non-carer-specific VCS organisations commissioned to deliver specific carer services
- commissioned carers' organisations subcontracting some services to other local VCS organisations or working in partnership with other VCS organisations on certain services
- larger national carers' organisations commissioned to provide a local online support offer.

We also heard about variation in whether statutory carers' assessments were carried out in house or delegated to commissioned carer support services. Adult and young carer assessments were managed separately. One carers' organisation that was not commissioned to deliver carers' assessments described how they were being asked to do so. However, they were resisting this request as they did not wish to change their relationship with the carers they support and become 'gatekeepers' to that support.



One site had longer-than-usual contracts for its VCS organisations, including the local carers' organisation. This was described as facilitated by the strength of the local VCS, and was experienced as positive because it enabled both commissioner and provider with their longer-term planning.

### **Streamlined commissioning processes are helpful in providing flexibility and greater co-ordination**

Professionals who had been in a place for several years described how carer services and commissioning had developed in their area. We heard about how commissioners had pooled or streamlined contracts to support more efficient delivery of services. Providers and commissioners talked about how this enabled greater flexibility and co-ordination, although it also had implications for voluntary sector organisations where there was more than one provider of carers' support. Competition for funding was a concern for some voluntary sector organisations, and we heard examples where the way services had been commissioned had led to a context of unhelpful competition between organisations – for example, services being unwilling to collaborate or share good practice, as well as risk of duplication.

### **Relationships are vital to commissioning and understanding local services**

Good relationships are always important to commissioning, but in the context of the small proportion of the budget for supporting carers, compared with the overall adult social care budget, commissioners told us about the particular importance of building relationships with their providers as part of getting the most from their limited budgets. As one pointed out, having a handful of provider relationships (versus the hundreds a home care commissioner might hold) means there is much more time to develop these relationships – and it also means commissioning 'by influence', not just cash. They described, for example, supporting the local carers' organisation to link up with an organisation supporting a local minority ethnic community to work together to improve support for carers from minority ethnic backgrounds. Another commissioner described work to understand the 'whole offer' locally, including grassroots community initiatives, not just services funded by the local authority. This means they can:

- develop relationships and support these services in non-financial ways (for example, with advice around safeguarding procedures)





- explore what is available and what they can learn for when they redesign services
- include those services when signposting people to sources of support.

*I think that's the thing, it's about having that wider-picture view, it's not just what the local authority funds, it's what else is out there. And that's the whole offer. And we don't always have to interfere in the whole offer, we can fund the core stuff in the middle. But also, being able to say, 'oh, but if you've got a direct payment, did you know this group exists over here and you could go directly to them and use it?'*

(Commissioner)

Carers' organisation leads also generally reflected these positive relationships. Carers' organisations included in the strategic partnerships described earlier spoke positively about the impact this positioning enabled them to have. We also heard about room for improvement – for example, relationships with health partners, or some relationships that were dependent on the individual in a particular role rather than necessarily being embedded in the organisation.

### **Integrated care systems have an important role to play in supporting unpaid carers**

The role of ICSs in relation to supporting unpaid carers varied across the four sites. In two, the ICS had a strong role in terms of supporting unpaid carers. Two sites talked about their ICB carers' lead, and the alignment with work in other areas within the ICS. However, there were also questions around the extent to which places or ICSs set the agenda in terms of carer support. Two key issues cited were the local history of relationships and the quality/availability of data to evidence health impact on carers. In another area, a senior ICB colleague chaired the carers' partnership group, and linked in to the ICB's carers' agenda, but noted that across the different places in the ICS, this agenda was not consistent.

By contrast, in the fourth site, there was much less discussion of the ICS role. The local carers' organisation described not feeling well represented via the local ICB-VCS alliance, and the local authority commissioner described the lack of integrated working as due to the ICS and its boards not yet being 'mature enough' – meaning that they were not yet taking a system view. This also reflected what



we had heard in phase one about VCS organisations sometimes struggling to be involved in conversations about integration, and a need for closer working between local authority and health sectors, with carer responsibilities seemingly left to local authorities – attributed to the focus of the Care Act on local authorities.

### **Regional and national networks can be a useful source of support**

Professionals in all four sites described linking into knowledge from other areas through a variety of methods, including peer visits and membership of regional networks. Two areas had had aspects of their work shared nationally via NHS regional links. Perhaps understandably, awareness of what was happening in other areas was more common among strategic professionals than providers (unless due to their personal experience). For example, one provider described how they found out what other areas offered when new clients came with different expectations that they could not meet.

Participants had mixed views on the national role in terms of supporting unpaid carers. Some described it as helpful – citing the influence of the NHS Long Term Plan in contingency planning and the NHS England quality markers for supporting carers in general practice (NHS England 2019). Others felt it was too remote or not able to manage the variation of circumstances in different areas – for example, differing levels of ICS maturity.

### **Pay attention to the impact of wider health and care issues on carers**

The services that someone receives from a local authority as a carer are clearly not the only ones that affect their overall wellbeing. In particular, the availability and quality of wider health and care services can be vitally important to carers. Poorly joined-up services, poor staff understanding of needs, workforce shortages or long waiting lists for support all mean additional pressure on carers. These pressures were visible in our focus groups across the four sites. Professionals supporting unpaid carers need to acknowledge these and, as far as possible, provide services that can mitigate some of these wider negative impacts.

*So everything took so long because he'd got two conditions that were both deteriorating. By the time I got the person that was going to help or provide the support, it was too late.*

(Focus group participant)



Some carers reported being on waiting lists for their own health needs – highlighting that if their health needs are not met, this could compromise their ability to continue caring. Some also reported having to juggle access to their own appointments as well as those of the person they care for. In this context, it is unsurprising that carers' own reported health and financial difficulties have increased over time (NHS Digital 2022a).

*But there seems to be a bit of a shortfall almost everywhere, short-staffed, we can't do this, and you don't get the same continuity with the same social work that you would hope to have. Meetings cancelled last minute or rearranged and that sort of thing, it's a... It's something that you have to, sort of, just either reassure the person you're caring for or just keep pushing on, because at the end of the day, it all seems to fall back on yourself, and, you know, when I was doing the double dual role and then trying to bring up both my daughters at the same time, it's just one of those things that can easily get on top of you.*

(Focus group participant)

The carers we spoke to told us how they often put their own health and wellbeing to one side while caring for someone else. Some noted that when they needed support for their own wellbeing, they were only offered access to services when they had reached breaking point. Across all four sites, carers highlighted the need for preventive mental health support. They shared experiences of not receiving support earlier, and the impact it had, both on them as an individual and on their ability to care for someone else.

*I've often felt that in the mental health service side of things – and I've only obviously just basically got pushed that way because of my wife's condition – a lot of stuff is reactive. If you're under stress and you're about to jump off the M25 bridge, they'll be there, but if you were just saying, 'I'm coping, I'm doing this', and I think it goes back to what [another participant] said, you need the right word that is the trigger word, that then makes something happen. And not everybody tells you that, and you only find out after you've been through it. So the good things to do are to actually understand where you are and what you need to do to progress to the next step, which is sort of, you know, goes back to timely information and advice. And that is sometimes hard to get.*

(Focus group participant)



Some carers who had support from paid carers spoke about the lack of continuity in the support they received. They found themselves needing to explain the conditions of the person they were caring for, and needing to train the other person on how to effectively care for them in their absence – resulting in additional stress for the person being cared for, as well as the carer feeling that they have created additional work for themselves.

*One of the things that is interesting is that I had so many [care workers], each one of those new carers has had to have somebody train them, and it's usually been me or someone who's a regular carer. So, you know, you have them come and go, so it's still... You're still involved very much in everyday life of our loved ones.*

(Focus group participant)

Carers' most consistent message was the importance of good health and care support for the person they were caring for in making a positive difference to their own health and wellbeing. The ability to smoothly access health appointments and social care support and adaptations could significantly reduce their own stress and time spent chasing different services.

### **Impacts of ongoing funding concerns on carers and local support services**

Funding was discussed in all four sites in the context of the support they provided for unpaid carers. The picture was not entirely negative; in one site, they described a pilot funded by Covid monies that had been made permanent, while two sites described how they had protected their carers' organisations from wider VCS funding cuts because they had shown their value during the pandemic. In another example, the agility of VCS organisations to distribute financial support compared with statutory bodies had been recognised, and the local carers' organisation was also delivering the Household Support Fund.

But more generally, the picture was of services cut, concerns that existing services were not secure, that there would be less early intervention and increased risk of carer breakdown. We heard about another pilot project to support carers when the person they care for is in hospital, but it was unclear how sustainable the funding for this was.



In one site, the wider economic environment was a strong focus of conversations – including in the focus group – and seemed to be felt especially deeply. Unpaid carers described issues around access to services due to cuts to social work jobs and fewer GPs, and all professionals acknowledged the lack of money in their services. While the wider social care workforce crisis was a common concern, in this site it was described as particularly acute, with local retail jobs paying more than social care jobs and descriptions of having to prioritise and ration people entitled to care and support due to the lack of workforce.

This wider workforce crisis can lead to additional pressures on unpaid carers, as previously discussed, including less access to respite or replacement care, and more difficulties ensuring that the person they are caring for can access appropriate formal care. Without reliable support in place, carers were forced to manage as best they could – often in incredibly difficult circumstances. As one parent caring for an adult son described:

*Over the past two years, my son has had 143 different [carer workers] come in, and out of that 143, I think there's been about 50 that have only come once.*

(Focus group participant)

This is 143 people that the carer has had to show how to support an individual with specialised needs. This amounts to a substantial amount of time to induct and train each of these 143 care workers, as well as the emotional impact of the sheer number of strangers in their home.

### **How the cost-of-living crisis is affecting carers**

During our research, we also gained insights into how the cost-of-living crisis is affecting carers. For example, in a focus group with unpaid carers, participants talked about not having the heating on at home, despite it being a cold, autumn day. Financial issues were also starting to affect those who had not previously had to worry about money. This is reflected in wider research highlighting the increasing financial pressures on carers ([Carers Trust 2022](#)).



Earlier in the report (see page 12) we briefly described the national and other support available to carers and the trends in local authority carer support since the introduction of the Care Act in 2014. Although the Act was intended to improve and extend the offer to carers, there is little evidence that this has happened. The number of carers provided with direct support has not changed since 2015/16 and more now receive advice, information and signposting rather than paid services such as direct payments. The number of people being provided with respite care has also fallen significantly since 2015/16.

We have argued elsewhere (Bottery and Mallorie 2023) that local authority finances are likely to be the major cause of this situation, which suggests that a key factor in improving the quality of services available to carers will be the wider financial context facing local authorities. However, this should not mean that local authorities are powerless, even in challenging financial circumstances. As carers repeatedly told us, simply being recognised and valued as an individual by local authority staff was vital; they wanted and expected to be treated with respect. This attitude – a hallmark of the cultural context within a local authority – does not necessarily come with a price tag.

### **Joined-up care is crucial to unpaid carers**

Unpaid carers have a huge range of recurrent responsibilities: regular communication with GPs, nurses and other professionals to support them while they care for another person at home; liaison with residential homes; access to medical information and explanation; and sufficient carer training. All of this emphasises the need for an integrated approach to health and care services to enable carers to streamline their interactions with local services.

Professionals in three sites described good examples of partnership working between statutory and VCS partners, with local authority, health and carers' organisations working together on a shared agenda to support unpaid carers. They highlighted the strength of local relationships and work to keep these strong – both between statutory partners as well as between statutory and VCS organisations. We also heard about the need to extend these relationships more widely across different sectors and organisations. However, according to the unpaid carers we spoke to, progress on integration was not always visible. They found that they often needed to be persistent with services, and advocate for the health and wellbeing of the person they were caring for within a disjointed system.



*It grinds me down knowing that every contact I'm going to have is going to be me hitting my head against a brick wall... They must think I'm a pain but I don't really care if it means getting what I think my parents deserve.*

(Focus group participant)

Despite the experience of the Covid vaccination programme demonstrating that services can co-ordinate to support unpaid carers, we heard more often about non-joined-up care and support creating difficulties for people's caring roles across the four sites. Here are just a few examples.

- A woman was discharged from accident and emergency (A&E) with referrals to community services and social services, but these were never received. The carer followed up with the social worker, who then offered inappropriate support, so they had to request a review. The follow-up support the woman needed was still not in place three months after the woman was discharged.
- A person caring for her mother (and holding power of attorney, which the GP had registered) found a letter from a secondary care service sent directly to the mother. If the carer had not (by chance) found the letter, her mother would have missed a very important appointment.
- A man with mental health and chronic substance use issues who attempted to end his own life was found by police, who contacted his GP and the drug service. Neither of these contacted the man's carer, who was left 'to pick up the pieces'.
- A carer who was rushed into hospital with their own health emergency reached out to the carers' emergency response service they had a plan with, but that service did not respond. The carer had to co-ordinate emergency care for the person they were caring for themselves, from their hospital bed.

Across sites, carers told us that one key priority would be for the wide array of systems that interact with individuals who are being cared for to be connected and co-ordinated in a more efficient and consistent way than what is currently available.

*There seems to be a yawning gap between communication, and when you get into that situation, that's a terrible impact on us as carers, because you're literally sitting there going, 'well, who's dealing with me? Is anybody dealing with me?'*

(Focus group participant)



## 5 Discussion

Throughout our literature review, data analysis, interviews and focus group discussions, a number of key themes emerged repeatedly.

### The gap between strategic intent and on-the-ground experience

*I suspect there's quite an enormous mismatch between the professionals' perception of what they do and how it helps, and the service users' perception of the service that they've received and how it has or hasn't helped.*

(Focus group participant and peer volunteer)

We set out to understand professionals' and carers' priorities in terms of supporting unpaid carers. The four local authorities that took part in this research were clearly highly engaged with carer issues and had given wide consideration to their statutory duties and how they would meet them (these were, after all, local authorities who had been identified to us during phase one of the research as doing something other areas might learn from). However, the thought and effort that had been put into carer support did not always translate into the support that carers wanted. One thing we noticed at several points was a disconnect between what professionals in the statutory sector were aiming to deliver, and unpaid carers' experiences of the support and services they received.

Three sites emphasised the value of maximising opportunities to identify carers from any health care contact – 'no wrong door'. For example, we heard how local social prescribing schemes were being supported with training by a local carers' organisation, with the aim that carers could receive support from different points in the system, not just the carers' organisation itself. But we also heard several examples where this had not happened.

*A friend of mine whose wife was at the end of her life, was getting no support from the GP surgery, didn't know where to turn to, and his mental condition was really going downhill. So, I got in touch with [local carers' organisation], and they got in touch with him, and because they have a direct access to assessments in the*





*council in situations like this for help, within 24 hours, he had district nurses, he had the Hospice, and he had people advocating for him. So, I mean, I think that's a tremendous thing, but had I not known about [local carers' organisation], had he not known me, poor soul, where would he have ended up?*

(Focus group participant)

There was also some disconnect between what the carers themselves were aware of across the four sites and what professionals told us about the support available. Commissioners and providers spoke about the importance of having information and advice available to unpaid carers, and talked at length about the range of services on offer and where to signpost people to health and wellbeing, financial and respite support. But they also told us about services that people did not use, while unpaid carers told us they did not know what was available or even where to start looking. Some professionals also spoke about how improved awareness will also increase demand for services.

We did, however, hear about examples of initiatives trying to address this. In one area, local commissioners described funding a primary care liaison role in the local carers' organisation to support the increased number of signposting and referral questions and requests. In another, we heard about how local ICB commissioners supported the development of an improved money advice offer locally, before asking primary care networks and social prescribers to signpost carers to it.

When they had managed to gain access to some support, carers sometimes found that the support offered did not meet their needs or the needs of the person (or people) they were caring for. In one example, the carer found that although they were told about different forms of support, they did not find something that was appropriate for the person they care for due to their rare type of dementia. They described support not being tailored enough to specific conditions as feeling like they are 'a square peg in a round hole' (focus group participant).

Co-production was another area where ambition did not always match experience. We heard about an example of the impact of a service change where although co-production was described, not all partners felt it had been adequate. In this site, they had recently made several changes, including changing the assessment process in response to assessor feedback. While the commissioner described how



this had improved the process, one of the local carers described experiencing it less positively. Although this is just one person's experience, it illustrates how an approach that works from one perspective might be experienced very differently from another.

*[Previously], when people telephoned through saying they wanted support, we would go through a triage that could take 60 minutes before you even actually talk to the person about what it is that they want. So you're digging away to try and find an issue... Or that's how the call-takers or assessors would feel. So now we're doing something called strength-based approaches, which is trying to have a proportionate conversation... So that we're not just looking at all the negatives, we're looking at, 'what's the issue? How can we help you today?' And then we would go down an opportunity of... if it was around going and seeking some aids and adaptations, 'could we give you the website and you support yourself there?' So it's really strength based rather than... making people dependent on us. And for some people they can't do that, so we would support them, but where possible, we're trying to support people with information, advice to do [things] themselves.*

(Commissioner)

*So, the other thing, I can remember the carers' assessment was absolutely wonderful and you got some lovely people who seemed really interested in talking to you. My recent experience is that they weren't as interested and they sort of asked, 'oh right, how can we help you?' I think I mentioned the garden because I live in a council house. And they said 'oh, well, you've got three sons haven't you, they can help you?' And that was it. So totally different to the way they used to be. I didn't quite understand that at all.*

(Unpaid carer)

Each of these examples highlights different aspects of the challenge of supporting unpaid carers: identification, advice and information, involving carers in developing services, and providing meaningful types of support. But they also relate to a tension some professionals displayed between wanting to provide services to support carers, and trying to 'protect' services from being overwhelmed by gatekeeping access or avoiding raising expectations that they cannot meet.



*I think the other double-edged sword is where we encourage involvement. Of course, it does raise more issues... There's a higher awareness that services should exist for carers... you bring things out from behind closed doors and, of course, you've... You know, be careful what you wish for, which can of worms do you want to open?*

(Carers Organisation lead)

### Improving social care is critical to improving many carers' lives

Unpaid carers told us repeatedly that what most mattered to them – and what would make the greatest difference to their lives – was an improvement in the quality and extent of the care being provided for the person they were caring for. However, in practice, the number of people receiving long-term social care support from their local authority has fallen since 2015/16 and the Local Government and Social Care Ombudsman (2022) recently described 'an under-resourced system unable to consistently meet the needs of those it is designed to serve'. The impact of this on carers is that the less publicly funded care that is available, the more care an unpaid carer might have to provide. And poor or limited care also makes it harder to co-ordinate and manage that support. The most striking example we were given was the carer who told us (see page 43) that her son – who has a complex health condition – had been visited by 143 different care workers in the past two years, of which 50 had come only once.

This means that, as with carers' services, the wider situation of adult social care within a local authority is critical to many carers. We were also told by carers that they often had to learn about how the 'system' worked in order to be able to navigate it successfully and to negotiate or lobby for improvements in the quality or frequency of the support they received. This suggests that carers' organisations may have a wider potential role to play in supporting carers to advocate on behalf of the person they care for, and in some ways, it was surprising that this did not seem to be highlighted as a core service by the local carers' organisations with whom we spoke. More fundamentally, perhaps, it suggests that many carers' lives will not improve significantly until there is a significant improvement in the social care support available to those for whom they care.



## The growing importance of integrated care systems

Although this work focused on the role of local authorities in supporting unpaid carers, it is clear that ICSs are key emerging forces in supporting unpaid carers. Since unpaid care goes far beyond the role of social care, relationships between an ICB and its local authority (or authorities) are likely to grow in significance. We heard how in two of the four sites, relationships between health and social care, and between the ICB and the local authority, were significant in their approach to supporting unpaid carers (see page 37), while in one site these relationships were described by the local authority commissioner as not mature enough. In the sites where these relationships were more developed, the ICB role in funding initiatives to identify and support carers was highlighted as a successful part of their approach. While unpaid carers are inevitably only a small part of the work of ICSs, as with other system-wide issues they are addressing, carer support directly involves health as well as social care. Integrated approaches appear to offer real promise – for example, to align approaches to supporting unpaid carers at ICS as well as place level, but that is by no means automatic. This will need leadership from leaders who understand the value of carers to the working of the wider system.



## 6 Conclusion

We were asked to look at what evidence is available for different types of interventions, what are the priorities (in terms of support) for carers and professionals involved in commissioning and delivering services for carers, and what are the barriers to and facilitators of access to different types of support. In this report, we have set out carers' and professionals' priorities and the barriers and facilitators to delivering that support.

It is clear that unpaid carers play a vital role in supporting the wider health and care system, and so providing them with effective support is crucial. Commissioners and providers in local authorities can improve the support they offer locally by developing a strong understanding of their local population and building their support offers according to this understanding. Embedding the carers' agenda in the wider system and building a shared awareness of the value of carers is also important. However, in the midst of all this, ensuring that carers are meaningfully involved and listened to is fundamental. We think it is fitting that the report concludes with the perspectives of carers.

*It sounds rather... well, perhaps trite, but I think the biggest priority for supporting carers is actually to provide decent services to the people that we care for, because then we wouldn't have to spend half our lives battling for what they should get anyway.*

(Focus group participant)

*I'm very conscious that you want to talk about us and our needs, but from what you've been hearing from other people and myself, unless our loved ones are cared for well and properly, we pick up the issues, and our mental health suffers considerably, and then we can't get the help either. So, it's a sort of circular thing, and there are barriers.*

(Focus group participant)

*Caring is blooming hard! It's really very difficult... I'm sorry to go on a bit about this, but I think it's hitting the core problem with the way things are going on at*



*the moment... we're fighting a battle to keep ourselves going and our families going. We shouldn't have to battle services to get support, which is what we all appear to be doing.*

(Focus group participant)

*At the end of the day, the child or the person you're caring for is happy, you as a carer are happy, and that's all you want in life.*

(Focus group participant)



# Appendix: Methodology

We took a two-phase approach to this work. The questions we were asked to explore were:

1. What more or less nascent local support is available for unpaid carers in England?
2. Of the support and types of support identified in 1, what support is considered highest priority by (different groups of) stakeholders?
3. What are the routes and barriers to accessing the identified support?

## Phase one

As part of our phase one analysis, we conducted a rapid literature review and analysis of existing quantitative datasets, as well as engaging with key stakeholders, to develop a taxonomy of support for unpaid carers.

### Rapid literature review

We undertook a rapid literature search of academic, grey and practice literature to gather existing evidence about:

- types of services provided for carers, whether directly for carers or those that benefit the carer indirectly, as well as any different models/variations in these types of services (eg, respite)
- availability of services for carers
- carer priorities
- any cited examples of good practice (ie, valued attributes and any evidence of impact) in carer support and how it is delivered (eg, combinations of support).

A search of four databases (The King's Fund Database, MEDLINE, PsycINFO, and Social Policy and Practice) and a web search (sources including the Carers Trust,



Carers UK, Care and Support Alliance, House of Commons Library, and Social Care Institute for Excellence) using search terms derived from the question list returned 378 publications, which were then screened and abstracts reviewed. A total of 135 documents were included for full review. Relevant key findings were extracted and themes summarised to contextualise the project.

### **Analysis of existing quantitative datasets**

To understand what we could learn about carer demographics and existing support for carers, we explored available data from the following sources.

- The Health Survey for England, which provides information about adults aged 16 and over living in private households in England.
- The Family Resources Survey, which provides information on the incomes and circumstances of UK households.
- The GP Patient Survey, an independent patient experience survey run by Ipsos on behalf of NHS England.
- The Survey of Adult Carers, which gathers the opinions of carers aged 18 or over who are in contact with English local authorities.
- The Adult Social Care Activity Finance Return (ASC-FR), which details the amount and type of support provided to carers by local authorities in England.

### **Stakeholder engagement**

The research team conducted informal interviews with several national and regional stakeholders in voluntary sector organisations and local government who support unpaid carers. These were followed by two online workshops to discuss and refine the initial findings from the phase one analysis. Workshop participants included the stakeholders we had engaged with, some additional national voluntary sector organisations, and PPI representatives. We limited our invites to 10 per workshop (not including the Department of Health and Social Care and colleagues from The King's Fund) to keep discussions manageable, but made sure we had a range of different voices at each workshop.





## Phase two

Based on the insights from phase one, we created a 'long list' of local authority areas that had emerged as having approaches to supporting unpaid carers from which key learning could be shared with other areas. From this list, we shortlisted four local authority areas in England to get a mix of geographies and types of support. In each of these four areas we spoke to commissioners, providers and voluntary sector organisations involved with delivering support for unpaid carers, as well as unpaid carers themselves.

We began our fieldwork in October 2022 with the initial phase of identifying stakeholders within each area. To access professionals, we initially contacted the Director of Adult Social Services in each area. We asked for four contacts who could give us a picture of the support provided to unpaid carers locally, including at least one commissioner, provider and voluntary sector organisation representative. We then arranged interviews with these stakeholders.

To recruit unpaid carers to the focus groups, we identified local carer centre contacts and liaised with them. We offered the option of in-person and online focus groups, and ensured that these were arranged at times that would be least disruptive to carers' responsibilities. All focus groups were ultimately held online. Focus group participants were offered a one-off payment to recognise their time and contribution, and we offered to cover relevant expenses such as payment for replacement care for their time away from caring.

We concluded the fieldwork in December 2022. In total, we undertook 18 interviews with health and local authority commissioners, local authority service leads, and voluntary sector carers' organisation providers (at least one of each per site). We also convened 4 focus groups with a total of 29 unpaid carers.

We recognise the limitations of these sampling methods in terms of experience and diversity of the participants. However, we were satisfied that a diverse group of carers with different experiences contributed to the research.

All interviews and focus groups were carried out online using Microsoft Teams and Zoom. Informed consent was received from all participants to record and transcribe the interviews and focus groups. We removed identifiers (names, places) from the



transcripts, and coded them against a framework developed by the research team using specialist qualitative analysis software. The research team further analysed the coded data to extract themes.

### **Advisory group and critical friends**

As part of the planning for phase two, with the support of Involve York, we convened a group of experts by experience independent from The King's Fund. This group involved four participants who are or have previously been unpaid carers. The role of the group was to advise on different elements of the project, including the scope and methodology of the focus groups and the emerging findings. The group met with the research team on two occasions during the project.

The findings of the project and draft report have been reviewed by internal and external critical friends.



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# About the authors

## **Deborah Fenney**

Deborah works in the policy team. She has a particular interest in health inequalities: her recent research topics at the Fund include disabled people's involvement in health and care design, the role of directors of public health during the Covid-19 pandemic, and the NHS's role in tackling poverty.

She is currently the learning lead for Healthy Communities Together, a four-year collaboration with the National Lottery Community Fund to support local partnership working.

Before joining the Fund in 2018, Deborah worked for two years as a senior analyst at the Care Quality Commission. Deborah holds a PhD in sociology and social policy from the University of Leeds, which explored inequalities in disabled people's access to sustainable lifestyles.

## **Clair Thorstensen-Woll**

Clair was a researcher in the policy team. Her areas of interest include population health, patient involvement and experience, and health inequalities.

Before joining The King's Fund, Clair worked for Healthwatch across three London boroughs where she led their policy and research functions and supported the representation of patient voices in local decision-making. She holds an MSc in social policy and social research from University College London.

Clair left The Fund in March 2023 and now works for The Brain Tumour Charity as a Senior Policy and Campaigns Officer.



### **Simon Bottery**

Simon leads The King's Fund's work on adult social care and is the author of its annual overview of the sector, Social Care 360.

Before joining The King's Fund in September 2017, Simon spent almost 10 years as Director of Policy at the older people's charity Independent Age, researching and campaigning on issues including care home quality, unmet needs for care, social care funding and the social care workforce.

Simon has wide experience in policy, communications and journalism, including as Director of Communications at Citizens Advice. He has also worked for ActionAid, in the commercial sector for Guinness and in BBC local radio.





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11-13 Cavendish Square  
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Email:

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Unpaid carers contribute the equivalent of 4 million paid care workers to the social care system. While many do not even identify as a carer, caring can be a big commitment and carers themselves need support with their own health and wellbeing. So why are they not always able to access the support they need?

This report looks into the support available for unpaid carers in England, the evidence available for different types of interventions, the support prioritised by carers and professionals, and the factors that impact access to support.

Based on a literature review and a review of national data, interviews with key stakeholders and four case study sites, the authors identified four insights to help commissioners and providers offer better support for unpaid carers:

- develop and maintain a strong understanding of your population
- build your local support offer according to this understanding
- embed awareness of carers in strategic-level and commissioning decisions
- pay attention to the impact of wider health and care issues on carers.

Unpaid carers play a vital role in supporting the wider health and care system and ensuring carers are meaningfully involved and listened to is fundamental to this work, so that any support truly meets their needs.

