

Caring in a complex world

Perspectives from unpaid carers and the organisations that support them

Overview

- Unpaid carers provide significant levels of support to family or friends – equivalent to 4 million paid care workers. Carers often need support with their own health and wellbeing, but they are not always able to access this.
- To understand the current picture of local support available for unpaid carers in England, we interviewed commissioners and providers of support to unpaid carers and ran focus groups with unpaid carers in four areas of England, spoke to national stakeholders and reviewed existing literature and national data sets.
- Many carers told us that access to good health and social care for the person they are caring for is vital for their own quality of life. 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.
- To better support unpaid carers locally, commissioners and services need to develop and maintain a good understanding of their populations, build local support offers accordingly, and embed awareness of carers in strategic-level and commissioning decisions. 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.
- 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. There are opportunities to align approaches to supporting unpaid carers at integrated care system (ICS) level as well as place level.

Why we did the research

Unpaid carers – anyone who provides care, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction and cannot cope without their support – play a key role in the health and care system. Caring can be a big commitment and carers themselves also need support with their own health and wellbeing. Yet, it's also clear that carers are not always able to access the support they need. We set out to understand the current picture of local support available for unpaid carers in England. We looked at what evidence is available for different types of support, what carers and professionals involved in commissioning and delivering services for carers prioritise, and what are the barriers and facilitators of access to these different types of support.

What we did

We reviewed existing literature, research and national datasets, and talked to key stakeholders: organisations who support and work with unpaid carers. We gathered insights on what's happening in local authorities in relation to types of services provided for carers, any different models or variations in these types of services and examples of good practice. We then chose four local authority areas that were identified as having approaches that others could learn from in their support for unpaid carers. 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, 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.

Differences in how 'carer' is defined may affect the number of people who identify as carers. The 2021 Census found that 4.7 million people were caring. Of these, 1.7 million provide less than 9 hours of care a week, while 1.4 million provide 50 or more hours of care a week. It's important to highlight the diversity of the many people who are carers – both in terms of their own characteristics, and the kinds of care they provide.

The Health Survey for England 2019 found that most unpaid carers were caring for family members. One in ten carers were providing unpaid care to a friend. Support was most likely to be provided for tasks such as keeping people company, keeping

an eye on them and other practical help. Help was least likely to be provided for tasks such as helping to deal with care services and benefits, personal care, giving medicines and physical help.

What we found

We developed a 'taxonomy' of the different types of support available to carers, and all of these types of support were offered in some form in our four local authority areas. But we also found that it is not possible to reliably identify good or poor practice from existing data sets, and consistent data collection and resource to understand and monitor meaningful outcomes for carers is a work in progress. However, we developed four insights based on what local people – professionals and carers – told us was important to them in terms of supporting unpaid carers locally. We hope they indicate some potential ways forward to improve support for unpaid carers.

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 and point carers 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 develop awareness of their local support offers among unpaid carers, at the same time ensuring 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 don't always reflect this diversity.

Awareness of carers needs to be embedded in strategic level and commissioning decisions. Professionals who 'get it' and advocate consistently are vital. But the work can't just rely on a few committed individuals – system-level carers' partnerships and strategies have a key role in advocating and embedding the carers agenda.

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.

Wider reflections

The four local authorities we spoke to for this research were clearly highly engaged with carer issues and had given wide consideration to their statutory duties and how they would meet them. However the thought and effort that had been put into carer support did not always translate into the support that carers wanted. At several points we noticed a disconnect between what professionals in the statutory sector were aiming to deliver, and unpaid carers' experiences of support and services.

Access to good health and social care for their loved one is a vital issue affecting quality of life for many carers, and so the wider social care context is critical. Carers said they often had to learn about how the 'system' worked in order to be able to navigate it successfully, suggesting a wider potential role for carers' organisations in supporting carers to advocate on behalf of the person they care for.

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 leadership who understand the value of carers to the working of the wider system.

About this report

This work was commissioned by the Department of Health and Social Care and funded by the National Institute for Health and Care Research (NIHR) Policy Research Programme (grant number NIHR200702). Views expressed and any errors are those of the authors only and not those of the NIHR or the Department of Health and Social Care.

To read the full report please visit www.kingsfund.org.uk/publications/unpaid-carers-caring-complex-world

The King's Fund is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible health and care is available to all.

www.kingsfund.org.uk  [@thekingsfund](https://twitter.com/thekingsfund)