

The Health Foundation's response to the House of Lords Adult Social Care Committee inquiry

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About the Health Foundation

The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK. Our aim is a healthier population, supported by high quality health care that can be equitably accessed. We learn what works to make people's lives healthier and improve the health care system. From giving grants to those working at the front line to carrying out research and policy analysis, we shine a light on how to make successful change happen.

Key points

- The adult social care system in England has been scarred by longstanding political neglect and underfunding. The government's current plans for the sector fall well short of what is needed to redress this. Significant additional investment and more fundamental reforms are needed to provide care to everyone who needs it, ensure staff are fairly rewarded, and make other improvements to the social care system in England.
- For social care reforms to be successful, people must see proposals as improvements on the current system. But the public has limited understanding of how social care operates and is funded. Improving public understanding of how the care system works may help increase support for further reform to the sector in the future.
- Longstanding weaknesses in social care data limit our understanding of important areas, including people's unmet need for care. As government continues work to tackle these problems, it must do more to consider inequalities, as well as engaging with the public and social care staff to build trust about how data will be used.
- Some aspects of social care are more 'invisible' than others. Debates around social care reform often focus on older people, neglecting the needs of people aged 18–64 years – who make up around a third of care users. Further reform and investment is needed to improve their access to services and the quality of their care.
- Government did not prioritise people using and providing social care services in the pandemic response, and COVID-19 has taken a disproportionate toll on them. Government oversight and expertise in social care have improved during the pandemic. But it has also made some existing problems in the sector worse, including workforce challenges, providers' financial instability, and people's unmet need for care.
- Unpaid carers play a vital role in society but government support for them has reduced in recent years. Additional funding and support can help unpaid carers live healthy lives, balance caring with other responsibilities, and access breaks. And without sufficient funding, policy changes and planning to support and develop the paid workforce, friends and family will be left to plug the gap.

The invisibility of adult social care and its consequences

We have focused on four aspects of the invisibility of adult social care: political neglect, public understanding, the role of data, and care for younger adults. We have also considered the status of social care in the policy response to COVID-19 and the effect of the pandemic on people using and providing care.

Political neglect

- The adult social care system in England has been scarred by decades of political neglect and underfunding. When the pandemic hit in 2019/20, spending per person on adult social care was lower in real terms than in 2009/10 and successive governments had failed to deliver much-needed reform. The impacts of this neglect are clear: many people go without the care they need, staff experience low pay and poor working conditions, and there is a high reliance on unpaid carers.
- The government's current plans on funding and reform are not enough to change this picture. Its ten year 'vision' for adult social care announced some important reforms and additional funding. But the plan stops well short of fundamental changes needed to provide care to everyone who needs it, ensure staff are fairly rewarded, and make other vital improvements to our social care system.
- We welcome the introduction of a 'cap' on the total an individual has to pay towards their care costs over their lifetime, which will protect some people against catastrophic costs. The Care Act 2014 set out that all personal care costs (including those covered by council funding for people with low assets or income) would count towards a cap. But under the government's [amendment to the Care Act](#), means-tested support does not count for an individual's progress towards the social care cost cap. This significantly [reduces protection against large costs](#), particularly for people with only modest wealth. Those in less wealthy regions will see the biggest erosion of protection –the opposite of 'levelling up'. And this change affects support for younger adults, meaning they may continue to pay for their care for decades. The policy change is a false economy.
- Social care staff are undervalued and underpaid. Most care workers are paid below the 'Real Living Wage' and zero-hours contracts are prevalent. There are chronic staffing problems, with over 100,000 vacancies, comparatively high turnover rates, lack of career structure, and burnout among staff. The government's white paper on social care provided limited solutions to these problems and nothing to improve pay. Increasing pay will require significant additional funding (see below). And any additional investment must be accompanied by action to ensure it reaches staff. This might include a minimum wage for the sector, changes to provider contracts, or a sectoral wage board – though these and other measures must be considered as part of a comprehensive strategy for supporting and growing the care workforce.
- Government funding for social care is barely enough to meet growing demand for care over the coming years – let alone improve care and provide more to people who need it. Not accounting for recent spending announcements to support the reform, the Health Foundation's REAL Centre has estimated that government must spend [an extra £9bn by 2024/25](#) to meet demands from an ageing population, improve access to care, and allow local authorities to pay care providers more to improve the quality of care (enabling increases in staff pay). Without enough money to deliver it, a vision for social care feels like hollow words.

Public understanding

- For social care reforms to be successful, people must see proposals as improvements on the current system. But the public has limited understanding of how social care operates and is funded. This lack of public understanding (combined with other factors including disagreement within government about what should be done) has contributed to [weak political action on social care](#) in the past.
- In 2018, the Foundation funded [deliberative work](#) with members of the public in England to explore their understanding of social care and attitudes towards reform. Participants had some awareness of the types of services covered by social care, and that these were distinct from NHS services. But people had limited detailed understanding of social care services and how to access them.

Most people had not thought about their future social care needs and how they might be paid for. This was largely down to a lack of awareness and public discussion about social care planning. People often assumed that they had been paying towards their future social care through taxation. Once participants were given more information about social care, they were clear that the funding model should change. People favoured the state having most responsibility for funding care – the cap is a welcome step in this direction.

- Our [latest public polling](#) from late 2021 suggests that people in the UK are not sure that social care has been fixed – only 8% agreed that the government had the right policies for social care. But 58% supported the decision to increase taxes to spend more on the NHS and social care and only 22% opposed it.

People in the UK are increasingly pessimistic about the state of social care – more pessimistic than about the NHS. In 2021, 69% thought the general standard of social care services had got worse in the last 12 months, compared to 41% in May 2020. This may partly reflect growing awareness of the pandemic's impact on social care and gaps in the government response. But our polling also suggests that public understanding of social care remains low. Half of respondents were neutral towards the quality of local services, likely linked to limited knowledge of them – those who either worked in social care or had used social care in the past year were more likely to give an opinion.

- Awareness-raising measures must be part of the government's implementation of the cap on care costs, to help people understand the support they can expect from the state, so that they can plan and prepare for their potential future care needs. Improving public understanding of how the care system currently works may also help increase support for further reform to the sector in the future.

The role of data

- In social care, there are [longstanding weaknesses](#) in how data are collected, shared and used. Data gaps limit our understanding of important areas including unmet need, unpaid carers, and the [provider market](#), affecting support for people who need care. And unlike in the NHS, there is a lack of timely data on performance in social care. Poor data also [affected protection from COVID-19 for people in social care](#). A member of [SAGE's Scientific Pandemic Influenza Group on Modelling](#) has said, 'we did not even know how many people were in care homes [in late March]. We can only generate models from the data available.'

- Good social care (wherever it is provided) requires a range of information, such as operational data to manage staff travelling between locations or administrative data to meet regulatory requirements. It also needs information about people with care needs and how they want to live. Last year, the Foundation and Future Care Capital held [workshops on social care data](#) with people using and providing care across the UK. People agreed that the system does not currently collect data about what matters to people who need care. People using care and their carers said that data are currently used to restrict their access to care, rather than empower them, and they often could not access data about themselves.
- The Health and Care Bill's provision for public and private care providers to share client-level data [should help address some structural data problems](#) in social care. But the focus continues to be on outputs (such as data on capacity) and less on improving data on people's outcomes and experiences. Government must be clear about how data will be used and engage with the public and social care staff to build trust.
- There was [much to be positive about](#) in last year's draft data strategy for health and social care – the latter featured prominently, as did the importance of data analytics capability. It is important that this capability is built across all social care settings, and not just care homes and the NHS.
- We still have little detail about some commitments in the draft data strategy, for example on an adult social care data framework. And proposals did not account enough for the complex relationship between data and inequalities. For example, increasing people's access to their own data risks some having more information than others, if inequalities in digital access are not addressed. In the final strategy later this year, government should include clearer commitments and more to tackle inequalities.

Care for younger adults

Debates about social care reform often focus on older people. But policies to improve social care will not be successful unless they also reflect the needs of younger adults.

People aged 18–64 years with learning disabilities, mental health problems and other social needs make up around a third of care users and over half of local authority spending on social care. [Health Foundation analysis](#) has illustrated some of the differences in care needs, services and outcomes between younger and older adults and their carers in England. Key findings with implications for policy include that:

- Growing numbers of younger adults need care. For example, the number of people with severe learning disabilities is projected to increase by 34% between 2017 and 2027. More nurses will be needed in future to care for them. Yet learning disability nursing courses struggle to attract students, have particularly high drop-out rates, and are becoming financially unsustainable.
- Many younger adults are likely to be going without the care they need. Estimated care needs have grown over the last decade, but the number of people accessing public support has fallen. Spending has not kept up with demand.
- Quality and outcomes vary for younger adults who draw on social care services. Most younger adults report being satisfied with their care. But there is evidence of very poor

care, and national targets to support more people with a learning disability or autism to live in the community have been repeatedly missed.

- Fewer younger adults fund their own care compared with older people, likely since most younger people will have built up fewer assets over their lifetimes than older people. This means that the government's reform to the funding model will do little to improve the lives of many younger adults with care needs. Further reform and investment is needed to improve their access to services and the quality of their care.

The COVID-19 pandemic

- The pandemic has taken [a disproportionate toll](#) on people who need and provide social care. The impact of years of political neglect of social care was laid bare for all to see. COVID-19 exposed longstanding problems, such as system fragmentation and the government's lack of oversight of the sector, and made some problems worse, including workforce challenges, providers' financial instability, and people's unmet need for care.
- During the pandemic's first wave, central government support and protection for people using and providing social care was too little, too late. [Our analysis of the response in England between January and June](#) shows the lack of priority given to social care compared to the NHS.
- Over time, [social care was afforded more attention](#) in the national pandemic response – although gaps in the response remained, including support for the workforce, younger adults with learning disabilities, and unpaid carers. The pandemic response has helped increase government oversight and expertise in social care. For example, data for policy makers improved and the Department of Health and Social Care boosted its policy team. Government must continue to strengthen its capacity, expertise, and leadership on social care policy so that it can effectively support local authorities and care providers.
- Providers have lacked financial resilience for many years, but this has become more apparent during the pandemic. Occupancy in care homes fell [from around 90% at the start of the pandemic to around 80% in February 2021](#). Care home profit margins declined through [October 2020 to March 2021](#) to the lowest level since CQC records began in 2015. And in spring 2021, over half of social care leaders reported to ADASS that [providers in their area had closed, ceased trading, or handed back contracts](#) in the past six months. Increased funding is vital but insufficient to address the precarious position facing care providers. There is likely a growing case for [more government intervention or regulation](#) to address market failures. And we need a better understanding of how the market currently works (particularly for self-funders).

Better support for unpaid carers

Most social care is unpaid and informal. The UK has a high level of informal care compared to [other OECD countries](#) – it is estimated that there are [over 5.8 million unpaid carers](#). Here we briefly outline evidence on the issues facing unpaid carers – from before and during the pandemic – and the implications for government support.

Caring before the pandemic

- [Health Foundation analysis](#) before the pandemic showed that the quality of social care services for unpaid carers varied. In the NHS Digital survey of adult carers in 2018-19, 64% of carers of people aged 18 to 64 were satisfied with services, compared with 73%

of carers of older people. Nearly half of younger adults' carers found it difficult to find information about services, compared with a third of carers of older people.

- Without support, unpaid carers can experience financial issues and physical and mental health problems. Half of all carers said that caring had caused them financial difficulties, and one quarter of all carers reported developing health conditions because of their caring role. [Our analysis](#) found carers of younger adults reported worse outcomes than carers of older people. This may be partly because carers of younger adults are more likely to be younger themselves, female, and have additional caring responsibilities.

Caring during the pandemic

- The COVID-19 pandemic has significantly impacted unpaid carers. Carers UK and others have highlighted that more people have had to provide unpaid care since the start of the pandemic. [Health Foundation analysis](#) found that two in three people providing care during the second wave had not previously been providing any care.
- Caring responsibilities are not shared equally. In [the second wave](#), nearly 70% of carers providing 20 or more hours of unpaid care each week were women. Carers with Bangladeshi, Caribbean, Indian and Pakistani ethnicity were more likely than others to provide very high levels of unpaid care. Carers providing 20 or more hours of care a week also reported worse health and over 60% had multiple long term conditions.
- [Our assessment of the pandemic response](#) in social care found persistent gaps in central government support for carers. In the first wave, respite services enabling unpaid carers to take breaks from caring often closed, and government provided minimal support to reopen them. Guidance for carers was often [unclear, delayed or outdated](#).

Government support

- The recognition of carers in the white paper on adult social care and the £25 million put forward to improve support for unpaid carers are welcome. But this follows years of reductions in government support. Spending on support for carers [decreased in real terms by around 30%](#) between 2014/15 and 2018/19. [The number of carers accessing support has decreased by 35%](#) in recent years.
- Additional funding and support can help unpaid carers live healthy lives, balance caring with other responsibilities, and access breaks. And without sufficient funding, policy changes, and planning to support and develop the paid workforce, unpaid friends and family will be left to plug the gap.
- Our analysis also shows that government support for unpaid carers must better reflect their diverse needs. For example, carers of younger adults are more likely to need support remaining in employment or education, as well as accessing state support. And greater policy attention must be paid to the needs of carers from ethnic minority groups.