



Why We Care

The reality of working in a social care system in crisis

February 2024



Foreword from our CEO



As a care provider and a charity that campaigns to improve the lives of people with a learning disability, we want to pay tribute to everyone working in social care, shine a light on their motivation to give back to society and showcase the breadth of skill required to support people with a learning disability. In this report, we share the findings from our survey with hundreds of frontline workers, highlighting what it's really like to work in social care, why so many are leaving the sector and we make recommendations on how it can be fixed.

At Mencap, we provide frontline care to more than 4,000 people with a learning disability and every day it is a privilege to see how our dedicated and compassionate staff enrich and add value to the lives of people they support and their families.

Sometimes they are helping people achieve huge milestones, supporting them to go to college, set up home

or get a job. Other times they are showing acts of kindness which might seem small but make a huge difference to the people we support. Our social care workers, who are doing such a crucial and important job, are facing huge challenges because of the lack of funding for social care.

Local authority finances are in a perilous state. They are only able to pay social care providers from the funding they are able to raise themselves and that they get from central government. Sector-wide low pay combined with the rising cost of living means many people working in social care are having to cut back on basic necessities or work long hours to make ends meet.

Hundreds of thousands are leaving the sector each year¹ and this then puts pressure on existing staff to plug the gaps.

People with a learning disability and their families are missing out too, unable to access the full amount of care they need because there aren't enough staff. Sometimes families will shoulder the care themselves or people with a learning disability will find their life is limited without support to make friends or get out into the community.

Like 90 per cent of the public², we believe those working in social care do not get the recognition they deserve.

Today, we are launching our Why We Care campaign, raising the profile of our brilliant support workers.

We are calling on all political parties to commit to:

- **A national long-term plan for social care workforce**
- **An £8.4 billion immediate cash injection into social care**
- **A minimum pay for social care staff that reflects similar roles in the NHS (band 3)**
- **A cap on agency charging**

[We urge people to sign our petition.](#)

Sign it if you work in the social care sector, if you or your loved one receives social care or if you simply believe we should live in a society where people with a learning disability are supported to live the life they deserve. By coming together and campaigning for change we can show that we care about those who care.

Jackie O'Sullivan
Acting Chief Executive, Mencap



Sign our petition

Our findings

A third (34%) of frontline staff surveyed proactively told us that they took on the role because they wanted to give back to society and improve the lives of those they supported.

A quarter (26%) said they were having difficulty recruiting and retaining staff and said this led to existing staff working significantly longer hours.

Two-fifths (39%) of people surveyed said they were facing financial difficulty as a result of pay in the sector.

Almost a third (28%) said the long hours affected their work/life balance and 1 in 6 (14%) said their mental health was affected.

A third of people have left the sector for good, enticed by higher wages in other sectors such as retail and logistics.

We are calling for:

- An £8.4 billion immediate cash injection into social care
- A minimum pay for social care staff that reflects similar roles in the NHS (band 3)
- A national long-term plan for social care workforce
- A cap on agency charging



Social care in crisis

Social care is in crisis, facing an increase in demand, a stagnant workforce and chronic underinvestment.

While the UK has an ageing population, 35% of social care in 2021/2 in England was for working age adults.³ Disability among working age adults has increased by 23% in the last decade⁴ and over the last five years, an estimated 87,000 more people of working age have requested social care support - a 15% rise.⁵

But as the number of people needing care rises, the provision is falling.

Hundreds of thousands of people working in the sector are leaving their jobs.⁶ Sector-wide low pay is one reason.

As of March last year, the most recent data showed that on average, a support worker gets paid £10.03 per hour just over minimum wage.

A third of people have left the sector for good⁷, enticed by higher wages in other sectors such as retail and logistics.

In 2021/22, over 205,000 adults aged 18 to 64 in England were not provided with adult social care support when they requested it.⁸

Even when people do get funded care

approved, they may wait months to receive it. In Spring 2023, the Association of Directors of Adult Social Services reported that 434,243 people in England were still waiting for an assessment, a review of their care plan, or revised care and support. For many – around 82,000 – the wait is over six months.⁹

Experts say that to meet the demand for staff by 2035, not only do these existing posts need to be filled- there will be a need for 480,000 additional social care roles.¹⁰

Providing short-term grants, rediverting funding from reforms, and one-off cash injections prevent the social care sector from putting long-term plans in place, and addressing issues with the workforce.

A lack of local authority funding is putting huge pressure on Integrated Care Systems, local authorities, NHS Trusts and social care providers who are responsible for improving health and care across England.

Local authorities are legally required to provide social care under the

Care Act 2014 but worryingly three quarters of Directors of Adult Social Services across English councils say they are not confident about being able to fully offer the minimum social care support required by law in their communities.¹¹

In a Local Government Association survey of council leaders and chief executives, 1 in 5 said it was very or fairly likely that their local authority issue a Section 114 which alerts when a local authority's expenditure will exceed its resources.¹²

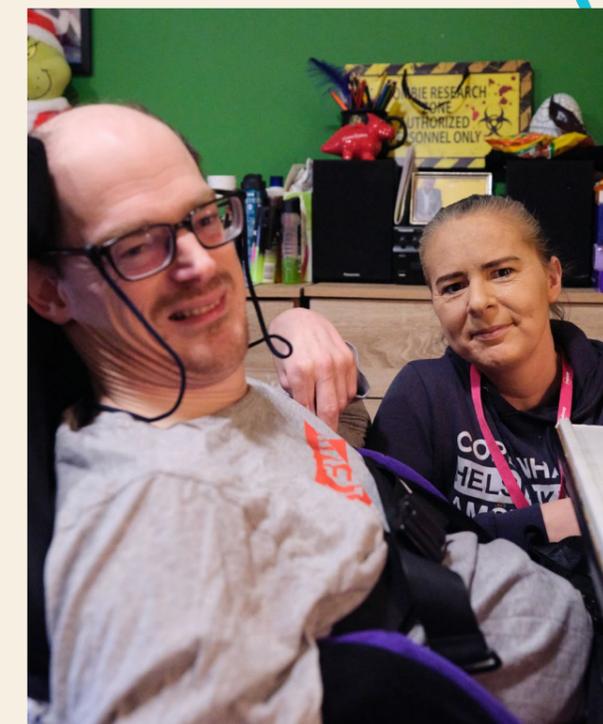
Social care providers, like Mencap, are constrained, only able to pay staff what they receive from local authority contracts, which hugely varies. In recent months, Mencap has had to reject contracts from local authorities because the funding that is offered does not match what is needed to deliver good quality social care.

Other charities are experiencing the same challenges. Research from the National Charity for Voluntary Organisations (NCVO) reveals that **73% of charities surveyed say they cannot meet the current demand for the public services they deliver with the funding they receive**¹³ due to increasing demand, higher operating costs, and no uplifts in line with inflation.

People might question why Mencap does not subsidise the pay our support workers get from other

funding sources. But the income we receive from funders and generous donors is used to fund a range of other much-needed services, such as our helpline, outreach programmes for people with a learning disability and families, and to campaign for change to outdated laws like the Mental Health Act. It would also fail to resolve the wider issue of chronic underfunding. The money to pay for social care must come from government.

We know more needs to be done to help support workers and a core part of our engagement with the UK government is pressing the case for greater social care funding and the need to tackle the issues facing the social care workforce.



What does a support worker do?

The role of supporting people with a learning disability can vary greatly.

Some people with a learning disability can live independently within the community and only need limited support with things like getting a job or managing their bills. Others may need full-time care and support with every aspect of their life and may also have physical disabilities.

Every day, social care workers support people to cook their favourite meal, buy something from a shop, go to college, make friends, or even achieve milestones like get married, get a job, and set up home.

People providing social care for people with a learning disability commonly need training in first aid, epilepsy, dementia or end-of-life care, medicines, medical feeding procedures and finances. They might be the sole person responsible overnight for looking after a vulnerable person, ensuring they get the medication to stay well or they might have to deal with challenging behaviours. However, many of the frontline workers we spoke to felt that the public did not fully understand the breadth of the work they do.

Whatever level of support people need, the 6,000+ frontline staff at Mencap are there around the clock.

“Often, we take our day-to-day lives for granted. Imagine you don’t have a learning disability and you are making a drink, cooking a meal, attending the doctors, and how easy it is for you to complete these tasks. Now imagine you cannot do these tasks, because you don’t know how to turn on the kettle, you don’t know what foods are required to make your meal, you don’t know where or how to get to your doctor’s. This is where I step in and offer you support and guidance along the way, I am your safety net, your advocate, your advisor, I make sure you are supported to be as independent as possible.”



Motivated by a sense of purpose

We spoke to staff who had been motivated to work in social care because they had cared for a loved one and felt it was a way they could share their skills and experience, with more than a quarter (27%) describing their role as rewarding, and others describing it as a 'privilege' or 'honour'. One told us:

"I work in social care because the relationships you build with the people we support are the most precious and amazing thing ever."

Mencap's frontline staff are a range of ages with varied journeys into social care. Some had been teachers, social workers, worked in retail or recruitment, or had been carers for their loved ones. But whatever their background, the common theme we heard from more than a third of staff (34%) was that they were motivated by a sense of purpose.



"It is a field that provides an opportunity to have a positive impact on society while fostering personal growth and fulfilment."

"I want to improve the lives of people in my community and strongly believe that we need to actively support all people regardless of disability or any other issue. I feel that we need to look after the disadvantaged and vulnerable."



Ray, a support worker from Liverpool, tells of the impact his work has on the families of people with a learning disability:

"A mum of a lad we supported came to see me in tears. She hadn't thought her son was capable of anything so she did everything for him but following our support he managed to travel home on public transport unsupported and when he arrived home, he asked her if she would like a cup of tea. He produced a perfect cup of tea and a sandwich cut into triangles, on a plate on a tray and served it to her. She was amazed and so grateful for the support he had received"

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"I left a long career in retail to pursue my passion and make a difference to the lives of people with a learning disability"

Shahid, 66, is a service manager at Churchfields, a Mencap-supported living service in Witham, Essex

"I left a long career in retail to pursue my passion and make a difference to the lives of people with a learning disability and along with my amazing team we support around 26 people of different ages, with different levels of intellectual ability. They are like an 'extended family.' We know there's no 'one-size fits all' when it comes to caring for someone with a disability.

Our job is to help them access the best opportunities and lead the life they want. It's highly skilled and rewarding work, particularly when you are helping someone who may find it harder to advocate for themselves or communicate in a way that's different to what we typically understand or expect in society.

We feel close to everyone we work with but a career highlight has been seeing love blossom between two of our residents - Barry, 67, and Betty, 78, a disabled couple living in opposite houses. We helped their relationship to flourish, even resulting in a marriage proposal!

Betty has a learning disability and cerebral palsy and uses a wheelchair. Barry has the same lifelong conditions and is registered deaf. We help them in the ways some people might expect - such as supporting their personal care routines, choosing their clothes, meals, and daily activities - but we have also really helped them have a loving relationship.

We worked closely with Barry and Betty to bring new opportunities into their lives and give them the agency to make choices as a couple. I made sure they had time together at each other's homes and that it was built into their care plans, arranging 'dates' to the cinema and the local theatre. I got Barry his own disability passport and car so he has more flexibility to go where he wants, such as for physiotherapy at the local pool, to a local boxing tournament, and even on holidays. My team even helped Barry with his marriage proposal to Betty, and choosing her engagement ring! We're enabling Betty and Barry to live the lives they want and deserve and it's the greatest privilege to do that."



Support workers regularly go above and beyond their job role.

I want the people I support to live - spectacular lives and I get a buzz knowing I have changed someone's life (Catharine, 57, Hexham, Northumberland) →

Caring for my husband after a brain haemorrhage spurred me on to give back and become a support worker (Nikki, 48, is a support worker) →

Why are so many social care workers leaving the sector?

1 in 3

of support workers said **long hours** affected their work/life balance

1 in 6

frontline staff felt their **pay is unreasonable** given the level of skill needed

1 in 4

of support workers said they felt their role was **undervalued** and **unappreciated** by society

1 in 6

of frontline staff said their **mental health** has been **affected** by the challenges in social care



"Support workers like me feel forgotten"

Catherine, 57, Hexham, Northumberland

"I've been a support worker for over 30 years and I feel so passionate about the job I do. You're helping people to do the things most of us take for granted and live the best lives they can.

The role is really varied, I might be supporting someone with their job application or interview practise, hold their hand as they go through chemotherapy treatment or be a shoulder to cry on when their loved one dies. You get to know your clients and what will make their lives better and you want to do everything you can for them.

I choose to be a support worker because the people we support could be us – our kids, our brothers and I want the people I support to live spectacular lives. I get a buzz from knowing I have changed someone's life.

Sadly, I think support workers are invisible and forgotten by society. People don't realise everything we do for the people we support and how we enrich their lives. Without us, some people will be unable to shower, go to the shops or get their medicine from the cupboard. Some people you see



working in shops and cafes with a learning disability wouldn't be able to work and be such a valued part of the community without us.

The current social care system is unsustainable for people working in it. I am being really affected by the low pay, working many hours of overtime each week to make ends meet. I have used food banks and I worry about my car giving out – it's 14 years old.

There is little difference in pay across the sector between new recruits and experienced staff, and other jobs offer more money for much less responsibility. But I have such bonds with the people I support and I can see I'm making a difference. As staff you turn up to someone's house every day for six months and they share their life history and their story so it's sad when I hear about people whose support worker has left. That person they have built a relationship with has just gone from their life."

"People are working back-to-back shifts because there is no one else to do the work"

Danielle, 30, is a service manager who lives in Sheffield

"As a manager, we have seen a real issue with recruitment and turnover, with staff not being able to afford to have a work/life balance or having to do lots of extra hours. People are moving into the private sector or getting a job at supermarkets. It makes me so sad because the people that really care and hang on in spite of the pay are the ones who are the best for the job because they really want to give their all. But everyone has a breaking point.

Often there aren't enough people to do the shifts because of unfilled vacancies or people being unwell or on annual leave. We have a duty of care to the people we support so I will often step in to cover the shifts even if I have worked all day and then have to do a night shift. If I can't help, whichever support worker who has been working on day might have to carry on working, doing back-to-back 14-hour shifts. It's classed as an emergency situation but it happens all the time. These people are having to drop everything to carry on working, social plans or even arranging childcare. It's no wonder people look for jobs with less pressure.



Like everyone, I am affected by the pay and cost of living. I walk to work because of the cost of fuel. I skip breakfast and lunch to save money and focus on one meal in the evening. I always get the yellow label items from the supermarket at the end of the night.

My team sometimes find it hard if the people they support want to go out for lunch or to a café. It's our job to support them to do this but sometimes the support worker can't afford to get a cup of coffee, which can lead to difficult conversations with the people we support.

A lot of people take our industry for granted. If you think about all the different things you do in your life – going to the doctors, going to work, even making a cup of tea – we help people to do that. It's having the skill to work out what's missing and the passion to fight for someone so their voice is heard."

[Read more stories](#)



Impact on people with a learning disability

The challenges facing the social care workforce are not only affecting frontline staff but people with a learning disability and their families too.



In 2023, Mencap received more than 1,000 enquiries to its helpline with people needing information or advice about social care. We are hearing about people with a learning disability who have had funding cut from 60 hours to 15 hours each week, with no explanation and other shocking stories such as support workers stepping in when there has not been adequate mental health provision within the community.

“One of the people we support had a mental health crisis. She was banging her head against the wall repeatedly. I called social services and was told she would get emergency support – but that would take 48 hours. I couldn’t let that woman just keep banging her head against a wall, so I went to see her, supporting her for two hours until she calmed down. I then had calls from her on and off throughout the night. I can’t imagine what would have happened if I hadn’t been there.”
Service manager

There is also a real concern that the social care crisis is removing the consistency of care that many people with a learning disability need as agency workers step into fill gaps in care.

Guidelines from the National Institute for Health and Care Excellence (NICE)¹⁴ advise that continuity of care can have a considerable impact on someone’s

wellbeing and quality of life as it can lead to forming positive relationships with care workers.

But frontline staff tell us that high staff turnover within the sector can mean a reliance on agency workers.

“So many skilful and able workers have been lost from the service because of poor wages, the result has been an increase in agency staff, which costs more and leaves the people we support nervous and worried, not always knowing who will cover a shift.”

“My client needs routine and any disruption to it can really affect his mental health and wellbeing. When one of his support workers fell sick, I ended up covering their shifts as well as my own. I knew if I didn’t and agency workers went in to see him, people he didn’t know, he’d end up not doing anything. He wouldn’t go out. He’d just sit in his chair all day staring at the wall. The relationships and trust we build with the people we support is important. Consistency of care is important”

Getting the right support worker for our son has been an ongoing nightmare

Jenn Smith, 37, from Hull is mum to Alastair, 20, who has Angelman Syndrome and epilepsy. They've faced huge challenges getting support workers to help Alastair because of government underfunding.

"Alastair is creative, loving and, like many young people, into skateboarding and surfing. He also has complex needs due to his learning disability which means he needs help with personal care, eating and communicating as he is non-verbal. This means when it comes to having a support worker, he needs someone who shares his passions, can get to know him and his non-verbal cues and give him tailored support. Until five years ago, I was doing all of Alastair's care with support from my husband Adam, 38.

Trying to juggle it with my job as a graphic artist and ensure Alastair got everything he needed was a huge amount of pressure and affected my mental health.

In 2018, the local authority assessed us and said Alastair needed 2:1 care, Monday to Friday. Initially we tried an agency who employed trained carers but they sent different people each time and often they didn't know or

understand Alastair so he would get frustrated. On one occasion they sent one of their office staff. I was furious that they would be so dismissive of the support someone with such complex needs would need.

Eventually we found Alastair a fantastic support worker called Jon* and they built an incredible bond over five years. Jon could tell from non-verbal cues what Alastair needed such as if he was thirsty or needed personal care. We self-funded Jon to attend a course to learn symbol-based language so the communication between the two of them was great – which meant Alastair was better understood and his needs met.

When Jon left the sector in November 2023, we struggled again to recruit new carers, and it took even longer to support and train them to fully understand Alastair's needs. We picked up the gaps in Alastair's care and now manage a team of six, who



provide most but not all of Alastair's assessed care needs. We are only able to pay minimum wage for this hugely important role due to government funding and have seen people turn to other roles that can pay more. All training is either given or funded by ourselves so the role has no official progression and no chance for career development.

When there are too few staff in social care it's people like Alastair and our

family that suffer. Alastair's 'voice' is often not heard, he has feelings of overwhelm and he misses out on having someone he bonds with who really 'gets him' and his needs. The government needs to recognise the important role carers play, how complex the role can be and fund it properly so people get a fairer wage and stay in the sector longer."

Recommendations for change

With a general election looming we are urging all political parties to take action to address the social care workforce issues:

1. Inject £8.4 billion into the social care system immediately →

Experts say that the government needs to invest £8.4 billion in 2024/25 to meet future demand, improve access to care and cover the full cost of social care.¹⁵ Properly funding social care will enable providers to recruit more social care staff and retain them. Reducing turnover will cut recruitment costs, the cost of training new staff and paying agencies to cover gaps in staffing.

Investing in social care will also have a wider impact on boosting the economy as for every £1 invested in social care, £1.75 is generated in the wider economy.¹⁶

2. Provide a minimum wage for social care staff that is similar to NHS band 3 staff →

Social care workers are skilled professionals and their pay should reflect that. We want social care professionals to get paid a minimum wage that is similar to NHS band 3 professionals who often have similar duties. If a workforce feels valued and properly compensated for the level of work they do, they are more likely to stay in their roles giving people with a learning disability the level of support and consistency they need to thrive.

3. Commit to introducing a National Long-Term Plan for the social care workforce →

Tackling the issues facing social care recruitment and retention requires a national approach. The next government must commit to developing a long-term funded plan for the social care workforce. This plan should clearly set out how the social care sector will recruit and retain a workforce to meet need across the entire nation. Planning on a national level will remove gaps in the provision of care and help to tackle the backlog of people waiting for social care. It will also relieve pressure on the NHS as the right community-based care can help prevent people developing health conditions that require hospital treatment. It will also speed up discharge by putting the right support packages in place when people are ready to leave.

4. A cap on agency charging →

The issues with retaining a social care workforce is leading local authorities and providers to rely on agencies to fill the gaps in care but this is expensive. Spending from learning disability social care providers was due to triple from 2021 to 2023.¹⁷ By government introducing guidance setting out a cap on spending for providers, it will leave more money to spend on the development of the existing workforce.



Data source

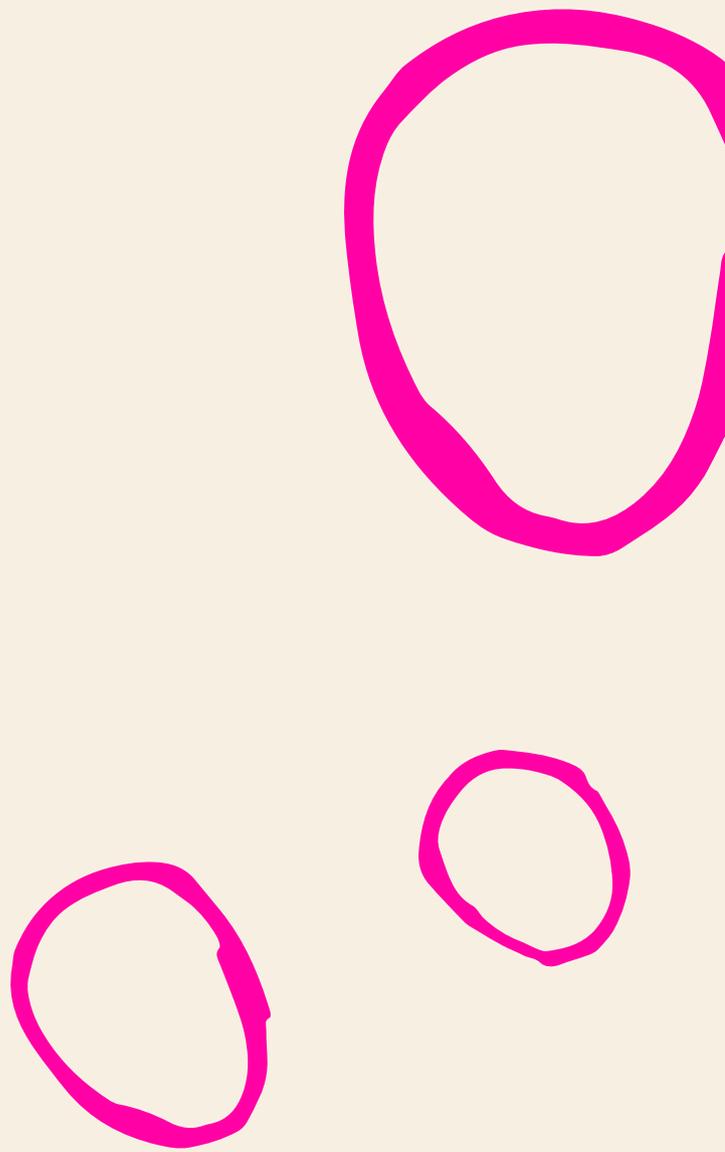
We surveyed 366 frontline staff supporting people with a learning disability including Mencap support workers, assistant service managers and service managers between 6 July and 27 July 2023 via an online survey, a printed survey with a Freepost address, voicemail, and email. We asked what motivated them to work in social care and how the impact of government under-funding of social care was affecting them. We removed duplicated responses and then analysed them and grouped them into themes including reasons why people work in social care, the financial impact of pay on support workers and how this directly affects workers health and wellbeing.

Acknowledgement

We want to express our huge thanks to all of Mencap's incredible staff who make such a difference to the lives of people with a learning disability and to everyone we surveyed who generously and honestly shared their insights and stories so we can shine a spotlight on what it is really like to work in social care and campaign for change.

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