

Adult social care position statement (October 2023)



"Social care support helps disabled people like me live the lives they want. But it's not getting the attention or funding it deserves. There are great things happening every minute of every day. I want people to know our half of the story and join our call for change."

Scott Watkin BEM, Head of Engagement

People with a disability should be able to live their life in the way they choose, like anyone else. SeeAbility is a charity whose vision is: ***'For inclusive communities where people with sight loss, autism, and learning disabilities participate as equal citizens.'***

The vast majority of people SeeAbility supports have a learning disability, or autism, or both, and many also have a visual impairment. We support people primarily of working age, who are funded by local authorities and occasionally by the NHS.

Social care is not just about personal care needs, but about support to develop friendships, relationships, and becoming an active member of the community and accessing opportunities such as employment. So much commentary on social care sees it as a service that helps prop up the NHS and ignores how critical it is for many working age disabled people's lives. This is why it needs to be valued in a different way.

We support the vision of the Social Care Futures movement¹, promoting social care as a solution, not a problem: **"We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us."**

Social care funding overview

SeeAbility supports people that can need a lot of help from social care services, as well as the NHS, housing, education and benefits system. We know what it is like to try and make systems and services work well

¹ See Social Care Futures <https://socialcarefuture.blog/>

around the person, and rely on our workforce and volunteers to deliver person centred social care support.

The number of people who need social care support grows each day, and often overlooked is that many of these people will be of working age. In fact long term social care expenditure across the age bands is now almost the same, with 50% relating to adults aged 18 to 64.

It is increasingly apparent that social care is under pressure like never before. This has been starkly exposed during the Covid pandemic, with new cost of living pressures exacerbating the issues further.

As MPs on the Health and Social Care Committee recently stated: *“The case for making a sustained investment in social care has never been stronger—the toll the pandemic has taken on this sector means that social care is no longer a hidden problem, but one that the country as a whole understands. We urge the Government to now address this crisis as a matter of urgency.”*²

The funding gap in adult social care

Prior to the pandemic it was estimated that £7.7 billion in savings had been made to adult social care budgets in the last decade. This is because funding for councils (including those responsible for adult social care) has dropped by 55% since 2010.

While there have been short term injections of funding into social care and more recently for Covid related costs (such as PPE), but there is agreement that the underlying funding gap across all aspects of adult social care is not being addressed – with immediate calls to put at least £7 billion back into the system each year and specifically focus on workforce pay and conditions.

More on the facts and figures around funding, numbers of people supported and the social care workforce is in the **Appendix**.

² Health and Social Care Committee (2020). Social care: funding and workforce

Social care for people with learning disabilities and autism

The result of underfunding means many people with learning disabilities or autism aren't receiving social care, or are relying on family and friends for their care and support. This affects not just those with milder learning disabilities but also those with higher support needs.

The scaling back of preventative support can mean that people with a learning disability or autism are not able to live an ordinary or fulfilling life. This can leave people's needs escalating, with admissions to hospital, particularly if people are unsupported with their visual impairment, sensory/behaviour related or medical needs. People are also waiting longer for assessments of support – this includes unpaid/informal carers who are also filling the gap.³ During the pandemic, it was estimated that an additional 4.5 million people in the UK had become unpaid carers for family/friends, with 10.58 million people now acting as unpaid carers.⁴

Despite national guidelines to assess individual need and a drive towards people having their own homes and tenancies, people also say they don't have enough choice of support and care. For example, SeeAbility supports some younger people who had previously been 'placed' in older people's nursing homes. Although commissioners increasingly favour supported living, there are concerns about the progress of the personalisation agenda in social care and how much choice and control people who draw on social care really have.

There are still just over 2000 people with a learning disability, autism or both⁵ in NHS funded assessment and treatment units due to behaviour that is described as challenging. Progress with the national programme intended to address this seems to have stalled, with hospitals still long term homes for some people. The majority of people could be better supported in the community, at a lower cost and in a much less restrictive way. But there needs to be the right investment in community care, and the right support for individuals. Many have been separated from their families who have been excluded from decisions on their loved one's care.

The Covid 19 pandemic and social care

During the pandemic, it became even more obvious that people with learning disabilities were being forgotten in the crisis, with a focus on older people's nursing and care homes for testing and vaccination plans,

³ See ADASS 2023 Spring Budget Survey.

⁴ See Carers Week 2022 research report "Make Caring Visible Valued and Supported".

⁵ NHS Digital Monthly Learning Disability Statistics July 2023 update

despite people with learning disabilities being up to six times more likely to die from the Covid 19 virus than the general population⁶ and already known to have a lower life expectancy due to avoidable health issues and discrimination. Being from a black or minority ethnic (BAME) background and having a learning disability is known to compound these issues further.

Many thousands of people with learning disabilities live in their own homes with care and support (including supported living), rather than residential care. Good accessible information, infection control and testing was just as vital for keeping safe, as well as for their support staff and families but many felt left behind. Reports of isolation and loneliness, (something that people with learning disabilities already experience high rates of) dramatically increased, and it was not easy for some to make connections or replace routines with a digital alternative. Temporary funding for digital support or upskilling the social care workforce was found but many of these initiatives have now ended.

Now there are new barriers and concerns that people using social care have, such as the cost of living and rising bills.⁷

Vision impairment in social care

Vision impairment is very common in people with learning disabilities, yet there is low awareness of this fact within social care provision and the impact that vision problems can have on a person with learning disabilities or autism. This can risk people needing more social care support if they aren't supported to access regular sight tests that can help prevent and address sight loss, and lack of recognition of existing sight problems. For more on the research into this and the policy solutions, see SeeAbility's eye care policy statement.⁸

Vision rehabilitation aims to help people adapt to their vision impairment through providing training in daily living skills, mobility, and communications, and supporting people to feel more confident and independent. However local authority vision rehabilitation services have been a casualty of cuts, and interventions can be time limited to six weeks or even 'one off' in terms of rehabilitation support. SeeAbility

⁶ Public Health England "Deaths of people identified as having learning disabilities with COVID-19 in England in spring of 2020" (November 2020)

⁷ See the ongoing "Coronavirus and people with learning disabilities study", Warwick University <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/>

⁸ See www.seeability.org/our-policies-publications/policy-positions/eye-care-learning-disabilities

continues to provide our own 'in house' vision rehabilitation for people we support because of this.

Providers of care and support

SeeAbility is achieving well above the national average CQC rating of 83% good or outstanding in social care with 100% of our services rated 'good'. The specialisms we offer, around positive behaviour support, autism, eye care, and vision rehabilitation, while engaging with initiatives such as STOMP (to reduce overmedication of people with learning disabilities) provide good outcomes for the people we support.

We are aiming to do more to understand how our support improves people's quality of life, and be ambitious for the people we support through fundraising, social inclusion and supported employment programmes to enhance the services we provide. However, as funding pressures continue to bite particular issues have arisen for SeeAbility and the people we support:

- While each provider must attract staff with competitive pay and quality training, it is always within the limitations of local authority or CCGs (now Integrated Care Boards) care funding. This means social care remains a lower paid career where wages are aligned to the national minimum/living wage, giving the perception that social care is 'low skilled' when in fact it is a highly skilled job providing increasingly complex support and social value. The pandemic threw this into sharp relief when social care workers were at the frontline, putting their lives at risk, to ensure that people were still supported through the crisis. Even the Real Living Wage is not a pay rate most commissioners are prepared to offer in their fees.
- Matters are made worse by the lack of a national social care workforce strategy, despite the calls for one and an immediate boost to pay to recognise the sacrifices of social care staff during the pandemic and bring parity of esteem to that of the NHS workforce. Piecemeal funding and current government policy on the workforce⁹ is not addressing the fundamental issue of pay.
- Retention is crucial in giving people we support continuity of care, and while our turnover rates are better than the sector average, new recruits can leave within the year. There is competition within the

⁹ DHSC. Next steps to put people at the heart of care. April 2023

social care sector given the number of vacancies, and from the private sector - particularly retail. The pandemic temporarily attracted more recruits to social care, but this has dissipated since the economy has opened up more and there are now an estimated 152,000 vacancies, in spite of government funded advertising campaigns.¹⁰ The knock on effects of this include an increased reliance on agency staff, which again impacts on both costs but also continuity and quality of care.

- Councils can seek to reduce packages of care, such as querying the need for one to one support even for people with lifelong and multiple needs. Cuts to advocacy services means it can be difficult to signpost people we support to independent help. Care and support generally continues to be about the 'basics of care', yet creative support around what people want and require, and inclusion of families, can deliver better outcomes related to a person's happiness and quality of life.
- The 'line' between what is long term social care support and NHS funded long term care is blurred and inconsistent. This can lead to repeated reassessments or delays in agreeing funding. There is also limited communication with social care providers during hospital admissions, to support discharge planning. More and more health care and nursing tasks are being delegated to social care providers, or NHS input is rationed/time limited. Particular concerns are medication administration using specialised techniques, physiotherapy, speech and language therapy, occupational therapy, wheelchair services or district nursing input. SeeAbility employs a team of specialist nurses but there is little parity in terms of being able to access the training, career progression and comparable pay and conditions to the NHS, and subsequently social care nursing turnover nationally is at 32.6% compared to 10.4% for their counterparts in the NHS.¹¹
- There is seldom continuity of social worker coordinating a person's care/or when packages are reviewed an increasingly limited engagement by local authorities. Knowledge on the impact of visual impairment and other health or sensory concerns can be poor.
- There is also varying engagement by both health and social care commissioners as to what types of service and support they want to see in their local areas. Although areas are aiming to become more

¹⁰ Skills for Care July 2023 "The size and structure of the adult social care workforce"

¹¹ Skills for Care October 2023 "The state of the adult social care sector and workforce in England"

integrated with the NHS through the introduction of Integrated Care Systems, it is hard to engage as a provider at that strategic level.

- While additional support did come forward during the pandemic, most of this has now ended, and the combined impact of new regulatory and financial requirements on social care providers continues to be overlooked in the way social care is legislated, funded and commissioned for. Examples include legislating for mandatory Covid vaccination for social care workers (which was then hastily withdrawn because of the impact of losing staff) and the ongoing annual rise in the National Living/Minimum Wage as well as energy costs. A new Health and Social Care Levy was due to raise £5.4 billion for social care over three years but this was also withdrawn as a policy. The impact of Brexit continues to be felt, adding to the shortage of staff despite some temporary changes to enable overseas care and support workers recruitment.

A move to proper reform – our 10 key recommendations

The pandemic and now the cost of living crisis has shown how the need for fundamental reform and a revaluing of social care cannot be ignored any longer (with most commentators agreeing the government’s White Paper and recent update to its People at the Heart of Care Plan¹² will not produce the fundamental change needed.

There are many issues to address but these are our key recommendations.

1. Urgent funding to stabilise social care and invest in the social care workforce

There should be immediate central government funding to help stabilise social care, so disabled people can access support and get the continuity of care staff they need. This must include an immediate wage boost for the social care workforce. The social care workforce must be given equal status, value and priority to the NHS workforce, so social care is seen as the skilled, rewarding and varied career it can be. It needs a national workforce strategy,

¹² **DHSC (2021) “People at the Heart of Care: adult social care reform white paper” and DHSC (2023) “Next steps to put people at the heart of care”**

addressing the difference in pay through appropriate funding and the need for professional registration, training and skills recognition, as well as making sure there are properly funded entry routes into the profession from vocational qualifications, apprenticeships and overseas recruitment, as well as a focus on the potential for more disabled people to be supported to join the profession.

2. A new vision for social care that values human rights

A person with a learning disability or autism has a lifelong diagnosis and should be provided with a continuum of support that meets their particular aspirations and needs at any time in life. Human rights, inclusion and equality should be at the heart of a preventative social care system that supports and enables people's wellbeing, valuing the role informal carers and the person's circle of support. This means changing a system which is broken and rationed on the basis of need, to one that sees social care as an investment in that person's life, grounded in their community, as promoted by the Social Care Futures movement.¹³

3. Support that starts early rather than at crisis point

There need to be cross government learning disability and autism strategies and leadership within government, with delivery plans that encompass not just health and social care, but housing, employment and community inclusion needs so people have opportunities as equal citizens. The 'Good Lives Framework' by Learning Disability England paves the way for what changes are needed.¹⁴ Public spending around the NHS, public health, social care and wider local authority budgets should be realigned and directed at preventative interventions. Most urgent is the need to end the scandal of institutionalisation where hospitals become homes, a cycle that continues to this day because of lack of community investment in social care alternatives in many areas.

4. Develop a long-term national funding solution

In the long-term, sustainable funding must be found. SeeAbility believes funding for social care should be raised and allocated through a national mechanism i.e. tax and/or national insurance increases. We do not support the means testing of domiciliary 'wealth', this could act as a disincentive for disabled people's

¹³ Social Care Futures <https://socialcarefuture.org.uk/>

¹⁴ Learning Disability England (2022) "Good Lives Framework"

aspirations to own their own homes and to live independently in their own homes. The distinction between health and social care funding is meaningless to most people. For people we support that their care and support is provided free at the point of need, which makes the divide even less apparent.

5. Align funding to a new vision for social care

There is clear preference by the public to see an element of central government ringfencing for both NHS and social care funding¹⁵, and a more comprehensive solution is needed rather than the piecemeal funding model of council tax, national grants and means tested contributions by disabled people. We support calls for an independent body like the Office for Budget Responsibility to assess the funding levels needed for both health and social care, but also to have a much greater understanding of how funding could be spent to deliver a new vision for social care.

6. Coordinate care better, reducing the need for assessments

Services must be more preventative, integrated and coordinated around the individual at a local level. We support having a lead person to coordinate health and social care for a person with a learning disability or autism, reducing multiple assessments and helping navigate systems. This would most likely result in cost savings and help information flow between social care providers and the NHS, particularly at crucial times such as hospital admission/discharge.

7. Investment in advocacy, information and peer to peer support

People with learning disabilities and autism need to have more clarity on why certain eligible needs are not going to be met, to be able to more easily challenge decisions including the 'choice' of services offered. Empowering people to do this means much better funding and investment in advocacy and peer support.

8. Stronger oversight of commissioning of care

We support the regulator CQC having a role of assuring the way that adult social care services are run by local authorities, and we were pleased to see this change being introduced under the Health

¹⁵ See Health and Social Care and Housing and Local Government Committees report on adult social care funding. Published 19 June 2018.

and Care Act 2022. It is important that assurance includes commissioning of social care, and analysis of whether sustainable fees are being paid to providers. Commissioning should be about outcomes for the individual and not just 'time and task' elements of care.

9. Gather better information what support is available, including from the third sector

The pandemic exposed how little is understood about social care support for people with learning disabilities, and a lack of data on the breadth of community living options that people now have, such as use of supported living. There is a need for better data, not just for commissioning better services but also so support can be targeted at times of crisis, and to understand the diversity of the learning disability population (including ethnicity). Data is also needed on the workforce that supports people with learning disabilities and more profile and value given to third sector provision, given its ability to provide innovation and ethos to delivery.

10. More recognition of sight loss and support in social care

The high prevalence of sight problems amongst people with learning disabilities in social care settings should be recognised and social care leaders should support people with learning disabilities and autism accessing the eye care they need. For those with registerable sight loss, there is a need to ensure that people are registered with their local authority, and investment in statutory vision rehabilitation services that can help people maintain their independence and confidence on an ongoing basis.

Appendix: Social care facts and figures

Social care analysis is being published all the time. The following facts and figures were based on up to date information as of October 2023. Some of this information was published prior to the pandemic taking hold and despite temporary financial support for the sector for Covid 19 costs, underlying pressures remain.

Social care is delivered or organised by 17,900 providers across statutory, not for profit and private sector, mostly under contract to local authorities. The social care workforce is of equivalence in size to the NHS (1.52 million people compared to 1.43 million people in the NHS) contributing at least £55.6 billion to the economy in 2022/23 (Source: Skills for Care 2023).

Gross expenditure on adult social care by local councils was £23.7 billion in 2021/22 (Source NHS Digital 2023). Councils are now spending an increasing proportion of their total budgets on adult social care: 28% in 2010/11 rising to an estimated 36.7% in 2022/23 (Source: ADASS spring survey 2023)

Since 2010 modelling has estimated total government funding for local authorities has fallen by 55% (to 2019/20) which inevitably impacted on adult social care. In 2023 council adult social care directors say they will have made £2.5bn in social care savings in the past four years, on top of £7.7 billion in the past decade. Savings have been achieved by reducing numbers of people receiving care, cuts to discretionary preventative services and 'efficiencies' (including fees paid to providers). (Source: ADASS spring survey 2023)

Since 2016 the government has recognised pressures through short term injections of funding, such as relaxing council tax raising powers through a 'precept' for adult social care only. There were also some short term injections of funding during the pandemic and since. However overall numbers of people receiving long term care has decreased year on year, to 817,915 people in 2021/22 meaning additional funding is going to meet the needs of those currently 'in' the system despite demand increasing due to demographics. (Source: NHS Digital 2023).

So, in spite of additional funding, the funding gap in social care remains. One parliamentary analysis found the cost to meet basic demographic and inflationary pressures (such as the annual National Living Wage rise and a modest uplift on care staff pay) would need an additional £3.9 billion a year by 2023/24, and a more recent report called for at least £7 billion to be immediately put back into the system. (Sources: Health and Social Care Committee 2020, Levelling up, Housing and Communities Committee 2022)

While it is true that only a third of adult social care users are of working age, this group tends to need more complex care packages, with learning disability residential care packages costing the most of all client groups. In fact long term social care expenditure across the age bands is now almost the same, with nearly 50 per cent of expenditure relating to adults aged 18 to 64. Expenditure on short and long term care for those with learning disabilities was £7.2 billion in 2022/23, with long term care supporting 152,175 people that year. (Source: NHS Digital, 2023). Councils continue to report that pressure on their budgets from younger people's needs outstrip the pressures caused by an ageing population.

Of the funding gap, £1 billion was the estimated shortfall facing learning disability services alone – this estimate was made in 2017 (Source: Learning Disability Voices) and is likely to have increased since then. Amongst learning disability providers, a recent 'sector pulse check' found over 42% had closed services or handed back contracts, with 84% in deficit or with a decreased surplus due to cost pressures including rising utility bills (Source: HfT and Care England, 2023).

Social care is a lower paid sector, where turnover in care worker roles is 28.3%, and there are high vacancy rates of 9.9%. There are an estimated 152,000 vacancies in social care. By 2035 there will be a need for another half a million full time equivalent jobs in social care in England alone (Source: Skills for Care 2022 and 2023).