

Written evidence submitted by Mencap (ASC0102)

Mencap's submission to the Health and Social Care Committee's inquiry into the cost of inaction on adult social care reform

About Mencap and Learning Disability

1. Our vision is for the UK to be the best place in the world for people with a learning disability to live happy and healthy lives. We do this by supporting the 1.5 million people with a learning disability in the UK and their families, improving access to health and care services, education and employment.
2. We directly support over 4,000 people with a learning disability to live their lives the way they want. A learning disability is caused by the way the brain develops before, during, or shortly after birth. It is always lifelong and affects intellectual and social development.

How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

3. We welcomed the Government's £680m additional grant funding for social care to Local Authorities (LAs) in the Autumn Budget¹ and ensuing finance policy statement², however this only scratches the surface of starting to meet the demand required in 2025/26.
4. Whilst this aligns with The Health Foundation's estimated need to meet the future demands of social care for 2024/25, to meet future demand, improve access, and cover the full cost of social care, this figure stands closer to £8.4bn³.
5. This figure precedes recent calculations that have analysed the impact of Budget announcements on independent social care providers. The proposed changes to employer National Insurance contributions (NICs) could cost an additional £940m combined with around £1.85bn to meet the new minimum wage rates from April 2025, which would total £2.8bn for the independent social care sector⁴.

¹ <https://www.gov.uk/government/publications/autumn-budget-2024>

² <https://www.gov.uk/government/publications/local-government-finance-policy-statement-2025-to-2026/local-government-finance-policy-statement-2025-to-2026>

³ <https://www.health.org.uk/publications/long-reads/adult-social-care-funding-pressure>

⁴ <https://www.nuffieldtrust.org.uk/news-item/will-the-autumn-budget-push-the-social-care-sector-beyond-breaking-point>

6. Continued underfunding of the sector, along with these recent added pressures for care providers, potentially risk a major interruption of provision for people drawing on care.
7. A recent survey from the Care Provider Alliance looking into how these additional pressures will affect social care providers found that if changes from the Budget take effect, 57% will have to hand back existing contracts and 73% will have to refuse new care packages from LAs or the NHS⁵.
8. Social care is a public service, but the way it operates makes it unlike other publicly delivered services, because it is predominantly delivered by a range of independent providers, many of whom are not-for-profit organisations. Many of these providers exist solely to provide a public service.
9. While other areas of the public sector are bring provided with financial support from the Government to cover the costs of NIC increases, social care providers are being treated differently.
10. As the NICs issue illustrates, social care often sits in a strange space, which governments often talk about as an important area to get right, but is rarely seen as a sector that is as urgent to tackle as other areas, such as the NHS.
11. LAs predominantly rely on external organisations to provide social care, and a substantial number of these are not-for-profit and voluntary providers, like Mencap. If many of these organisations are unable to take on extra care or have to hand back existing contracts, LAs risk being unable to fulfil their statutory duties under the Care Act 2014 to meet the needs of people receiving social care.
12. Social care is a significant part of LA spending, with the Association of Directors of Adult Social Services (ADASS) reporting that adult social care accounted for 37.2% of LA budgets on 2024/25, increasing from 36.7% in 2023/24⁶.
13. LAs rely heavily on various additional mechanisms to fund social care, such as council tax and the social care precept, as well as central Government funding, but these budgets are set annually which does not provide time or the space for long-term thinking. A multi-year settlement from central Government, which ringfences funding for social care, would provide a much more reliable way for LAs to manage their social care budgets⁷ and we welcome a commitment from Labour to this.

⁵ <https://careprovideralliance.org.uk/press-release-urgent-call-to-address-devastating-impact-of-budget-on-care-and-support>

⁶ <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>

⁷ <https://www.local.gov.uk/publications/autumn-budget-and-spending-review-submission-2024>

14. We know that people receiving social care requires continuity of staff and services to support their own wellbeing and build positive relationships with care workers⁸. However, this is particularly important among people with a learning disability, because social care often provides more than just support with daily care activities for this cohort.
15. Social care can provide people with a learning disability support to avoid social isolation; attend activities that are important to them; communicate effectively and navigate potential behaviour that challenges⁹; and provide reassurance through difficult health and life transitions¹⁰. These factors are dependent on people being able to build trusting relationships with their care workers or at day services.
16. It is therefore essential that any funding and reform prioritises stability and continuity of care for everyone, but especially people with a learning disability who draw on care.

What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?

17. If the social care system is to achieve the statutory duties and aims of the Care Act 2014, then fundamental reform of the way it operates is essential. Consistent funding and wider reform inaction limits the ability of LAs to meet eligible needs, provide high-quality support, and adequately recognize the skill and expertise of the care workforce.
18. Ad-hoc financial support for the social care system, often through short-term grants or leveraged by cuts in other areas, is an unsustainable way of funding the scale of reform required. While the specific mechanism by which that funding is raised is for the Government to determine, Mencap advocates for the following measures:
 - a. It should be funded through general taxation.
 - b. Risk should be pooled on a whole adult population basis.
 - c. Contribution should be compulsory.
 - d. Funding should be sufficient to enable LAs to deliver support that is based on meeting eligible needs rather than on rationing resources.
19. Mencap proposes the following reforms to provide the best support to people with a learning disability and working-age disabled adults (WADA) receiving social care:
 - a. Increased eligibility for those with mild-to-moderate needs.
 - b. Remove charging for social care to implement a 'free at the point of need' approach.

⁸ <https://www.nice.org.uk/guidance/qs182/chapter/quality-statement-3-continuity-of-care-and-support>

⁹ <https://www.nao.org.uk/reports/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/>

¹⁰ <https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-021-01612-1>

- c. The Government needs to move at pace to start the Fair Pay Agreement and establish interim measures to uplift care worker pay, so that the sector does not continue to lose more of its valuable and experienced workforce. This is a workforce that has 131,000 vacancies¹¹, hundreds of thousands of workers leaving the sector for good, and a predicted need for 480,000 additional social care roles by 2035¹².
- d. The Government must provide detail for its plans around the National Care Service, including a comprehensive strategy developing career progression routes; increasing training opportunities; and improving recognition of care work as a skilled and valued occupation, in-line with Skills For Care's Workforce Strategy¹³.
- e. Incentivise LAs to take more creative risks with the services available in each area and think innovatively to commission high-quality care and support.
- f. Allocate funds to LAs and providers in a fairer way by delivering a new social care funding formula that is underpinned by stronger data collection requirements on LAs and is more closely aligned to identified current and projected local need.

What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

- 20. Most of the people with a learning disability who draw on our social care services are WADA living in supported living settings who require tailored and carefully planned support, often throughout the course of their lives, to maintain their independence and wellbeing.
- 21. Much of the public discussion around adult social care focuses on older adults, but support for working-age and lifelong disabled adults has become the largest area of expenditure in adult social care, making up 63% of the net adult social care budget in England in 2022/23¹⁴. In that same year, 68% of social care spending for WADA went towards supporting people with learning disabilities¹⁵.
- 22. Expenditure for working-age and lifelong disabled adults grew by 32% between 2019/20 and 2023/24, faster than expenditure growth in any other part of adult social care, such as care for older adults¹⁶.

¹¹ <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/Size-and-structure/The-size-and-structure-of-the-adult-social-care-workforce-in-England-2024.pdf>

¹² <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/Size-and-structure/The-size-and-structure-of-the-adult-social-care-workforce-in-England-2024.pdf>

¹³ <https://www.skillsforcare.org.uk/Workforce-Strategy/Home.aspx>

¹⁴ <https://www.countycouncilsnetwork.org.uk/new-analysis-reveals-two-thirds-of-social-care-commissioning-budgets-are-spent-on-working-age-and-disabled-adults-as-councils-call-for-this-forgotten-group-not-to-be-overlooked/>

¹⁵ <https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/social-care-nutshell>

¹⁶ <https://www.countycouncilsnetwork.org.uk/new-analysis-reveals-two-thirds-of-social-care-commissioning-budgets-are-spent-on-working-age-and-disabled-adults-as-councils-call-for-this-forgotten-group-not-to-be-overlooked/>

23. The same County Councils Network and Newton research found that the net increase in expenditure for support for 18-24-year-olds for adult social care is expected to be at least 40% more by 2030, partly due to the increasing number of young people with Education, Health, and Care Plans (EHCPs) transitioning to adulthood¹⁷.
24. In 2021, the National Audit Office predicted that the cost of social care for WADA would increase by 90% by 2038 compared with 2018 (from 9.6bn to 18.1bn)¹⁸.
25. Many people with a learning disability draw on social care to help them access their local communities and build their independence. As such, a lack of appropriate support due to inaction can have a devastating impact on a range of factors, including engaging with employment, family, and friends.
26. We conducted research into loneliness in 2022, which found that when asked why their loved one was finding it more challenging to leave the house, nearly half (47%) of family members said that that reduced social care support was a barrier¹⁹.
27. Closure of day services, including day centres offering clubs, activities, and support for people with a learning disability - in the absence of robust alternatives - cut off a vital lifeline for many who rely on these services to help with socialisation, wellbeing, and independence. This puts people at risk loneliness, mental health breakdown, and further entrenches inequalities experienced by people with a learning disability.
28. Key to addressing this is identifying and meeting unmet need and planning for future demand. While there is more data on older care users, which shows that 2.6m people aged 50 and over are living with some form of unmet need²⁰, there is much less equivalent data for younger adults.
29. Healthwatch found that as many as 1.5m WADA in England may not be receiving support, despite potentially being eligible for social care²¹.

overlooked/

¹⁷ <https://www.countycouncilsnetwork.org.uk/new-analysis-reveals-two-thirds-of-social-care-commissioning-budgets-are-spent-on-working-age-and-disabled-adults-as-councils-call-for-this-forgotten-group-not-to-be-overlooked/>

¹⁸ <https://www.nao.org.uk/reports/adult-social-care-markets/>

¹⁹ <https://www.mencap.org.uk/press-release/new-research-mencap-reveals-widespread-loneliness-almost-third-people-learning>

²⁰ <https://careandsupportalliance.com/budget-2024/>

²¹ <https://www.healthwatch.co.uk/report/2024-07-16/missing-millions-exploring-unmet-social-care-need-disabled-adults>

30. With estimates like these, combined with the projected increase of young people who will need to access social care within the next 10-15 years, overcoming inaction is not only essential, but could be transformative for the lives of people with a learning disability if the right support is implemented.

Where in the system is the cost of inaction on adult social care reform being borne the most?

31. The cost of inaction of funding and reform passes all the way from central Government, through to LAs, and onto those directly receiving social care services.

32. We have seen this reflected in the number of enquiries that we have had into our Learning Disability Helpline, with social care being the top enquiry topic since April 2024.

33. Within these enquiries, some of the top areas that people need advice about are: problems with and challenging decisions about their care plan; information about and challenging decisions around adult assessments; and finding local advocacy services.

34. The number of calls and the nature of subtopics from our helpline enquiries indicate that people with a learning disability and their loved ones are not receiving enough of the right information about social care and are also not getting the outcomes from assessments and care plans that they need.

35. These are essential parts of social care services that LAs provide and they are likely to be a direct result of the financial pressures that they are facing, which are stretching the capacity of LAs across the country. 81% of councils predict that they will overspend on their adult social care budget in this financial year²².

36. ADASS also found that as of the end of March 2024, there were 418,029 people waiting for an assessment in England, care or direct payments to begin, or a review of their care plan²³. These numbers have returned back down to the levels that are comparable to waiting times in November 2021, but they are still at historically high levels.

37. A lack of the right social care can put people with a learning disability at risk of institutionalisation, including in mental health hospitals. This can occur when the right specialist support is not provided in the community, leading to crisis situations and emergency admissions to in-patient units.

²² <https://www.adass.org.uk/documents/adass-autumn-survey-2024/>

²³ <https://www.adass.org.uk/documents/adass-spring-survey-2024/>

38. People can remain stuck in in-patient units for long periods of time. NHS Digital data shows the main reasons for delayed discharge of people with a learning disability and/or autistic people from mental health hospitals are a lack of the right social care and unsuitable housing²⁴.

What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?

39. The inaction on funding and reform of adult social care is putting extra pressure on the NHS. Reforming social care needs to be an essential part of the Government's new 10 Year Plan for Health, but action within the social care sector promises to return much more than merely support for the NHS.

40. Funding social care should be seen as an investment rather than a cost, because reforming and working to improve the systems that are in place can provide a productive economic return.

41. For Demos, a focus on prevention would require a large shift in the way that the state makes decisions and allocates its funds, which would require an initial upfront cost to tackle underlying problems in a particular sector, but would provide longer-term stability for communities, rather than reacting to perpetual crises due to sustained inaction²⁵.

42. Feeding into the Government's own messaging, particularly the shift from sickness to prevention, recent research found that earlier action and support (EAAS) investment can provide significant social return on investment.

43. A joint study examines a prevention spending model (PSM) of how much money could be saved if LAs invested in activities that promote adults' health and wellbeing and help to prevent health and care needs arising and increasing in future.

44. Looking at 10 areas of intervention that have been analysed in the PSM shows that EAAS save approximately £3.17 for every £1 invested and that if scaled up across all LA areas, would deliver a net benefit of approximately £7.6bn²⁶. At an estimated cost of £23m per LA, in return, there would be an approximate saving of £11.1bn to LAs, the NHS, and the voluntary, community, and social enterprise (VCSE) sector.

²⁴ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2024-mhsds-february-2024>

²⁵ <https://demos.co.uk/wp-content/uploads/2023/04/the-preventative-state.pdf>

²⁶ <https://www.local.gov.uk/publications/earlier-action-and-support-case-prevention-adult-social-care-and-beyond#annex>

45. Even in its current underfunded state, adult social care sector was estimated to contribute £68.1 billion gross value added to the economy in England in 2023/24 (up 13.2% from 2022/23)²⁷.
46. Even just focusing on the charity sector alone, social care providers are the largest subsector, accounting for around one-fifth of charity organisations. This social services subsector also contributes the most to the UK's economy, at around £3.4bn per year²⁸.
47. Looking beyond these figures, another important area to consider is that for WADA, social care provides more than just support for people's personal care needs but can help people to find meaningful work.
48. Healthwatch's report on unmet need shows that 22% of WADA drawing on support said their care supports them to work, study, or volunteer²⁹.
49. Although an accurate figure is difficult to establish, some of the data suggests that only around 5% of people with a learning disability are in work^{30,31}. However, research that Mencap commissioned NDTi to investigate found that 86% of respondents with a learning disability who are currently out of work, want to get into work³².
50. This illustrates that as well as directly contributing to the wider economy and supporting with a shift from sickness to prevention, appropriate investment in social care could also support with wider Government aims around employment for WADA and people with a learning disability.

To what extent are the costs of inaction on adult social care reform considered by the Government when evaluating policies, including within the Budget and Spending Reviews? How should these costs be assessed and evaluated?

51. Successive governments have made repeated promises to reform adult social care: from the failure to fully implement the suggestions from the Dilnot Commission³³ (such as the cap on care

²⁷ <https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx>

²⁸ <https://www.ncvo.org.uk/news-and-insights/news-index/uk-civil-society-almanac-2023/executive-summary/#the-voluntary-sector-contributes-about-20bn-to-the-uks-gdp>

²⁹ <https://www.healthwatch.co.uk/report/2024-07-16/missing-millions-exploring-unmet-social-care-need-disabled-adults>

³⁰ <https://www.nuffieldtrust.org.uk/resource/supporting-people-in-employment>

³¹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment-research-and-statistics>

³² <https://www.mencap.org.uk/sites/default/files/2023-09/Learning%20disability%20and%20work%20-%20final%20report%2031.10.22%5B77%5D%20%282%29%20%281%29.pdf>

costs within the Care Act 2014); to the failure to deliver reforms detailed in the Health and Care Act 2022³⁴ (such as the cap and floor on care costs and the Fair Cost of Care); and to the stripped back vision that was delivered in the Next Steps to Put People at the Heart of Care policy paper³⁵.

52. Whilst a change in government often presents new opportunities for many policy areas, the first few months of this Government have not painted the most optimistic picture for the prospect of reversing the inaction in adult social care.
53. As previously mentioned, the 2024 Autumn Budget has laid out a potentially catastrophic threat to the adult social care sector. Even with more positive Government announcements around reform, such as the National Care Service or a potential cross-party mechanism to achieve consensus around a future vision for social care, the sector is still eagerly awaiting further detail on what these proposals may look like.
54. People with a learning disability often require social care throughout their lifetimes, so a delay in reform and funding is a delay that is directly passed onto their ability to lead a life that maximises their wellbeing and independence.
55. The Government must provide an updated vision for social care reform as a matter of urgency and begin work to find long-term solutions to get social care back on a sustainable footing.

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<https://webarchive.nationalarchives.gov.uk/ukgwa/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/>

³⁴ <https://www.legislation.gov.uk/ukpga/2022/31/contents>

³⁵ <https://www.gov.uk/government/publications/adult-social-care-system-reform-next-steps-to-put-people-at-the-heart-of-care/next-steps-to-put-people-at-the-heart-of-care>