

Written evidence submitted by Autism Alliance UK) (ASC0067)

Health and Social Care Committee: Inquiry into the Cost of Inaction on Adult Social Care Reform

The Autism Alliance UK is pleased to make a submission to the call for evidence from the Health and Social Care Committee as part of its inquiry into the cost of inaction on adult social care reform.

About the Autism Alliance UK

The Autism Alliance UK represents specialist not-for-profit organisations that provide support for autistic people and their families. Together, our members support tens of thousands of autistic children, young people and adults, including in adult social care. We are submitting evidence because autistic people experience unacceptably poor outcomes across health and social care, and because their experiences are fundamental in planning and delivering effective reform, both at a local level and a system level.

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?

In short, inaction on social care reform is maintaining high levels of expenditure on crisis services, tying up resources in the NHS, preventing people from becoming well and becoming employed, and limiting patient access to the NHS. A lack of informed decision-making within Government is simply no longer a convincing or acceptable excuse for these poor and worsening outcomes.

Latest estimates suggest that over 1 million people across the country are autisticⁱ. Seen through the experiences of autistic people and their families, inaction on adult social care reform has three types of cost: damage to people's lives, lost economic potential, and cost-ineffective spending.

Autism is a different way of perceiving and interacting with the world, and autistic people face shockingly poor outcomes because of a long-entrenched and continuing lack of understanding and adaptation across services and society, compounded by system-level failures in accountability and funding. As a result, almost 80% of autistic people experience poor mental health, the highest of any group in societyⁱⁱ; life expectancy is lowerⁱⁱⁱ; and suicide rates for autistic people are 9 times the average^{iv}.

Autistic people are more likely to have needs for care and support, and where the right support is provided it can have life-changing impact, enabling autistic people to live full and happy lives. However, research carried out by Cordis Bright and commissioned by the Autism Alliance found that over 11,000 autistic people – most likely those with a mild or moderate learning disability – are getting no support at all^v, despite being eligible under the criteria set out in the Care Act 2014. Accompanying research from the Autism Alliance^{vi} found that even where care is provided, almost half of autistic adults say it does not meet their needs; almost two thirds get no support in the process of trying to find care; and almost 60% don't even try to get support because they feel there is no point.

These unacceptable outcomes are the direct result of inaction on adult social care reform.

Without the right support, most often provided through social care:

- **Autistic people experience mental health crisis.** Research by the Autism Alliance showed that 77% of autistic adults reach crisis point before care is provided^{vii}. This can result in family breakdown and confinement in mental health hospitals, where autistic people face restraint, medication and trauma. Analysis of data commissioned by NHS England suggests spending on confining autistic people in locked inpatient settings could account for over £250m per year^{viii}. The cost of supporting autistic people to live in their communities is likely to be either the same or lower, yet this does not happen because there is insufficient funding in social care, and the system is unable to shift funding from crisis services to early support.
- **Autistic people are unable to enter and remain in employment.** The current employment rate for autistic people is just 3 in 10, one of the lowest rates of all disability groups^x. Research from Pro Bono Economics commissioned by Autistica found that the economic benefits of doubling the employment rate for autistic people (currently just 3 in 10) would be between £900 million and £1.5 billion each year^x.
- **The families of autistic people are also held back in employment.** Although not focusing specifically on autism, recent research by Support SEND Kids^{xi} shows that 3 in 4 parents of children with SEND have been forced to give up work or cut their hours, because of failure to meet their children's needs in the education system. The similar failure to meet the needs of autistic adults has a comparable impact on parents and carers. As well as accessing employment, unpaid carers who are able to work also face barriers in progressing. Many people also claim Carer's Allowance because of their caring responsibilities.

The link between providing the right support, better outcomes and more cost-effective spending is not just assertion. New research from the London School of Economics^{xii}, commissioned by the Autism Alliance UK and Autistica, shows there are services, therapies and supports which have both strong evidence of effectiveness for autistic people *and* strong evidence of economic benefit. Taken together, these economic benefits are likely to be considerable.

At the highest level of policy, social care is the key to success for the country – both in economic growth, and in social wellbeing and flourishing, recognising that the two go hand in hand. Levels of physical illness^{xiii} and poor mental health^{xiv} are at very high levels, with many who could become employed denied the most basic and reasonable adjustments required. By itself, the NHS cannot cope. Social care generates £50 billion of economic activity^{xv}, but the sector has nowhere near the visibility and funding that would reflect this significance: absurdly, care workers are paid at lower rates than those in the NHS, despite their skills and commitment, and the vital contribution they make to society and our economy.

The Government's rhetoric is about fixing the foundations for growth, but to grow we need *everyone* to contribute, and without action on social care reform, this is simply not possible.

Just as worryingly, as a country we have sleepwalked into a paradigm where picking up the pieces after crisis is seen as the default, on the basis that 'people should be able to take control of their own lives'. This is disastrously wrong. People have strengths, but also needs, and ignoring needs prevents people from realising their strengths. These are not 'wants', but basic physical and psychological needs which are the basis for wellbeing and the foundation for people to develop and thrive. Other countries have models of social welfare which recognise this, and systems that prioritise growth by focusing on wellbeing as the basis for creating opportunity.

All this is abundantly clear, and yet absurdly nothing is changing. Pushing large amounts of money into the NHS, laudable as that is, will not create the fundamental, system-level shift we need. It will only mean further loading the system towards crisis rather than prevention, which is the opposite of what the Government has said it wants to achieve.

Society has evolved, both through the impact of medicine and through increased clinical and societal awareness of neurological difference, and the implications of not acting on social care are now at a point where they will soon be disastrous. We need politics to catch up with policy and society, and for our politicians to finally act. The stakes could not be higher, for the country and for us all.

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?

The Transforming Care programme, launched in 2011, and the subsequent Building the Right Support programme launched in 2015, were supposed to deliver the right community support for autistic people and people with a learning disability – through adult social care and health-commissioned services. Yet at the end of 2024, the number of autistic people without a learning disability confined in mental health hospitals is 120% higher than it was in 2015^{xvi}. Successive targets for reducing confinement set by the Government, in both Building the Right Support and the NHS Long-Term Plan have been missed. There was no accountability for this from the previous Government. Nothing changed as a result of the failure.

Although some of the increase in the confinement of autistic people is due to diagnosis taking place after admission to hospital, the fact remains that the number of autistic people locked away is increasing in 2024 – a shocking indictment of our society and of the public services which, by law, have a duty to support them and help them thrive.

The biggest barrier to the success of these policies has been the inaction on adult social care reform. The continuing gap between requests for care and support and the care provided – data suggests close to 1 million people with requests for care do not receive anything – shows that the system is wildly out of step with need. Reform of the social care funding model would make the single greatest difference in closing this gap.

Alongside this, there is undoubtedly scope to switch NHS resources from crisis services to community support, but when the mismatch between need and supply is so great, it is understandably difficult. The processes which enable individuals to transfer from mental health hospital to living in their communities are not effective in a budget-constrained environment. Some progress could be made through more direct action from Government which ‘challenges and breaks’ current ways of working across health and social care commissioning. But reform of adult social care funding is the only long-term, sustainable solution.

For autistic people and their families, the impact of this failure of policy and delivery is clear. Autistic people continue to miss out on the support they need to thrive and live their lives in their communities; more autistic people continue to be confined in mental health hospitals; and more resource is used to respond to crisis instead of helping people flourish and avoid crisis. This perpetuates itself. The system is back-to-front, operating in a way which is wholly irrational, and reform of adult social care is the key to turning this around.

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

Inaction on adult social care reform has been devastating for autistic adults and their families, and despite positive efforts from some local commissioners to carve out programmes that can help at the margins, the prevailing outcome continues to be failure.

The cost to autistic people’s lives, and their families’ lives, is huge. Research carried out by the Autism Alliance in 2023 showed that a staggering 77% of autistic adults reach crisis point before care and support is provided^{xvii}. This is a wholesale negation of the legal framework set out in the Care Act 2014, and of the intent behind the Autism Act 2009. To this extent, the law is being broken every day across the country.

As a result, many families experience breakdown, and large numbers of autistic people continue to be locked away in mental health hospitals. The average length of stay for autistic people in these facilities is almost 5 years^{xviii}. There are countless stories of excessive restraint, overmedication and trauma, and shocking cases of abuse continue to come to light^{xix} almost fifteen years after the exposure of Winterbourne View^{xx}.

With the right care and support:

- Autistic adults won’t need to fight for acceptance and understanding and will be able to protect their mental health and wellbeing to a much greater extent. As a result, they will have better lives.

- The parents and carers of autistic adults will be able to hold together their families, and many will be able to find and maintain employment.
- Many autistic adults will be able to take up employment, bringing valuable skills and making a considerable contribution to economic growth. As noted above, the potential gains of doubling the employment rate for autistic people are between £900 million and £1.5 billion per year^{xxi}.
- Communities and community organisations will be stronger because of greater acceptance of difference, and increased participation of autistic people in society, and the greater focus on rewarding and joyful interactions this brings.
- Specialist care providers will move from barely surviving^{xxii} to thriving, creating and strengthening social capital as well as releasing time and energy to contribute to a step change in research into ‘what works’ in helping autistic people thrive.
- The economy and public finances will benefit through increased employment, a stronger social care sector, and more cost-effective spending across education, health, social care and justice^{xxiii}.

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

By far the greatest impact is on people with eligible needs for care, and within this group, autistic people are disproportionately affected. The cost of inaction is also being borne by specialist care providers, particularly in the not-for-profit sector, who after years of sustained underfunding^{xxiv} are either handing back contracts or using their reserves to subsidise the public purse. Many specialist autism care providers are measuring their lifespan in a very few years without significant change to the funding model for social care^{xxv}, enabling local commissioners to pay fees that cover costs, and allowing pay levels for care workers to increase.

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

Other organisations will provide detailed description of the contribution of social care to the economy. However, it is worth reinforcing again the considerable economic potential we are failing to realise by not supporting autistic people through adult social care^{xxvi}. Some of our greatest advances, inventions and contributions, particularly in science and technology, have come from autistic people who received the support they required to work.

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?

If it was clear how the Government considers the costs of inaction, we would be in a marginally better place! But even this information is not in the public domain – one reason why the legal charity Access Social Care have been campaigning for transparency, accountability and clarity on planning assumptions^{xxvii}. The Information Commissioner’s Office has ruled that the Treasury must release this data, yet Government is continuing to appeal this decision.

Following Budget 2024, the Government has signalled the start of consultation across a range of policy areas, including health and social care. It is assumed these consultations will lead to plans. In the case of social care, it is vital that these plans do not mean more warm words and more delay. Lives are being lost now because of inaction. The political stigma attached to social care needs to be dropped. The Government needs to be brave enough to walk towards care, and bold enough to co-produce and implement an ambitious strategic plan with cross-party support. The need for care is the greatest leveller we have as a society. Not one human being has been without need for care and yet this essential skill has not been valued by those in power.

It is also important to recognise the strategic significance of social care for working-age people, and within this social care for autistic people and people with a learning disability. Physical support for older people and ‘learning disability

support' (including support for autistic people) are the two biggest areas of social care expenditure at a national level^{xxviii}. The scale of this need has clear economic implications, both in realising economic potential and for cost-effective public spending, alongside the overwhelming social and moral case to provide care.

An acute area of concern is the lack of a plan for community support for autistic people and people with a learning disability, following the failure of Building the Right Support^{xxix}. The Government has confirmed that powers in the Mental Health Bill relating to autistic people and people with a learning disability will not be activated until 'sufficient' community support is in place – but without a plan to secure this support, someone who is accountable for delivering it, and a clear definition of 'sufficient' and how this will be measured, the planned reforms to the Mental Health Act will simply not achieve their objective.

To assess and evaluate the costs of inaction, the Government should:

- Immediately disclose its planning assumptions for adult social care, and openly consult on these with stakeholders and people with lived experience of care. The scale of the need must be known and explained transparently to identify options, agree solutions and lead a rational conversation across commissioners, services and the public.
- Immediately review the relationship between NHS funding, local authority funding and the provision of adult social care, identifying the current and future size of the funding gap in care and the social and economic impacts for care providers, communities and individuals.
- Immediately commission a review of existing evidence showing the benefits of social care – both social and economic – and how these accrue for other services and sectors.
- Immediately commission action learning pilots to measure the economic benefits of investment in social care for all other parts of the system, including education, health and justice. These should be carried out rapidly, with license to depart from normal bureaucracy, but not so quickly that the quality of evidence is undermined; and social care reform should begin alongside the pilots.

Recognising the unacceptable experiences of autistic people and their families in social care, and across all public services, the Government should immediately establish a task force, including autistic people and with cross-party support, to stabilise and evolve the autism assessment and diagnosis system.

It is scandalous that over 200,000 people are waiting for autism assessment^{xxx}, but the reform of assessment is also a huge opportunity. The existing assessment model does not reflect the new reality that the demographics have changed and estimates of autism prevalence are higher than 20 years ago, following increases in clinical and societal awareness of autism. As a result, our understanding of the need for support at all life stages is way behind where it needs to be. A well-functioning autism assessment system, with a properly funded workforce, using new technology, and based on the highest standard of evidence, could inform planning and practice across education, health, and social care. This would be a long-term (5-10 year) piece of work, but an essential contributor to the reform of adult social care. It could and should also cover other types of neurodivergence.

Because of the stark inequalities they face, because of the singularly low levels of understanding of autism across services and society, and because of the overriding importance of neurodiversity as an indicator of continuing social change, autistic people's voices and experiences should be at the heart of the reform of adult social care. It is crucial to understand that a focus on autism is not a narrow point of impact but is likely to have important positive impacts for the healthcare system overall, and for the experiences of all patients.

Autistic people's experiences are a litmus test of the Government's three planned shifts for healthcare, because improvements in their outcomes depend explicitly on preventing crisis, increasing community support and better use of new technology. If the system is working for autistic people, recognising need and providing an appropriate and informed service, it is very likely to be working better for everyone. This makes it vital that the voices of autistic people are enabled, heard and acted on directly as part of planning for, and implementing reform across both health and social care. To succeed in its ambition, the Government needs to ensure a future healthcare system that is innovative, responsive, and reflects our current society.

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