A New Path Ahead

Why systemic change is the key to better lives for autistic people

Short Public Policy Report – April 2026

Contents

Purpose of this report

This report has been produced to inform the Independent Review into Mental Health, ADHD and Autism, commissioned by the Government in England in December 2025[1], and the development of the next National Autism Strategy for England under the Autism Act 2009. It responds to the current pressure on autism diagnostic services, the persistent harms experienced by autistic people, and the opportunity to align autism policy with wider public service transformation priorities, including SEND reform plans[2], the NHS Long Term Plan[3] and cross-government work on employment and health inequalities. It complements the recommendations made by the House of Lords in 'Time to deliver: the Autism Act 2009 and the next autism strategy', published in November 2025.[4] Although much of the content has a focus on England, the recommendations are for all governments across the UK.

This report has had input from autistic young people and adults, parents/carers of autistic children and adults, researchers, clinicians and charities. A list of those who have contributed is at **Annex A**. The process was as follows.

- A group of charities, researchers, and clinicians, including autistic members and others with lived experience as parents/carers, worked on an initial draft of the report and reviewed subsequent drafts. Several members of the group span the charity, research and clinical fields.
- Feedback and direct input were provided by a reference group of seven experts by experience, comprising autistic adults and parents/carers of autistic young people and adults.
- A draft of the report was also discussed by a group of autistic young people aged between 16 and 25 from the Ambitious about Autism Young Advisors group. **As well as feedback, they provided quotes about their and their families' experience which are included in the report.**

Summary and recommendations

This report makes one overarching point: that if governments across the UK move towards the use of strengths and support needs assessment for autistic children, young people, and adults across health and public services, this must be accompanied by substantial systemic investment and change. Without this, there will be substitution rather than reform, with needs assessment used to restrict access to diagnosis and support rather than to improve outcomes. This will result in further harm and lost lives.

Autistic children, young people and adults are part of our society. Like all people they have strengths and support needs, and with the right support they can live a good quality life and contribute to the UK economy and to their communities. As well as improving lives, there is now clearer evidence of the substantial economic benefits of providing this support, thanks to recent work, including from Pro Bono Economics and the London School of Economics.

However, across education, health, social care, respite care, support for carers, housing, employment, and justice, public services regularly fail to make adjustments or provide support for autistic people, and there is underinvestment in specialist autism services that meet higher support needs.

As a result, autistic people face some of the greatest harms of any group in society, with unacceptably high rates of mental health crisis, self-harm and suicide; premature mortality; greater risk of physical health conditions; exclusion from education and the wider community; and one of the lowest employment rates. As well as damaging lives, this leads to increased cost which with early identification of need, and the right support, would be avoidable.

Diagnosis is fundamentally important for autistic people and their families. When it is accompanied by support, an accurate autism diagnosis enables self-understanding and a supportive family environment. It also enables access to specific health services and bespoke social care packages, which are required by many autistic people and can have a substantial impact on health-related outcomes.

Support and adjustments are also vitally important for autistic people. There is now better evidence that effective support is likely to be cost-effective and potentially cost saving. The requirement to provide support and adjustments is written into law and is not dependent on a diagnosis. However, because of long-term pressure on funding for public services, diagnosis is being used as a condition for accessing support and adjustments across public services. In many cases even a diagnosis is only accepted if the individual has a coexisting health condition. Alongside this, underinvestment in the capacity of clinical assessment services means there are long waiting lists. This creates a double barrier for autistic people, making it less likely that support is provided.

Autistic children, young people and adults face systemic barriers which have been present for decades: stigma, poor understanding of autism, and weak or non-existent accountability for autistic people's outcomes. We should be under no illusion that any of these barriers are going away: on the contrary, risks to the public perception of autism could mean they become further entrenched.

Assessment of strengths and support needs, carried out separately to clinical assessment, has great potential to address this system failure, by making support needs visible in a consistent format across all public services independently of clinical diagnosis, and enabling regular re-assessment of need. The interim report of the Independent Review into Mental Health Conditions, ADHD and Autism has recognised this, noting that the International Classification of Functioning (ICF) could provide a suitable model for identifying needs early and coordinating support across education, health and care systems. In education, the use of strengths and support needs assessment was recommended by the Neurodivergence Task and Finish Group.

However, any attempt to transition to this 'needs-led' model across public services will fail unless governments across

the UK invest to protect access to diagnosis and to make systemic changes: increasing the capacity and efficiency of current clinical assessment services, widening clinical assessment pathways to reflect neurodevelopmental approaches, embedding 'stepped' models of care, and addressing deep-rooted issues of stigma, poor understanding, and poor accountability. In England, a new National Autism Strategy would be the ideal vehicle for this change, and the 2025 House of Lords 'Time to deliver' report provides a strong blueprint and recommendations.

Crucially, this investment and systemic change must start and take effect **before** any transition to strengths and support needs assessment is completed nationally.

This is because:

- There is too much cost pressure on the system to switch from a diagnosis-gated model to a model led by support needs, and parts of the system are at different stages of 'readiness.'
- Levels of need amongst autistic people and their families are acute now, and lives are being lost. Services must improve now, not in ten or fifteen years.
- Current public narratives around 'overdiagnosis' are becoming reinforced, and risk entrenching stigma and prejudice just at the point when it needs to end.

> *The barrier of claiming benefits to accessing support, which is its own incredibly distressing, invalidating and dehumanising experience.*

Without investment and systemic change, existing system pressures and persistent stigma will stop needs-led approaches from working. Instead, there will be substitution, with strengths and support needs assessment used to restrict access to diagnosis and support, rather than complementing current pathways, and lower referrals to clinical autism assessment will be prioritised irrespective of assessment of need. The focus on preventing crisis will remain weak. Thresholds will continue to be applied rigidly and used to determine who 'deserves' support. This will result in further harm and lost lives. It will also make public spending less, rather than more cost-effective. Cost commitments will increase, for example in mental health and justice.

Getting it right, however, will enable not only better lives for autistic people and their families, but wider opportunities to improve lives and economic performance, for other marginalised groups and across the broader population. It will be an 'invest to save' approach, designed to deliver more cost-effective spending in the long term. Over time, it will also allow a natural adjustment in the rate of referral for clinical assessment, rather than an artificial suppression of need.

Recommendations for the governments of England, Scotland, Northern Ireland and Wales:

1. **Increase the capacity and efficiency of clinical assessment, while transitioning to a model with wider neurodevelopmental and mental health focus.** This would reduce waiting lists to protect lives now, and support accuracy in diagnosis, while building a more efficient and effective assessment model for the future. In England, it would require only a small proportion of existing allocations for Integrated Care Boards.
2. **Invest in embedding stepped care models across health and social care services** that reflect the diverse needs of autistic people and provide support when it is required, to reduce the escalation of need and the chances of crisis.
3. **Invest in addressing the systemic barriers** faced by autistic people, focusing on stigma, poor understanding of autism, and poor accountability for autistic people's outcomes.
4. **In parallel, co-produce, test and scale an evidence-based, acceptable, standardised assessment of strengths and support needs** across education, healthcare, employment and justice, initially for those waiting for clinical assessment, then broadening to all autistic people. This would build on international models and growing evidence in England. *Do not scale this until public services are meeting support needs and there is evidence of improvement in outcomes for autistic people.*

Across the UK, governments should work with autistic people and their families, charities, researchers, clinicians and others to scope, co-produce and take forward these recommendations. Those involved in the production of this report are ready to support this process.

A note on terminology

In this report, we use 'autism' to represent the concept of autism, and 'autistic' to describe the human experience of autism. When we refer to 'autistic people', we mean autistic children, young people and adults. We recognise that autistic experience is diverse, and in referring to 'autistic people' we mean every autistic person, whatever their type and level of support need and however this changes through time.

The benefits of support and the cost of failure

Autistic children, young people and adults are part of our society. Like all people they have strengths[5/6] and individual support needs, and with the right support can live a good quality life[7] and contribute to the UK economy and to their communities. Current estimates suggest that between 1% and 1.2% of the UK population is autistic,[8] although the Independent Review into Mental Health Conditions, ADHD and Autism is reviewing these figures (hereafter 'the Independent Review').[9]

Autistic people experience and process the world in specific ways which are different to non-autistic people.[10] Some autistic people have greater autonomy and can navigate life and employment with little support. Others have higher support needs and may require intensive levels of care. All autistic people's experiences are individual, and strengths and support needs can change through life, at transition points, and in response to changes in the external environment. (See **Annex F** for further information.)

We now have clearer evidence of the substantial economic benefits of supporting autistic people both through specific autism-focused support and through adaptation in mainstream services, thanks to work by Pro Bono Economics and the London School of Economics. For example:

- Doubling the employment rate for autistic people, including through supported employment programmes, could bring 100,000 individuals into the UK workforce.[11]
- The Paediatric Autism Communication Therapy (PACT) study has demonstrated long-term benefits, showing societal savings of £43,050 per child after six years.[12]

Some types of support for the general population also show strong potential to deliver economic benefit if adapted for autistic children, young people and adults. For example:

- Mental Health Support Teams in schools show significant potential, with recovery rates of 59 per cent for anxiety and 49 per cent for depression, and a high benefit-to-cost ratio of 22:1.[13] This is important because autistic children and young people are at far greater risk of developing mental health conditions than the general population.
- The KiVa anti-bullying programme has shown cost-effectiveness, generating a return of up to £7.52 for every £1 spent by reducing the long-term consequences of bullying.[14]

However, across education, health, social care, respite care, support for carers, housing, employment, and justice, public services regularly fail to make adjustments or provide support for autistic people, and there is underinvestment in specialist autism services that meet higher support needs.

> *Some families struggle so much with young autistic children and they have to fight and wait and struggle before getting support. This causes so much harm. More crisis support should be available.*

Autistic children and young people in mainstream education are treated in ways which force them to suppress their support needs.[15] Seclusion and exclusion are used in many schools. Parents of autistic children, young people and adults are reduced to despair, exhaustion, and sometimes unemployment and underemployment battling a system which does not recognise their children's support needs, or their own, and often tends to blame parents instead of help.[16]

Autistic adults in crisis are refused support from specialist social care or mental health services and not provided with housing that reflects their support needs.[17] There is poor understanding of intersectionality, increasing the risk of failure for many individuals and families. A lack of consistency in support and how eligibility is applied also makes it harder to navigate services. These systemic injustices increase risk of trauma, mental health difficulties, self-harm and suicide in autistic people and their parent carers.[18]

When individual support needs are unmet, autistic people experience profound distress. This distress has a physiological basis, making it distinct from a mental health condition. It is not a choice, but an involuntary and inevitable reaction to the external environment.[19/20] Many autistic people hide and suppress their distress continually, typically at considerable cost to their mental health.[21/22]

When distress persists, it leads to harm and escalating support needs. As a result, autistic children, young people and adults face some of the greatest harms of any group in society.

These include:

- Poor mental health – almost 90% will develop a mental health condition such as anxiety, depression or suicidal ideation during their lives: the highest of any group.[23/24]
- Premature mortality – estimates suggest this is between 6-15 years lower than the average for the population, although more research is needed.[25]
- High rates of self-harm (3 times as likely as non-autistic people) and suicide (7-9 times as likely).[26]
- Increased risk of physical health conditions.[27]

- Persistent absence from education – 13,000 autistic children are missing 50% or more of the school year[28] – and high rates of exclusion (over 2 times as likely).[29]
- Low employment rate (around 30%).[30] At graduate level, autistic people consistently face the worst employment outcomes of any disability group with only 43% finding full-time work within 18 months of leaving university, and 12% still unemployed after that time.[31] Autistic people also face the largest pay gap of all disability groups, receiving a third less than non-disabled people on average.[32]
- Persisting incidence of abuse in mental health hospitals – from Winterbourne View (2011)[33] to the present day[34] – and abuse of social vulnerability and relationships.

As well as the unacceptable human cost, the economic cost of this failure is considerable. For example, the low employment rate for autistic people means the UK is missing out on up to £1.5 billion of economic benefit each year. It also means spending is highly cost-ineffective – the amount spent annually on confining autistic people in mental health hospitals could close the gap in care preventing autistic people from living in their communities and contributing to society and the economy.[35]

The importance of autism diagnosis and support

Diagnosis is fundamentally important for autistic people and their families. When it is accompanied by post-diagnostic support,[36/37] an accurate autism diagnosis can enable autistic adults, as well as children and young people, to develop personal strategies that have been shown to mitigate the risk of escalating mental health needs.[38] Families seek clinical assessment to protect their child's mental health and to support better understanding of their child, and many parents report that their children reach serious "crisis points" while waiting for support in a system that is not meeting their needs.[39]

For some people, diagnosis alone is important. For others, diagnosis opens access to specific health services and bespoke social care packages, which can have a substantial impact on health-related outcomes. Parents and schools provided with information and support post-diagnosis can meet more of their children's support needs.[40] Diagnosis is important for public health management because it mitigates health inequalities: for example, ensuring talking therapies are provided in adapted formats because standard formats are often not as effective for autistic people. Having a diagnosis is also important at transition points, when a change in the individual's environment can lead to unmet support need and distress. In these cases, diagnosis can prompt re-evaluation of support need.

> *Autistic people are actively discriminated against at times and denied access to mental health care because they're autistic.*

When problems are reported with diagnosis, they reflect the systemic barriers autistic people and their families face across society and services: a lack of understanding, stigma and discrimination, and a lack of support. These barriers are discussed later in the report. Some reported negatives are about the clinical assessment process itself, which can focus on deficits and, without post-diagnostic support, can increase isolation.

As well as diagnosis, support and adjustments are vitally important for autistic people, across public services and wider society. Like every person, with the right support autistic people's lives can be rich and fulfilling. They can participate in their communities, and many can thrive in employment. There is no reason for this to be any different for autistic people.

There is now better evidence that effective support for autistic people and their families is likely to be cost-effective and potentially cost saving.[41] For example, a young autistic man needed 4:1 support, and was caught in a vicious cycle of distress and behaviour, until a day service that understood him and his experiences offered more appropriate support. They were able to support him 1:1, which improved his quality of life/experience of support and saved public money.[42]

Support can take many forms, but to be effective it should:

- Be **autism-informed and personalised**, whether as a specific service or through the adaptation of an environment, which could be a public service, a workplace, or a public space. Support should also reflect co-occurring strengths and needs, for example related to other forms of neurodivergence and mental health needs.
- Be **intersectional**, reflecting race, age and socio-economic status, and how barriers vary in specific circumstances, for example for people and families in rural areas.
- Be **acceptable for autistic people** – that is, reflect their needs and experiences in ways which do not cause alienation, distress and trauma.
- Be delivered by people with appropriate **expertise** in supporting autistic people and **understanding** of autistic people's experiences.
- Be **timely and responsive**, starting at the earliest possible point and being available when needed. This makes it less likely that needs will escalate. For late

diagnosed autistic people, support should be available at the earliest point both pre- and post-diagnosis.
- **Change** as an individual's needs change, which they do throughout life – this is sometimes referred to as 'stepped' support in a healthcare context.

Post-diagnostic support should include concrete, practical steps for individuals and families. In more progressive local authority areas, for example, a range of support is offered based on different types and levels of need including drop-ins, peer support, counselling, support for managing emotions, and strategies for parents/carers supporting children. The Bristol Autism Spectrum Service have provided post-diagnostic services for adults continuously since 2009 including an advice service with weekly 1:1 and group sessions with multidisciplinary clinicians such as psychologists, nursing and social workers; mental health support groups; and social prescribing.

It is important to note that with the right support, autistic children, young people, and adults can live a good quality life and many may not need to seek clinical assessment. However, this should not be 'forced' artificially: in the long term the number of people seeking assessment should be in the context of the system meeting individual support needs.

Building on the summary above, at **Annex B** we have provided a set of principles to guide policymakers, service commissioners, accountable officers, and public bodies in ensuring effective support for autistic people is in place. At **Annex C** we have set out a list of evidence-based programmes which can guide the commissioning of acceptable, effective, and cost-effective support for autistic people and their families.

The systemic barriers faced by autistic people and their families

As noted in the interim report of the Independent Review, diagnosis is being used as a condition for accessing support across education, health, social care, employment, housing, and justice. In many cases even a diagnosis is only accepted if the individual has a coexisting health condition. This happens despite the Care Act 2014, Children and Families Act 2014, and the Equality Act 2010, which link support and adjustments to need rather than depending on a diagnosis. Poor implementation of these laws, lack of meaningful accountability and the underfunding of public services have prevented the original policy intent from being realised.

Alongside this, and also noted by the Independent Review, underinvestment in the capacity of clinical autism assessment services relative to increasing referrals means there are long waiting lists. 85% of people wait more than the 13 weeks recommended by NICE, with waiting times often running into years or even indefinitely,[43] compared to only 8% of people waiting more than 13 weeks for other forms of diagnostic test or assessment.[44] Inequality of access to diagnosis does not align with duties placed on the NHS in England under section 13SA of the National Health Service Act 2006 or its Public Sector Equality Duties under the Equality Act 2010. This creates a double barrier for autistic people, making it less likely that support is provided, and increasing the risk of poor outcomes. Research from Bournemouth University has shown the urgency of accelerating capacity in clinical assessment services to prevent suicides.[45]

> *I suspected I was autistic before I got a diagnosis but it was so relieving to have it confirmed, it gave me a better understanding of myself and allowed me to reframe things more compassionately.*

Autistic children, young people and adults face systemic barriers across society and public services. These barriers have been present for decades. They are evidenced through poor outcomes persisting during this time despite specific action to address them.

Focusing on England, since the Autism Act 2009 there have been three Government autism strategies, the publication of statutory guidance, many commitments, and dedicated programmes such as Transforming Care/Building the Right Support. In that time, outcomes for autistic people have barely changed, and in some cases have declined. This is because these strategies and policies did not engage with, or address, the systemic barriers autistic people face, and because there are no consequences when services fail to implement statutory guidance or strategies and policies.

The systemic barriers are:

- **A culture of stigma together with poor understanding of autism**. Research shows that 91% of autistic people feel that society either never or only sometimes accepts them.[46] Polling from 2022 shows that over a third of people (35%) still believe autism is a learning disability, and 39% think that autistic people lack empathy. 65% of neurodivergent people would not disclose their neurodivergence to their line manager at work through fear of it being used against them.[47] Even where professionals have a reasonable understanding of autism, often it is still not nuanced enough to reflect how autistic people's

experiences intersect with age, sex, ethnicity, poverty and other factors; and more research is required to identify and understand these intersectional experiences.

- **Weak or non-existent accountability** for autistic people's outcomes. Despite every Integrated Care Board being required by the Health and Care Act 2022 to have a designated executive lead on autism and learning disability, when an autistic person in that area reaches mental health crisis, or self-harms, or takes their own life, there are no clear consequences. Little accountability is shown by the Minister responsible for the National Autism Strategy in England. In many ICB areas there is minimal compliance with statutory guidance issued under the Autism Act 2009. Fundamentally, those responsible for policy and service delivery know that the system will protect them, and there are no effective or affordable remedies for failures.

> *Support for adults with autism is rare and difficult to find, especially in some areas, but is very unreliable.*

Alongside these barriers, **planning and funding processes** do not prioritise specialist autism services and do not incentivise early support and crisis prevention. Spending and commissioning decisions are governed by short-term cost control, not lifelong value for money. Funding is not ring-fenced for autism, and the connection between good support and better outcomes is not tracked or consequential for future funding allocations. There is no consistently used framework of services and supports which work well for autistic people, reflecting the latest evidence. Targets and KPIs often fail to measure indicators of good quality of life for autistic people, or track risk factors. Many mainstream services, including CAMHS, routinely tell parents and carers they don't or won't support autistic people. In social care, autistic adults without a learning disability find that services and activities in their area are designed for people with a learning disability and that mainstream services are not adapted for autistic people or for people with a learning disability who are also autistic. Too often, social care packages for autistic adults with higher support needs can be poor or inadequate, failing to meet their individual support needs. There are substantial interdependencies between service failure and **workforce investment**, particularly in education and social care. These must be addressed as part of mainstream reform programmes, including the NHS 10-Year Plan, SEND reform, and the future model of social care being considered by the Casey Commission.

There is also **inconsistency** in eligibility criteria for support: for example, autistic adults without a learning disability are not eligible for a Disabled Person's Bus Pass unless they have a care plan, but those with a learning disability are eligible, despite many without a learning disability facing distinct and substantial barriers in using public transport without additional support. Different local authorities also have different thresholds for support, which undermines the principles of national consistency set out in law – for example, someone living in Harrow gets a core offer of 100 hours of respite care per year if their child gets middle/higher rate Disability Living Allowance. Across the border in Hillingdon, the criterion for respite is much higher and will generally only be given to families with children who have moderate/severe learning disability.

Finally, there is, and continues to be **a substantial power imbalance** in systems of policymaking, commissioning and service delivery. Autistic people and their families have historically not been listened to or represented in decision-making, and this remains the case today.[48]

We should be under no illusion that any of these barriers are going away: on the contrary, current risks to the public perception of autism could mean they become further entrenched.

The opportunity: assessment of strengths and support needs

Assessment of strengths and support needs, carried out separately to clinical assessment, has great potential to address this system failure, by making support needs visible in a consistent format across all public services independently of clinical diagnosis, and enabling regular re-assessment of need. In education, this opportunity was recognised by the Neurodivergence Task and Finish Group.[49]

The first steps towards introducing strengths and support needs assessment are already being taken, across both health and education. In England, models of 'functional assessment' are being considered by some Integrated Care Boards. Some local authorities have been using their own 'neurodiversity assessments' to determine SEND support needs in education.

It is vital that these tools are evidence-based, informed by lived experience, and acceptable to autistic people and their families. The ideal would be to have a single, standardised tool or framework, and the interim report of the Independent Review has recognised this, noting that the World Health

Wider systems fail to support autistic people, especially in mental health, physical healthcare and education.

Organisation's International Classification of Functioning (ICF) could provide a suitable model.[50] A range of evidence shows that the ICF could be a suitable basis for strengths and support needs assessment for autistic people.[51/52]

Although its name implies use in a purely clinical context, in practice the ICF is well-suited to recording and updating strengths and support needs. One of its features is to distinguish between constraints arising from individual 'function' and constraints created by the environment, which is helpful in adapting public services. Economic evaluations of the ICF are underway and there is broader international evidence demonstrating it can be successfully implemented at national scale.[53]

The risk: needs assessment without investment or systemic change

Across public services the Government is planning to reduce costs. Cost reduction sits behind many current reform plans, both explicitly, as in welfare reform, and implicitly, as in SEND education. For autistic people this carries the risk that implementing strengths and support needs assessment is pursued within existing or reducing cost envelopes, and without any additional investment.

An intention to seriously pursue realignment of services around strengths and support needs assessment would be positive. However, the experience of the 17 years following the Autism Act 2009 in England, and in other parts of the UK, shows that unless there is systemic change, any attempt to transition to this 'needs-led' model across public services will fail. Parents are particularly aware of the risks of poor implementation,[54] and in an education context the importance of systemic change has been recognised by the Neurodivergence Task and Finish Group.[55]

To succeed the Government will need to create the capacity across the system to enable real change to happen and proactively address the systemic barriers that block the way. Both will require investment – and with pressure on public finances, this must be an **'invest to save'** approach, designed to deliver more cost-effective spending in the long term, combining genuinely new expenditure and funding released through increased efficiency.

The investments required would need to focus on three areas: clinical assessment, as an important area of risk in the system; healthcare pathways, as the most direct enabler of needs-led support; and wider public services, where strengths and support needs assessment can become the established currency.

Recommendation: investment and systemic change

Addressing the governments of England, Scotland, Northern Ireland and Wales, we recommend three key investments:

1. **Increase the capacity and efficiency of clinical assessment, while transitioning to a model with wider neurodevelopmental and mental health focus.** This would reduce waiting lists to protect lives now, and support accuracy in diagnosis, while building a more efficient and effective assessment model for the future. It would involve:

a. Addressing the backlog in clinical assessment and maintaining capacity at levels that reflect expected referrals. In England, this would require only a small proportion of existing allocations for Integrated Care Boards. This would be around £443 million for two years falling to £200 million thereafter, or 0.35%/0.16% of ICB Core Allocations – see technical note in the box below. Part of this cost could be covered by efficiencies in clinical assessment processes that could be made now.[56] This would involve developing a well-evidenced mechanism for triage, using data and digital technology to improve capacity planning and the accuracy of screening, and other efficiencies in process and design.

b. Boosting the assessment workforce through suitably trained clinicians, building in a transitional approach to training focusing more widely on neurodevelopment and mental health. This would require a recurrent staff recruitment and training fund for clinical assessment services, revalued annually based on rolling estimates of referral volume. This could be part-funded through more efficient delivery of assessment across children and adult services.

c. Testing and scaling wider assessment pathways covering neurodevelopment and mental health. This would reduce the incidence of misdiagnosis and improve understanding of individual support need. It would build on current work in this space, including the neurodevelopmental credential being developed by the Royal College of Psychiatrists, and the transdiagnostic integration of services being piloted by the North East London NHS Foundation Trust.

2. **Invest in embedding stepped care models across health and social care services** that reflect the diverse needs of autistic people and provide support when it is

required, to reduce the escalation of need and the chances of crisis. This would mean building on pathfinder models with proven cost-effectiveness, such as the Early Care Pathway for Autism piloted in Greater Manchester.[57]

3. **Invest in addressing the systemic barriers** faced by autistic people, focusing on stigma, poor understanding of autism, and poor accountability for autistic people's outcomes. A proposed set of actions is provided at **Annex D**.

In parallel, building on international models and growing evidence in England, the UK Government should **co-produce, test and scale an acceptable, standardised assessment of strengths and support needs** across education, healthcare, employment and justice, initially for those waiting for clinical assessment, then broadening to all autistic people. This could be based on the International Classification of Functioning.

Investment in clinical autism assessment

Using an average of the confirmed 2026/27 discretionary NHS tariffs for face-to-face autism assessments[58] of £1,250 per case, the NHS in England would need to spend around £200 million per annum to complete the assessment process for an estimated annual 160,000 referrals,[59] meeting the 13-week waiting time target set by NICE. This would require a spend from existing resources of only 0.16% of ICB Core Allocations for 2026/27.[60] This level of investment is marginally above the level of recurrent savings envisaged from abolishing NHS England and reducing ICB headcount in 2026. In addition, there would need to be a non-recurrent spend of around £243 million over the next 2 years to remove the backlog of 195,000 cases waiting more than 13 weeks for an assessment.

National scaling of strengths and support needs assessment cannot succeed unless public services have the capacity and culture to genuinely respond to the individual needs of autistic children, young people and adults. We are still far from this point. Crucially, this means that the investment and systemic change recommended needs to take effect **before** the transition to strengths and support needs assessment is completed nationally.

This is because:

- There is too much pressure on the system to switch from a diagnosis-gated model to a model led by support needs, and parts of the system are at different stages of 'readiness.' Without systemic change, strengths and support needs assessment will be used to restrict access to diagnosis, and diagnosis will continue to be used as a condition for accessing support.
- Levels of need amongst autistic people and their families are acute now, and lives are being lost. Services must improve now, not in ten or fifteen years.
- Current public narratives around 'overdiagnosis' are becoming reinforced, and risk entrenching stigma and prejudice just at the point when it needs to end. This can be seen in the polarising media headlines[61] following the interim report of the Independent Review. Any further increase in stigma would entrench the systemic barriers autistic people face, making it even less likely that support and adjustments are provided.

Without investment and systemic change, existing system pressures and persistent stigma will stop needs-led approaches from working. Instead, there will be substitution, with strengths and support needs assessment used to restrict access to diagnosis and support, rather than complementing current pathways, and lower referrals to clinical autism assessment will be prioritised irrespective of assessment of need. Long waiting lists for clinical assessment will continue, leading to further escalation of need amongst people waiting to be assessed. The focus on preventing crisis will remain weak. Thresholds will continue to be applied rigidly and used to determine who 'deserves' support. This will result in further harm and lost lives. It will also make public spending *less*, rather than more cost-effective. Cost commitments for public funding will increase, for example in mental health and justice.

The benefit: saving lives, more cost-effective spending

The case for systemic change for autistic people through investment and reform is strong. It will save lives, address an unacceptable social injustice, and enable more cost-effective spending of public funds. It is the only way a needs-led approach can be implemented successfully.

Existing data and analysis shows some of the potential savings available to the Government from this approach:

- After 6 years, programmes to support parents of young autistic children showed societal savings of over £43,000 per person.[62]
- The Government spends around £534 million per year confining autistic adults and adults with a learning disability in mental health hospitals:[63] even reducing this by 25% would save over £133 million per year.
- The estimated productivity loss from parents and carers of autistic children aged under 6 years having reduced employment opportunities is £560 million annually.[64/65]

- The benefit to cost ratio for providing the right mental health support for autistic children and young people is 22:1, and programmes supporting inclusive school environments for autistic pupils show a return of over £7.50 for every £1 invested.[66]
- Doubling the employment rate for autistic adults would create up to £1.5 billion of benefit for the economy per year.[67]
- In 2009, the National Audit Office concluded that identifying and meeting the needs of just 8% of autistic adults would result in public sector savings of £67 million.[68]

> *It is ridiculously depressing and distressing to be told simultaneously that you're making it up and your diagnosis was a mistake AND that you're incapable of anything and deserve to be removed from society.*

These figures are indicative and require refinement through detailed modelling. However, they demonstrate that investment in systemic change is likely to deliver significant long-term savings alongside improvements in quality of life.

In England, a new National Autism Strategy, led from the Department of Health and Social Care but with a cross-Government remit, would be the ideal vehicle to lead this change, and the House of Lords 'Time to deliver' report provides a strong blueprint. A suggested high-level implementation plan is set out at **Annex E**. The National Autism Strategy should be focused on both improving outcomes and enabling more cost-effective public spending. Similar approaches could be implemented in Scotland, Northern Ireland and Wales. In Australia, the Mental Health Commission plays both a leadership and operational role, providing evidence and advice to continuously improve mental health and prevent suicide.[69]

The pressure on funding across public services, and the level of change required, suggests this would need to be at least a seven-year programme. The need for cross-Party support would be vital. This timing would allow public services to build the capacity and new ways of working to meet individual support needs, while protecting access to clinical assessment. It would also allow a natural adjustment in the rate of referral for clinical assessment, rather than an artificial suppression of need.

All aspects of the systemic change programme would be fully informed by lived experience, and all new resources would be co-produced with autistic people and their families. Across the UK, governments should work with autistic people and their families, charities, researchers, clinicians and others to scope, co-produce and take forward the work required. The people and organisations who have contributed to this report are ready to support this process.

Getting this right would also create opportunities to improve lives and economic performance more broadly, for other marginalised groups and across the wider population. Autistic people's experiences are a powerful test of wider public service reform as aspects of autistic experience set a high bar for identification of need, specific support, and service adaptation. For more detail on this, see **Annex F**. In this way, a change programme with an initial focus on autism could be broadened out to all types of neurodivergence, and potentially mental health, creating wider benefits and even greater cost efficiencies and savings.

Conclusion

The message of this report is simple. Action to address the harms faced by autistic people and their families will not succeed without substantial **investment and systemic change** across clinical autism assessment and wider public services. This is evidenced by the failure of UK policy to improve outcomes for autistic people since the Autism Act 2009 in England, and in the preceding decades.

The current pressure on clinical autism assessment services should be an inflection point for real and sustainable change at a system level: addressing unacceptable social injustice, driving economic benefits, and creating higher quality, more cost-effective public services. Introducing strengths and support needs assessment without systemic change will only mean more lost lives.

Autistic children, young people and adults deserve the same chance as everyone to live a good quality life and contribute to their communities and the economy. The Government in England, and others across the UK, can make this happen: but it will need a long-term plan, genuine systemic change, and investment to enable this change. Anything less will simply repeat the mistakes of the past.

Annex A

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Annex B

Principles to guide policymakers and service commissioners

Policymakers and service commissioners should:

- Understand the fundamental importance of meeting individual support needs as a basic principle of public service. It is not 'nice-to-have': it is essential.
- Understand that individual human brains work differently, and that there need to be different ways of engaging with public services.
- Put understanding others at the heart of their roles, and at the heart of public services. People's experiences are rich, varied, and nuanced, and this helps make public service so rewarding. Continual curiosity, not judging, and not making assumptions, are fundamentally important in helping more people thrive and succeed.
- Understand that transitions matter. They are predictable failure points and must be proactively well-managed. They are a test of whether public services are working, and need attention, resource and specific processes.
- Recognise that integrated service planning and delivery is not an inconvenience, but an opportunity to achieve greater impact and make better use of scarce public funds. Silo working only increases the risk of harm. See collaboration as the way things are done, not as an optional extra. This is particularly important across health and social care, and health and education.
- Understand that meeting individual support needs is not about doing more but working differently. Every additional action to meet a previously unmet support need will enable a reduction in other actions you would ordinarily take. Seeing individual support needs as a barrier limited by available resource is missing the point.
- Treat accountability as part of the job, not a threatening consequence to try and avoid. Being accountable doesn't need to mean being punished – it is a way of acting that stops problems from happening. Being accountable means calling things out if they aren't working. To be accountable, the system should support you to do the right things.

Design principles for public services that meet support needs should include:

- Autism-informed curiosity about a person's needs.
- Identified support need triggers support.
- Diagnosis matters but is not a requirement for support and should not be artificially suppressed.
- Prevention/early support.
- Equity by design.
- Co-production.
- Transparency.
- Accountability.
- Data minimisation and trust.

Public services that meet support needs for autistic people and their families should involve:

- Early identification of potential autistic traits through universal services (health visiting, early years settings, schools).
- Standardised, acceptable, and evidence-based strengths and support needs assessment, accessible without requiring diagnosis.
- Coordinated support planning across all relevant services.
- Transition support at key life stages (school entry, secondary school, post-16, employment).
- Access to specialist services when needed, without repeated assessment.
- Adaptation of universal services to be accessible to autistic people and meet support needs.
- Reasonable adjustments made in services in advance of an autistic person accessing them.
- Clear accountability and quality standards across all services.
- Meaningful involvement of autistic people and families in design and delivery.
- Autism-specific training/CPD paths for the workforce, augmenting existing professional training such as SEND in education and the Care Workforce Pathway for adult social care. The skills and approaches required may be highly specific to an autistic individual, but some recurring features apply, particularly contemporary knowledge of autism and skills acquired through coursework combined with practical experience (e.g. supervised practice in a range of settings).

Annex C

Evidence-based support for a needs-led system for autistic people and their families

The table below is a starting point for the creation of a National Commissioning Framework **(see Annex D)** for services and support for autistic people and their families throughout the life course. It would require further evidence-building facilitated by the Government, ideally through the Research Action Plan committed to as part of the 2021-2016 National Autism Strategy but not subsequently delivered. Services and support included in a National Commissioning Framework should be acceptable, effective, cost-effective and be based on proportionate and high-standard evidence.

Source: Assessment of current evidence around services and support carried out by the Care Policy and Evaluation Centre, London School of Economics,[70] together with input from report contributors.

Life stage and/or process	Service/support	Current status of evidence
Early identification of potential autistic traits, carried out in community settings	SACS-R	Strong evidence of sufficient accuracy in predicting subsequent diagnosis.
Early support to families where potential autistic traits have been identified	PACT/iBASIS Stepping Stones Positive Parenting programme	RCT evidence of effectiveness and cost-effectiveness.
Early years learning	SCERTS Autism Education Trust Early Years Standards Framework	Strong evidence of positive impact.
Screening for autistic/ neurodivergent traits	New tools to be developed based on evidence-based criteria	Further evidence required.[71]
Pre-diagnostic support	Local autism hubs Advocacy for parents Autism Central	Evidence of effectiveness.
Clinical assessment	NHS England National Framework and Operating Guidelines	Further work required on quality and consistency – not within the lifetime pathway.
Post-diagnostic support	Low-level support, psychoeducation, peer support, delivered in community settings	Systematic review showed evidence of effectiveness.
Strengths and support needs assessment	Tool or framework to be developed based on the International Classification of Functioning	Work is in progress.
Clinical supports/ therapies (adapted)	Adapted mental health support for autistic children, young people and adults Annual health checks for autistic adults Mindfulness-based therapy PEACE service for eating disorders	Evidenced by NHS England. RCT evidence.
Clinical interventions for co-occurring conditions e.g. common mental health conditions	Common mental health conditions: • Depression NG222 • Anxiety CG113 • Social anxiety CG159 • OCD CG31	NICE guidelines.
Facilitating access to public services	Specialist Autism Teams	Some evidence of effectiveness and potentially cost saving.
Models of adaptation across public services	A range of possible frameworks: • Education: Good Autism Practice (Principles and Framework), Mental Health Support Teams in Schools, KiVa anti-bullying programme • Social care: Independent Guide to Quality Care for Autistic People • Employment: Individual Placement and Support, Bee Neuroinclusive Code of Best Practice for Employers	Some additional evaluation required.

Annex D

Actions to address the systemic barriers faced by autistic people and their families

Commissioning

A National Commissioning Framework for autism-specific services and support, reflecting the latest and highest standard evidence and regularly reviewed and updated. The framework would be used at all stages in the system, from planning (e.g. Joint Strategic Needs Assessments) through to reporting against outcome targets. It would include a mandatory list of data items and topics that must be covered in local planning, and these would be regularly reviewed/refreshed.

Implementation of legislation

Action to ensure statutory duties on local authorities, local health bodies, and publicly funded service providers are implemented, so there is systematic use of both standardised strengths and support needs assessment and the National Commissioning Framework.

Accountability

Specific accountability for autistic people's outcomes in national government (e.g. a Secretary of State), in service commissioning, and in service delivery, with real consequences. This would include both independent scrutiny of outcomes collected directly from autistic people and their families, and direct remedy for individuals and families through a Commissioner for Autistic People. Autism Partnership Boards would be mandatory and enforced and separate from learning disability and mental health partnership boards. Bringing autism assessment and diagnostic services within the scope of registration and inspection covered by the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Part 3) would increase accountability on providers. Similarly bringing autism waiting times for assessment and key lines of enquiry into the statutory framework for assessing the performance of ICBs and local authorities would strengthen accountability for local policymakers and commissioners.

Investment in research and evaluation

Although there is now better evidence showing 'what works' in identifying and meeting autistic people's support needs, additional investment is required as understanding of autism continues to develop. The 2021 National Autism Strategy in England committed to a Research Action Plan, which never materialised. This should be reinstated and delivered. An 'autism evidence observatory' jointly hosted by key bodies across health, education and care, could be one way of achieving this. Local innovation is often ahead of national policy, and there needs to be a way of capturing this at a national level, to avoid fragmented responses and to take advantage of the best available evidence and opportunities. One example is the Bee Neuroinclusive Code of Best Practice,[72] which has been embedded in the Greater Manchester Good Employment Charter, increasing its mainstream visibility, support, and likelihood of adoption.

Adapting public service environments

To ensure that strengths and support needs assessment translates into real adjustments, a range of supporting elements would be required in a systemic change programme. This would include mandatory autism training for all public service staff including an appropriate Level 5 qualification for an 'autism lead' in each service/organisation, incentives to adapt environments, and – for some public services, notably education – training focusing on meeting individual needs when supporting a larger number of people. It would also require the Government to explicitly prioritise moving towards a more relational model of support in public services. This, and piloting strengths and support needs assessment, would require investment in support for the workforce, particularly across health, education and care, including additional training and peer-led support.

Changing culture

A lack of understanding and acceptance remains the greatest systemic barrier for autistic people and their families, and changing this is a vital enabler of success. The most important priority would be strong, sustained leadership from the Government, visibly championing acceptance and understanding and focusing on autistic people's strengths as well as support needs. At an operational level, culture change could be supported by public information campaigns focusing on understanding autism, embedding understanding of autism and the acceptance of autistic people into compulsory education (e.g. Learning About Neurodiversity at School,[73] schools programmes delivered by the Centre for ADHD and Autism Support), and widely available public education on autism including through community groups.

Continued…

Benefits realisation

It is crucial for system leaders to be able to see the benefits of meeting support needs and making adjustments, particularly in terms of integrated service planning and delivery. A benefits realisation model would capture this information and feed it back into the system rapidly, creating a positive feedback loop and increasing the incentives for commissioners to plan for and invest in autism-specific services, and for public service leaders to ensure their services make adjustments.

Annex E

Suggested high-level implementation plan

Systemic change for autistic people and their families would require phased implementation over at least seven years, co-ordinated through a National Autism Strategy:

Phase 1: Foundation (Years 1-2) • Immediate investment to stabilise current clinical assessment capacity and reduce waiting lists • Establish cross-departmental governance and delivery structures • Build on existing evidence to further co-produce and test acceptability of strengths and support needs assessment • Pilot strengths and support needs assessment for individuals and families on waiting lists in small number of areas • Create and fund national workforce recruitment and training programmes • Establish baseline metrics, evaluation framework and benefits realisation plan • Develop specification for neurodevelopmental pathways and stepped care approaches • Develop national commissioning framework • Begin changes to accountability • Begin implementation of culture change actions.

Phase 2: Pilot (Years 2-3) Begin expansion of strengths and support needs assessment in additional areas (target 25%-30% coverage) • Maintain investment in clinical assessment capacity • Continue to fund workforce recruitment and training programmes • Pilot national commissioning framework • Establish data infrastructure for wider public services • Pilot neurodevelopmental pathways and stepped care approaches • Early evaluation of pilot areas with course correction as required • Complete changes to accountability • Evaluate impact of culture change actions and adjust as required.

Phase 3: Expansion (Years 3-5) Ongoing quality assurance of strengths and support needs assessment • Implement neurodevelopmental pathways nationally with stepped care approaches • Link clinical assessment capacity investment to next stage planning approaches • Evaluate and scale national commissioning framework • Begin embedding of accountability and quality mechanisms • Begin integration of commissioning and funding streams • Comprehensive evaluation of whole system approach for autistic people and their families.

Phase 4: National Coverage (Years 5-7) • Complete national rollout of strengths and support needs assessment and national commissioning framework • Full integration of commissioning and funding streams • Embedding of accountability and quality mechanisms • Continuous improvement based on evaluation findings • Transition planning for long-term sustainability.

Each phase requires:

- Sufficient resourcing with ring fenced budgets
- Clear milestones and success criteria
- Regular progress review and adaptive management
- Meaningful co-production at all stages
- Transparent reporting to Parliament and the public.

Key dependencies include workforce capacity, local authority cooperation, IT infrastructure, and sustained political commitment across government changes.

Ministerial accountability for the programme should be formalised through:

- Ultimate accountability through the Secretary of State for Health and Social Care, in line with responsibility for national autism strategy
- Joint ministerial ownership of programme delivery between the Secretary of State for Health and Social Care and the Secretary of State for Education, with designated lead Ministers
- Annual report to Parliament on progress against defined metrics
- Cross-departmental delivery board chaired at Director General level, with autistic representation

- Public dashboard showing key performance indicators across all relevant services
- Independent evaluation of implementation quality every two years
- Parliamentary Select Committee scrutiny at least annually.

This accountability structure should be established through Ministerial direction and supported by cross-government concordat.

The Government must co-produce every aspect of reform with autistic people and their families, including:

- Funded, representative advisory panels with decision-making authority, not just consultation rights
- Payment at appropriate rates for lived experience expertise
- Accessible formats and communication support to enable full participation
- Autistic leadership in governance structures at national and local levels
- Regular evaluation of co-production quality using recognised frameworks
- Clear accountability for acting on co-production input.

This goes beyond consultation to genuine partnership in design, implementation, and ongoing refinement. Co-production must be adequately resourced and valued as essential expertise, not optional input.

Successful implementation requires anticipating and mitigating key risks:

Risk 1: Insufficient Workforce Capacity and Knowledge of Autism
Likelihood: High
Impact: High - could delay implementation and maintain long autism assessment waiting lists
Mitigation: Immediate investment in workforce capacity and training on autism; creative use of peer support and assistant roles; phased rollout to match capacity development; international recruitment if needed.

Risk 2: Cultural Resistance to Systemic Change
Likelihood: Medium-High
Impact: Medium - could slow adoption of systemic change in some areas
Mitigation: Strong Ministerial leadership; incentive structures favouring innovation to address culture change; showcasing early successes; involving frontline staff in design of systemic changes; adoption of co-production best practice by Local Authorities and the NHS.

Risk 3: Inadequate Financial Resources for Systemic Change
Likelihood: Medium-High
Impact: High - could undermine entire approach
Mitigation: Clear business case (supported by National Audit Office and/or HM Treasury) demonstrating long-term cost-effectiveness and potential for savings; ring-fenced funding; multi-year funding settlements; reuse of efficiency savings from streamlined clinical assessment and reduced crisis interventions.

Risk 4: Fragmented Implementation
Likelihood: Medium
Impact: Medium - could create postcode lottery
Mitigation: National standards and quality framework; clear regional/sub-regional accountability for systemic change; performance management; sharing of best practice; regular evaluation.

Risk 5: Loss of Political Priority
Likelihood: Medium-High (across electoral cycles)
Impact: High - could lead to abandonment of systemic change
Mitigation: Cross-party consensus building; statutory underpinning through Autism Act/other UK legislation and strengthened statutory guidance; public campaign; regular Parliamentary reporting.

Risk 6: Failures of Accountability
Likelihood: High
Impact: High - would undermine prioritisation and delivery of systemic change
Mitigation: Independent scrutiny and direct remedy processes; registration/inspection of autism assessment services; enforce mandatory Autism Partnership Boards.

Regular risk review and adaptive management will be essential throughout implementation.

Annex F

Autism as a strong test of public policy

Autism provides a particularly strong test for any policy aiming to meet needs, as aspects of autistic experience set a high bar for identification of need, specific support, and service adaptation. This is for several reasons.

- **Autistic experience is diverse**. Although some core aspects of autistic experience are the same, all autistic people's experiences are individual. Some autistic people have high autonomy but experience considerable distress, which can have severe consequences over time. Some autistic people require intensive levels of care. An individual profile of strengths and support needs can be uneven, with significant strengths in some areas alongside considerable support needs in others. Strengths and support needs often change through life, at transition points, and in response to changes in the external environment.
- Many core aspects of autistic experience are **in tension with 'traditional' policy and service design**. As examples:
  - Not only are needs 'invisible', they also can be actively 'hidden' through masking. Masking also means that the signs of escalating needs can be harder to identify. For example, employers may not offer support to autistic employees because they 'appear to be coping'.
  - Social/communication approaches often don't align with what policy or service delivery 'expects'. One way of understanding this is through the 'double empathy problem', highlighting that failures in communication between autistic and non-autistic people are mutual, not solely resting with the autistic person.
  - Repeated movements, sometimes referred to as stimming, can be perceived by teachers as undermining authority in classroom environments, when these movements are vital for self-regulation.
  - Sensory sensitivity is a challenge to the physical environment itself. This could mean lighting, sound, smell, or the presence of many people in a space.
  - Monotropism can make it hard for autistic people to switch attention. For example, this may be misinterpreted as a lack of compliance in schools.
  - Alexithymia means not being able to identify your own emotions, or those of others. This can make it harder to identify support needs in many services, and can lead to misinterpretation of co-occurring health conditions by healthcare staff, resulting in delayed or inappropriate treatment.
- Autism also has high **co-occurrence** with:
  - Other types of neurodivergence – ADHD,[74] dyslexia,[75] dyspraxia, dyscalculia, Tourette's.
  - Learning disability – mild, moderate, severe, profound/multiple.[76]
  - Physical health conditions – constipation, epilepsy, sleep disorders, hypermobility, migraines, allergies, autoimmune conditions, gastro-intestinal problems.[77/78]
  - Mental health conditions – anxiety, depression, OCD, schizophrenia.[79]
- Finally, the **consequences** of policy failing to provide the right support for autistic people are often severe: meltdown/shutdown, burnout, self-harm, mental health crisis, suicide. As well as the unacceptable human cost, these consequences also drive avoidable cost through the system.

If policy works for autistic people, identifying and meeting their needs, it is likely to work for many other groups, particularly those with 'invisible' or 'hidden' needs. This includes people who are neurodivergent in other ways, and people who have mental health conditions.

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