



# Real Change for Autistic People and their Families

A New Approach for the UK

June 2023

# We need to see Real Change.

**Despite dedicated legislation, successive Government strategies and countless commitments, the lives of autistic people in the UK are not improving.**

Comparing autistic people's outcomes now with outcomes 15 years ago shows that little, if any progress has been made. On some measures, we are going backwards.

- The proportion of autistic adults getting the support they need to live in their communities is barely higher now than it was in 2003.
- Parents of autistic children are still fighting a system of education and care that seems stacked against them, just as they were 15-20 years ago.
- The autism employment gap is still one of the widest for any group in society, with only 29% of autistic people in any kind of employment, compared to 16% in full time paid work only in 2016, and 15% in 2007.
- The proportion of patients in long term mental health facilities who are autistic is higher now than it was in 2015.
- Shocking cases of abuse of autistic people and people with learning disabilities in mental health hospitals continue to come to light, more than a decade after the exposure of Winterbourne View hospital.

This has to change. Autistic people face huge inequalities and unacceptably poor outcomes.

Over 1 in 100 people is autistic, and with greater awareness across society, the number of people being identified as autistic continues to grow.

The next General Election provides an opportunity to introduce bold reforms that will unlock the change autistic people desperately need to see.

Achieving Real Change for autistic people and their families means looking at how the whole system works. Individual initiatives, however well targeted, have little effect unless the underlying causes of system failure are addressed.

**This policy paper sets out a framework for reform that Governments across the UK could use to focus on achieving Real Change. The Autism Alliance urges all political parties to engage with this framework and commit to reform that will, finally, make a difference.**

# Real Change for Autistic People and their Families



**Rationale:** Despite dedicated legislation and successive national strategies for autism across the UK, we have not seen real change in outcomes for autistic children, young people and adults. This is because policy has not focused on the underlying drivers of change at a system level.

**Objective:** A step change improvement in outcomes for autistic people over 5 years.

Timely autism assessment for children, young people and adults, with excellent early support for families

- The number of people/families on the waiting list for autism assessment.
- The proportion of people/families on the list who have been waiting longer than the recommended 13 weeks.
- The proportion of people/families who say they had the right support before and after their assessment.

A schools system that works for autistic children and young people, prioritising their wellbeing

- The proportion of autistic children who say they enjoy school.
- The proportion of autistic children achieving grades 5 and above in English and Mathematics GCSEs.
- The proportion of autistic children not in school (fixed term/permanent exclusion, managed move, direction off-site).

Supported pathways to employment for autistic people who want to work and are able to work

- The proportion of autistic young people aged 18-25 who transition to employment and further learning, rather than becoming NEET.
- The proportion of autistic adults in all types of paid employment.

The right support, in the right place, at the right time for autistic adults, maximising their quality of life

- The proportion of autistic adults who say they can get the support they need to live in their communities.
- The number of autistic adults who are in long term mental health inpatient care.

## Accountability

- Single Minister accountable for autistic people's outcomes and reducing inequalities, held to account by an Autistic People's Forum.
- Definition of a core set of targets as measures of success; cascading of these targets to local level, with a new statutory duty on Integrated Care Boards and local authorities to report on improvements in autistic people's outcomes against these measures.
- Direction to Ofsted and CQC to make quality of support for autism/SEND a limiting judgement at inspection for education and social care.
- Commissioner for Autism and Learning Disabilities to champion rights and hold the system to account.
- Review to End Cruelty in Care, reporting directly to the Prime Minister.

Plus other policy measures covering employment and justice

## Funding

- National autism early support programme for families, based on the latest research and focused on maintaining wellbeing, building families' confidence and resilience, minimising escalation of need and preventing crisis.
- Short term bridging fund for autism assessment, SEND education and social care to create headroom for reform.
- New funding model for autism assessment, designed to meet demand.
- Mandatory pooled budgets for autism and learning disability across health and social care, overseen by Integrated Care Boards.
- New funding incentives for Integrated Care Boards to deliver better outcomes for autistic people.
- Task Force to End Confinement in Long Term Inpatient Care.
- National research programme for autism, representing 1%-2% of national health research funding, shaped by autistic people and focused on maximising quality of life.

## Culture

- Mainstreaming autism acceptance and co-production across Government.
- Mandatory autism training for all staff in schools, other educational settings, and children's services.
- Revised statutory SEND code of practice setting out the approaches and flexibility that autistic children and young people need in mainstream education settings, based on best practice.
- Completing and embedding the mandatory Oliver McGowan autism training for health and care staff.
- Nationwide peer education service for parents/carers and professionals, including information and advice on supporting autistic people to thrive.
- Strengthened statutory guidance to mental health services on autism to increase accountability for meeting autistic people's needs.
- Annual review of cases under the Mental Capacity Act and Mental Health Act.

**Key dependencies:** funding for adult social care, funding for the SEND system in education, funded workforce plans for education and social care focusing on specialist roles that are important for autistic people.



The Autism Alliance represents autism charities across the UK. Together, we are campaigning for Real Change for autistic children, young people and adults. There have been successive Government strategies for autism, but although there has been some progress, the most important outcomes for autistic people have not improved as they should have improved. To deliver Real Change, the Autism Alliance has developed a framework for reform to inform party Manifestos in the lead in to the next General Election.

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### Scope

The purpose of this policy paper is to inform the development of Manifesto commitments by political parties in the lead in to the next General Election, expected no later than January 2025. The paper proposes a new model of reform for autistic people and their families, in order to deliver Real Change measured through better outcomes and reduced inequalities. Although the core focus of the paper is England, the model of reform proposed could frame a UK-wide approach, and individual aspects of the model are consonant with policy being considered or implemented in Scotland, Northern Ireland and Wales.



# What is Real Change?

Improving the lives of autistic people has been a priority for Government for almost a decade and a half. In England the Autism Act was passed in 2009, providing the first dedicated legislation for autism, and was followed by national autism strategies and programmes, the most recent in 2021. Autism has also been a priority for Governments across the UK, with strategies and some dedicated legislation.

- **Northern Ireland** – Autism Act (Northern Ireland) 2011, Autism Strategy 2013-2020, Autism (Amendment) Act (Northern Ireland) 2022.
- **Scotland** – Scottish Strategy for Autism in 2011, Outcomes and Priorities document in 2018, Learning Disability, Autism and Neurodiversity Bill announced in 2021.
- **Wales** – ASD Action Plan in Wales in 2008, renewed in 2016, updated delivery plan in 2018, followed by Statutory Code of Practice in 2021.

Some progress has been made. Awareness of autism is now almost universal, and the NHS has a dedicated national programme to tackle health inequalities for autistic people. Individual organisations have invested in autism awareness and training programmes. In England, the Department for Education funds the Autism Education Trust, providing training and resources for schools and other educational settings; and the NHS has launched mandatory autism training for health and social care staff following the tragic death of Oliver McGowan in hospital in 2016 and the tireless campaigning of his family. In Scotland, consultation is underway on a new Learning Disability, Autism and Neurodiversity Bill, and in Northern Ireland a new Independent Autism Reviewer role is being established, subject to the return of Government.

However, data shows that despite this progress, despite a wide range of targeted activity, and despite dedicated legislation and successive Government strategies, the most important outcomes for autistic people have not improved as they should have improved in the past decade and a half. **There has not been Real Change.** The system of care, education, health and justice is still failing autistic people too often.





The examples below, comparing outcomes 5-15 years ago with outcomes now, illustrate that Real Change has not been delivered:

The position 5-15 years ago	The position now
<p>In 2011 BBC Panorama broke the harrowing story of abuse at the Winterbourne View Hospital. The subsequent serious case review report told how staff tormented, bullied and assaulted patients, and the Government set out a Programme of Action in response.</p> <p>A 2003 survey by the National Autistic Society found that 60% of parents of autistic children, and autistic adults, had found it difficult to get the support they needed from social services.</p> <p>The proportion of autistic adults in long term inpatient mental health hospitals in 2015 was 38%.</p> <p>Surveys by the National Autistic Society in 2007 and 2016 showed that the proportion of autistic adults in full time paid work was 15% and 16%<sup>3</sup>.</p> <p>In 2009, the Lamb Review<sup>5</sup> called for a radical overhaul of the SEND system, showing how it was consistently failing families.</p> <p>In 2003, a national newspaper published an article about the poor experiences of parents of autistic children trying to negotiate the system<sup>8</sup>.</p>	<p>Since Winterbourne View, there have been other similar cases, including at Whorlton Hall and Cawston Park; and in September 2022, Panorama again revealed shocking abuse of autistic people and people with learning disabilities, at the Edenfield Centre.</p> <p>In 2019, a report from the All-Party Parliamentary Group for Autism, supported by the National Autistic Society, found that 71% of autistic adults say they are not getting the support they need<sup>1</sup>.</p> <p>The proportion of autistic adults in long term inpatient mental health hospitals in April 2023 was 64%, despite successive plans to support autistic people to live in their communities<sup>2</sup>.</p> <p>In 2022, ONS data showed that only 29% of autistic people are in any kind of employment, compared to more than half of disabled people<sup>4</sup>.</p> <p>Autistic children continue to be failed by the system. 2021 figures showed that only 26% of autistic pupils feel happy in school<sup>6</sup>, and in 2022 only 20% of autistic children achieved grades 5 or above in English and Mathematics GCSEs, compared to almost 52% of all pupils<sup>7</sup>.</p> <p>In 2023, there are consistent reports on social media and in the press of a lack of acceptance and understanding of autism, and families fighting for the basic support they need, whether in education, health or social care.</p>

This is more than a failure of the state. It is a tragedy for each and every autistic child, young person and adult who has been failed by the system, and whose chances to thrive have been irretrievably damaged by services that do not recognise and meet their needs.

# Why is Real Change important?



There are a range of arguments that autistic people's outcomes should be prioritised in national policy. That this is recognised is borne out by dedicated legislation (the Autism Act 2009) and successive Government autism strategies. However, the arguments need to be repeated.

- **Inequality** - Autistic people experience some of the greatest inequalities of any group. Life expectancy is just 54, compared to 70 in the overall population<sup>9</sup>, and autistic adults without learning disabilities are nine times more likely to die from suicide<sup>10</sup>. 79% of autistic adults will experience poor mental health<sup>11</sup>, and 42% of autistic children experience anxiety compared to 3% of non-autistic children<sup>12</sup>. Educational outcomes for autistic children are persistently worse than for pupils in most other groups<sup>13</sup>. Autistic people have one of the lowest employment rates of any group<sup>14</sup>, and experience a gap in pay with non-disabled employees of almost 34%<sup>15</sup>. These effects are compounded for autistic women and autistic people from Black, Asian and minority ethnic communities<sup>16</sup>.
- **Scale** - At least 1 in 100 people is autistic, and the number may be higher than this: recent research points to a prevalence rate of 1:67<sup>17</sup>. Autistic

people are not on the periphery: they represent a significant part of our society. As well as this, the number of people being identified as autistic is continuing to increase, due to increased awareness across society and changes to diagnostic criteria. Between 1998 and 2018, the number of people diagnosed as autistic in the UK grew by 787%, and evidence suggests a trend of greater diagnosis of autism without learning disability<sup>18</sup>.

- **Visibility** - Autistic people have differences in social and communication approaches, self-regulation and sensory sensitivity, but these may not be easy to recognise, or may not be evident all the time. Around 6 in 10 autistic people do not have a learning disability<sup>19</sup>, but face significant – and often hidden – challenges in living their lives.
- **Social change** - Attitudes to autism continue to change, part of a wider shift in society towards embracing neurodiversity. As with all social change, this is in large part beyond the Government's control, but there is an opportunity to reinforce this change, and a risk in being behind the curve.
- **Economic benefit** - Alongside the social and moral case, there is a powerful economic rationale for seeking Real Change for autistic people. Autistic people can make a considerable contribution to the economy. Many have exceptional skills, but are held back by societal and workplace norms. Some autistic people need additional support, but the cost of providing this support is escalating because the system frequently fails to provide the right support, in the right place, at the right time. The total cost related to autism has been estimated at £32 billion across the economy<sup>20</sup>.

# How is the system currently performing for autistic people?

It is positive that across the UK, dedicated autism strategies and action plans are in place. Governments should be commended for prioritising autism within national policy. However, reviewing administrative and survey data from the current year and recent years, it is clear that poor outcomes for autistic people and their families are persisting, across education, health, care, justice and employment. We do not see a positive trajectory in any of these measures.

Across the system, a range of 'failure points' are apparent, including:

- Large waiting lists for autism assessment, with long waiting times – in March 2023, 157,579 people were waiting for an assessment in England, representing an increase of 35% in the past twelve months; and 84% of people on the waiting list for assessment have been waiting longer than the 13 weeks recommended by the National Institute for Health and Care Excellence<sup>21</sup>.
- A lack of the right support in the community, in the right place, at the right time – 2019 data from the Autism All-Party Parliamentary Group in England showed that 71% of autistic adults are not getting the support they need<sup>22</sup>, and despite Government commitments to reduce the number of autistic people in long term inpatient care, the number has grown since 2015 and now stands at 1,320<sup>23</sup>.
- The shocking persistence of abuse of autistic young people and adults, and those with learning disabilities, in mental health hospitals.
- A lack of compliance with the law - in February 2022, Healthwatch England found that out of 139 NHS trusts, only 35% fully comply with the legally binding standard to help patients with sensory needs and learning disabilities<sup>24</sup>, and there are still examples of autistic pupils being unlawfully excluded from school, and care for autistic adults not being provided in line with duties in the Care Act 2014.
- A discontinuous, poorly supported journey through education for autistic children – in England, exclusions of autistic children have more than doubled in the last ten years, from 2,282 in 2010 to 5,988 in 2021<sup>25</sup>, and only 26% of pupils say they feel happy at school<sup>26</sup>. 74% of parents say that their autistic child's school place does not fully meet their needs<sup>27</sup>, and new 'safety valve' arrangements for local authorities with high deficits in funding for special educational needs and disabilities, risk a further deterioration in autistic children's outcomes if not well managed.







These 'failure points', and others, show where the system is not working for autistic people and their families, but are not themselves the causes of this failure. For example:

- **A lack of support for autistic adults in the community** is due to underfunding in adult social care and the impact of this on the availability of care and support services; the social care workforce crisis, itself due to underfunding and resulting low pay in the sector; the lack of capacity in the autism assessment system, meaning that many autistic adults do not get the diagnosis they need; and the configuration of funding incentives across health and care, which do not support a shift towards timely support and crisis prevention.
- **Large waiting lists and long waiting times for autism assessment** are due to a lack of planning for the growing demand for assessment; a shortfall in specialist roles in the health and care workforce, and the absence of a funded national workforce plan for the assessment system; and a need for innovation in the design of assessment services.
- **Continuing high exclusions of autistic children** are due to insufficient acceptance and understanding of autism in the school workforce; the pressure on schools created by underfunding, which has also driven a shortage of key specialist roles; the lack of consistent early support for families of autistic children; and weak accountability for the quality of SEND provision, particularly in mainstream educational settings.

In England, following the Autism Act 2009, we have seen legislation which enshrines rights that are fundamental for autistic people and their families: the Equality Act 2010, the Children and Families Act 2014, and the Care Act 2014. These laws should be retained and protected. But implementation of these Acts has not been fully funded, and as a result, we continue to see autistic children, young people and adults being let down by the system and failing to realise their potential, with profound implications for their lives.

The latest autism strategy in England has been in place since 2021, so it could be argued has not had sufficient time to make an impact. However, although the Strategy is all-age, and includes measures in all key areas of policy and delivery (assessment, culture, care, education, health, employment, justice) it does not focus on measurable change in core outcomes for autistic people, or on the underlying drivers of change. This is a missed opportunity.

This is also true across Scotland, Northern Ireland and Wales, where despite some strong plans there has been a similar lack of progress in improving core outcomes for autistic people. The Autism (Amendment) Act 2022 in Northern Ireland is perhaps the best opportunity so far to take forward genuine system reform, but at the time of writing implementation of the Act awaits progress in re-establishing Government.



# What do autistic people and their families say they want?

The voices of autistic people and their families are the most important guide to reform, and should be central to the design of a system that delivers Real Change. It is vital that their views determine the ways in which we measure the success of the system, and that system-level targets and ambitions reflect the outcomes they believe will improve their lives.

Some of the ways in which autistic people are different are shared, but every autistic person is individual – and recognising and engaging with individual interests, needs and experiences is fundamental to autism acceptance, understanding and better outcomes.

A range of charities and public organisations have gathered insight from autistic people and their families on the operation of the system<sup>28</sup>. These have different contexts and relate to different aspects of system performance, but there are some overarching themes.



Consistently, autistic people of all ages say:

- They want their voices to be heard and their needs reflected in the design and implementation of policy;
- They want to be able to show their authentic selves;
- They want early support that promotes their wellbeing and the wellbeing of their families;
- They want the choice of timely autism assessment, and consistent provision of pre- and post-diagnostic support for themselves and their families;
- They want to see adjustments that reflect their needs, across the delivery of all public services, in employment, and across society;
- They need timely, appropriate support in the community that meets their needs, and prevents the escalation of needs towards crisis;
- They want to go to school, to achieve and to thrive in employment where this is possible, and need appropriate support and adjustments to help them pursue these goals;
- They want to live independently wherever possible, as part of their own communities and close to their friends and families.

**Families of autistic children, young people and adults want these things too – and want to stop battling with a system that seems stacked against them, and all too frequently reduces them to exhaustion.**

# How do we achieve Real Change?

## Achieving Real Change for autistic people and their families will require system-level reform.

Since 2009, autism policy has not focused on the whole system and the underlying drivers of change. Instead, over time, and within the framework of national strategies for autism, we have seen attempts to steer the system through guidance and targeted initiatives. In England, these have included an Autism Innovation Fund, the 'No voice unheard, no right ignored' consultation, the Transforming Care programme, and statutory guidance for local authorities and health services issued in 2015 (under the Autism Act 2009). The Government has also brought forward its Mental Health Bill, which includes measures to improve outcomes for autistic people and people with learning disabilities.

While this action has been welcome and has led to some improvements, we will not see Real Change while system-level barriers remain. To achieve Real Change, system-level barriers need to be addressed directly.

Three main barriers can be identified: **accountability**, **funding**, and **culture**.

## Accountability

Accountability for improving outcomes and reducing inequalities for autistic people is not strong enough or clear enough. Schools, local authorities and health services do not operate under the oversight of sufficiently sharp accountability models related to autism, and the incentives to identify and meet the needs of autistic children, young people and adults remain weak. This is particularly damaging in a period of scarce resources, where organisations face huge pressure on funding. There continue to be collective failures of accountability in preventing abuse in care. And across the system – including at Ministerial level – it can be unclear who is ultimately accountable for autistic people's outcomes. A dilution of accountability takes energy away from change, and also makes it less likely that the right data will be collected and used to improve outcomes.





## Funding

Meeting the needs of autistic children, young people and adults carries a cost. This can be an uplift for mainstream services, or an investment in specialist services. Underfunding across the system, particularly in education, care and health means there is not enough funding to meet demand, whether for assessment, the right educational provision, or specialist social care. Demand is rising as more people are identified as autistic, putting further pressure on the system. Alongside this, the funding system lacks sufficiently strong incentives for local commissioners to focus on timely early support and crisis prevention, meaning that needs continue to escalate and costs continue to rise. Initiatives to tackle this – such as Building the Right Support – are having little effect.



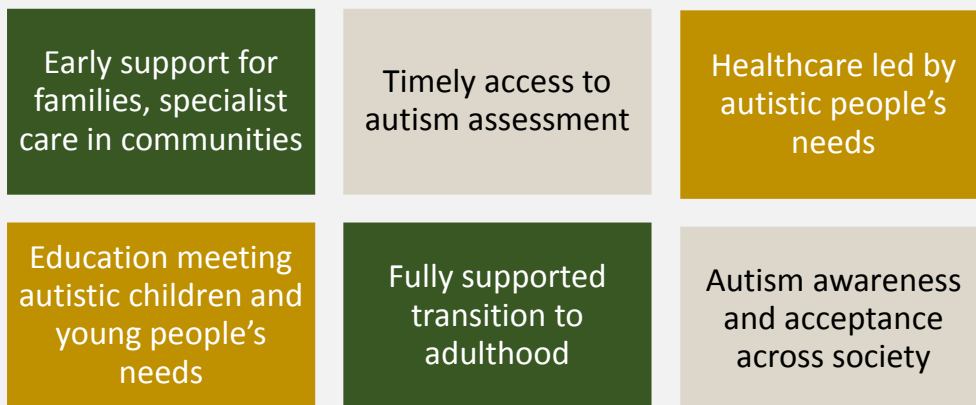
Addressing these barriers will require a bold commitment to reform, and a commitment to see this reform through. It will require a sustained focus on implementation, using the right data to provide confidence that change is taking place, and to hold different parts of the system to account. It will need a mindset of collective responsibility and taking ownership amongst professionals, regulators and Government. It should be underpinned by a theory of change showing how the system works; how actions lead to impact; and how we can track the effect of addressing system-level barriers. But above all, it must focus on the achievement of Real Change in outcomes.

## Culture

Outcomes for autistic people – as with other marginalised groups – are strongly determined by culture. The ways we act in the moment, the individual decisions we make, and how these scale up at the level of society, have potentially the greatest impact on autistic people's lives, from local commissioning decisions to the diligence and compassion with which care is provided. Although positive social change is underway, there remain significant gaps in autism acceptance and understanding: and therefore the motivation to prioritise, make adjustments and meet needs. Training is important, but it is embedding sustainable changes in culture that counts.

# A Real Change Programme

Building on the current National Autism Strategy, the Autism Alliance proposes **Real Change for Autistic People and their Families** – a once in a generation flagship programme to unlock better outcomes and reduced inequalities for autistic people and their families.



Real Change would be a cross-Departmental programme at the heart of Government, led by a single accountable Minister (in Education, or Health and Social Care). Although the programme would require a short term investment of new funding to enable the system to 'catch up' with current demand for autism assessment, SEND education and adult social care, its overarching objective would be to **make better use of existing resources**, recognising wider economic conditions and the difficulty of large new spending commitments in the next Parliament.

However, it is important to note that the Real Change programme would have a fundamental dependency on mainstream funding and workforce policy across education and social care. Without sufficient funding to meet demand, and sufficient specialist capacity in the workforce, a model based on timely support and crisis prevention is not viable. It is vital that these wider reforms are progressed, and the Autism Alliance joins with other organisations and consortia calling for Government to take decisive action to ensure a funding settlement,

and workforce planning, that recognises the needs of children and young people with SEND, autistic adults and adults with learning disabilities and allows these needs to be met.

The defining principle of the Real Change programme would be **timely support and crisis prevention**. An efficient system of autism assessment that is supportive for families at all stages. Schools where all staff are autism trained, and support is put in place at the earliest opportunity, giving autistic children and young people the best chance to thrive, achieve and progress. Well-supported transition for every autistic young person to adulthood. Health services that, by default, recognise and respond to the individual needs of autistic people, providing person-centred healthcare. Sufficient specialist care and support for autistic adults, provided at the right time and in the right place, enabling them to live in their communities. Employment support and justice services that reflect autistic people's differences and needs. And employers committed to including and supporting autistic people to thrive in the workplace.



The Real Change programme would be **outcome-led**, positioning a set of headline targets as the measures of success of the programme, the focal point for Government delivery, and the mechanism for public accountability. The headline targets would be **co-produced with autistic people and their families**, reflecting the changes they believe are most important for their lives, mapped to key areas of change for policy and practice. Alongside this, other targets would be set for each area of change to support implementation of the programme.

Area of change	Potential headline targets
Timely autism assessment for children, young people and adults, with excellent early support for families	<ul style="list-style-type: none"> <li>• The number of people/families on the waiting list for autism assessment.</li> <li>• The proportion of people/families on the list who have been waiting longer than the recommended 13 weeks.</li> <li>• The proportion of people/families who say they had the right support before and after their assessment.</li> </ul>
A schools system that works for autistic children and young people, prioritising their wellbeing	<ul style="list-style-type: none"> <li>• The proportion of autistic children who say they enjoy school.</li> <li>• The proportion of autistic children achieving grades 5 and above in English and Mathematics GCSEs.</li> <li>• The proportion of autistic children not in school (fixed term/permanent exclusion, managed move, direction off-site).</li> </ul>
Supported pathways to employment for autistic people who want to work and are able to work	<ul style="list-style-type: none"> <li>• The proportion of autistic young people aged 18-25 who transition to employment and further learning, rather than becoming NEET.</li> <li>• The proportion of autistic adults in all types of paid employment.</li> </ul>
The right support, in the right place, at the right time for autistic adults, maximising their quality of life	<ul style="list-style-type: none"> <li>• The proportion of autistic adults who say they can get the support they need to live in their communities.</li> <li>• The number of autistic adults who are in long term mental health inpatient care.</li> </ul>
Compassionate, informed care services in which autistic people, and people with learning disabilities, can live free from abuse	Further work would be required to define one or more appropriate measures of success for this area.
Substantial increases in autism acceptance across society, and greater sharing of knowledge and skills in supporting autistic people to thrive	Further work would be required to define one or more appropriate measures of success for this area. This could be based on the Autism Attitudes Index being developed by research charity Autistica.

The programme would have an initial time horizon of **five years**. This would set Government an ambitious timescale within which to achieve Real Change, but one that with the right focus and prioritisation, is achievable. Each headline target would be benchmarked in the first year of delivery, reviewing evidence and data from the previous ten years. Data against each target would then be collected during every year of the programme, and published with full transparency, together with an implementation plan for the subsequent year showing how any challenges will be addressed.



The presumption would be that challenging headline targets, representing a considerable degree of stretch, are necessary to drive Real Change across the system. Government would be held to account for the delivery of Real Change both through a new statutory **Commissioner for Autism and Learning Disabilities** and through an **Autistic People's Forum**, before which the accountable Minister would appear.

The Real Change programme would also recognise and measure the significant **financial benefits** of providing the right support: a system that identifies and recognises the individual needs, interests and experiences of autistic people, and meets their needs, is more likely to prevent an escalation towards crisis, and more likely to reduce the 'whole of life' cost associated with autism. The Autism Alliance hopes to say more on financial benefits later this year.

Finally, **planning for sufficient capacity** across services and support, based on the best available data on autism prevalence and diagnosis, would be another key principle of the Real Change programme, built in at every level.

**Prioritising timely support and crisis prevention as a defining principle of the system would enable a step change in improving autistic people's lives while making better use of available resources.**





# A system that works for autistic people and their families

Timely access to autism assessment with pre/post diagnostic support

Education that meets autistic children’s needs, with sufficient specialist education to meet the needs of children with the most complex needs

Acceptance of autism across society with adaptations and supportive behaviours

Specialist care and support in every community for autistic adults with additional needs

High quality information about autism, based on the latest research, available and accessible by default



Local support for families, focusing on autism and led by other families

Fully supported transition to further/higher education and employment

Specialist employment support with employers championing opportunity for autistic people

Healthcare based on the latest research, led by the needs of autistic people, free of abuse



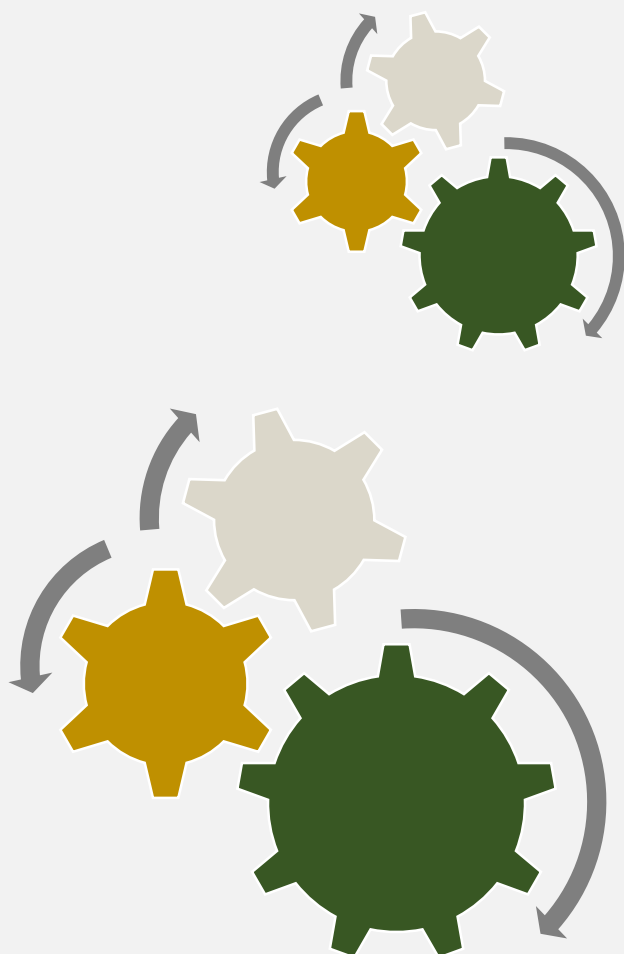


# A Programme of Reform

The purpose of a Real Change programme would be to **reform the system** so that it is set up to deliver better outcomes for autistic people and their families. To achieve this reform, the programme would deliver through three core workstreams reflecting the system-level barriers to real change:

# 1

**A new accountability for autistic people's outcomes** – a single Minister in Government accountable for improving outcomes and reducing inequalities for autistic people; definition of a core set of targets as the measure of success of the programme; cascading of these targets to local level, with a new statutory duty on ICBs/LAs to report on improvements in autistic people's outcomes against these measures; new direction to Ofsted and the CQC to make the quality of autism/SEND support a limiting judgement at inspection in education and social care; and a Commissioner for Autism and Learning Disabilities to champion rights and hold the system to account (as proposed by the Transforming Care Steering Group in 2016<sup>29</sup>). This would be supported by a high profile Review to End Cruelty in Care reporting directly to the Prime Minister, with a respected and influential chair, and a remit to end the persistent culture of cruelty to autistic people and people with learning disabilities in mental health hospitals, and to propose tough new measures to strengthen collective accountability across the NHS, local government and regulators.





## 2

**A rebased funding system for public services that works for autistic people** – alongside a short term investment of new funding, the programme would deliver reform of key funding models: a new funding model for autism assessment that makes more efficient use of available resources to meet demand; new incentives to recruit SEND specialists in key roles as part of a plan for the education workforce; in adult social care, stronger incentives to move commissioning towards timely support and crisis prevention so that autistic children and young people have the right support throughout their education, and autistic adults have the right care and support in their communities. In healthcare, these changes would be supported by a Task Force to End Confinement in Long Term Inpatient Care, to plan and deliver the reforms to practice, funding and collaboration that are needed to reduce, and eventually end the unnecessary long term confinement of autistic children, young people and adults (and people with learning disabilities) in mental health facilities.

Within this workstream, specific reforms might include:

- ✓ **A national autism early support programme for families**, based on the latest research and focused on maintaining wellbeing, building families' confidence and resilience, minimising escalation of need and preventing crisis. This would be delivered through the NHS but commissioned from a range of sources, including NHS-led therapies, social care, and a range of community support. It should be led by other families with lived experience of autism.
- ✓ **A short term bridging fund for autism assessment, SEND education and adult social care**, to create the financial headroom required for funding reform to take place without negative impacts on assessment, education and care for autistic children, young people and adults.

- ✓ **A new funding model for autism assessment** designed to meet expected demand. This could include the short term mobilisation of community spaces as assessment centres to reduce waiting times, staffed by a nationally funded field force of clinical specialists; statutory commissioning of local pre/post-diagnostic support for families; and innovation in local delivery models guided by the NHS National Framework for assessment, including greater use of technology to aid assessment, supported by new IT systems to increase efficiency and free up clinician time.





- ✓ Amending the Health and Care Act 2022 to require **mandatory pooled budgets** for autism (and learning disability) across health and care, overseen by Integrated Care Boards.
- ✓ **New funding incentives for Integrated Care Boards** to deliver better health and care outcomes for autistic people, with a proportion of each ICB budget released on evidence of positive change (eg. for every 5 percentage point reduction in the proportion of autistic people in long term inpatient care). As acknowledged in the Hewitt Review, ICBs (in Scotland, Health and Social Care Partnerships) represent a strong opportunity to make a shift to upstream investment in preventative services – in this case, from over-reliance on inpatient care to providing the right support in the community – but will need the right funding incentives, together with determined strategic leadership. Delivering on the aims of Building the Right support should be a primary objective of the Real Change programme.



### 3

**A strong focus on reinforcing positive social change for autistic people and their families** – mainstreaming autism acceptance and an understanding of the needs of autistic people into all areas of Government business, including by co-producing policy directly with autistic people; implementing mandatory autism training for all staff in schools and children’s services, together with a revised statutory SEND code of practice setting out the approaches and flexibility that autistic children and young people need in mainstream education settings, based on best practice; completing and embedding the Oliver McGowan mandatory training on learning disability and autism for all staff in health and care services; and continuing to build on gains in autism acceptance across society by providing nationwide peer education on autism for parents/carers and professionals, including information and advice on supporting autistic people to thrive. This workstream might also deliver strengthened statutory guidance to mental health services on autism to increase accountability for meeting autistic people’s needs; and an annual review of cases under the Mental Health Act and Mental Capacity Act, to identify and share good practice in handling assessment and outcomes for autistic people and people with learning disabilities, and to highlight examples of poor practice.

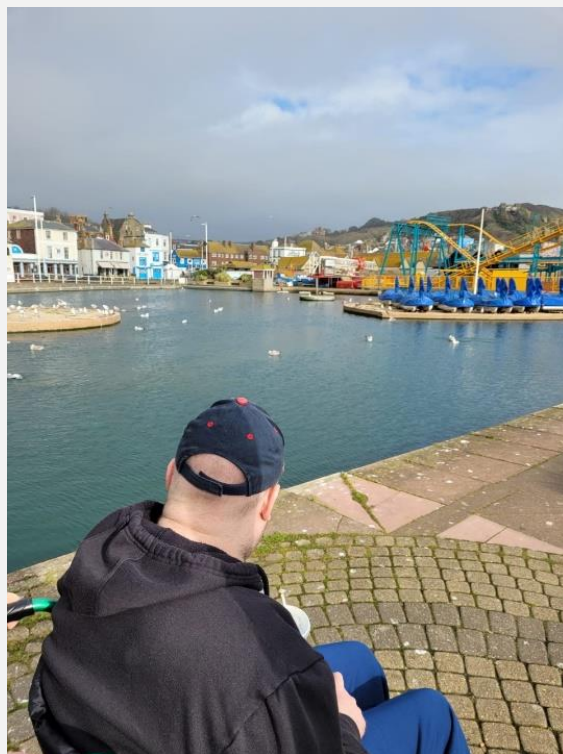


Alongside these three core workstreams, the programme would also include further reforms in employment and justice. These would be agreed in the context of existing activity, including the Autism Employment Review being carried out by Sir Robert Buckland KC MP, and might include:

- **New standards for employment transition support** for autistic young people and young people with SEND, delivered through schools, further and higher education and an enhanced Access to Work pathway funded at scale, supported by autism training for all careers advisers.
- **An Employers Autism Compact**, led by the Government with major national employers, covering recruitment practices and the working environment, and with support and resources for micro, small and medium-sized businesses.
- **Scaling and embedding autism training and best practice** in working with autistic people across the criminal and civil justice systems, elevating the voices of autistic people as reform continues.

The Real Change programme could act as a unifying, underpinning model of reform for autistic people and their families across all parts of the UK, providing a coherent framework for improving outcomes and reducing inequalities. In the Devolved Administrations, elements of the programme are already in place or being considered. In Northern Ireland, an Independent Autism Reviewer is being recruited to scrutinise the implementation of policy (subject to the return of Government), and in Scotland, Ministers have committed to introduce a Commissioner for Autism and Learning Disabilities.

For local government, the programme could support commissioners to meet the needs of autistic people in line with the Equality Act 2010, the Children and Families Act 2014, the Autism Act 2009 and the Care Act 2014. And for Integrated Care Boards, the programme could finally unlock progress in enabling more autistic people to move from long term inpatient care into community-based care, and mark an end to cruelty in long term care towards autistic people and people with learning disabilities.



# Conclusion

It is hugely positive that autism is recognised in dedicated legislation across the UK, and that targeted strategies for autism are in place at a country level. However, without addressing underlying system level barriers, this good work is unlikely to deliver Real Change for autistic people and their families – particularly recognising the huge financial pressure faced across the system, which is likely to continue in the years ahead.

The time is right for a bold change of approach to finally deliver Real Change for autistic people, focusing on system thinking and the underlying drivers of change. In doing so, the 'rule of the specific' applies. Without a dedicated change programme for autistic people that focuses on the whole system and maintains that focus, the gains we all want to see are unlikely to be realised.

There are strong arguments for the next Government to prioritise autism as part of its policy and reform programme. Although they are too often marginalised, autistic people are not a marginal group. The prevalence of autism across the population is significant, and the number of people identified as autistic continues to increase. In England, autism is the most prevalent need amongst children with an Education, Care and Health Plan; and provision for autistic people and people with learning disabilities represents the largest single block of expenditure in adult social care. The inequalities faced by autistic people across the UK, and across every area of the system are stark, persistent and unacceptable. The ways in which autistic people are different may not be easy to recognise, or may not be evident all the time, reinforcing inequalities and making poorer outcomes more likely. The cost of failing to meet autistic people's needs is high, everywhere in the system, and the potential financial benefits of raising achievement, providing the right support, and increasing employment are considerable.

However, this is not about elevating autism above other priorities for education, health and care. Rather, driving Real Change for autistic people and their families can be a spur to reform across the whole system, in which there are failures for a range of groups. Autistic people need Real Change, but a system that works better for them can work better for everyone.

**It is time for autistic people and their families to see Real Change. We urge all political parties to engage with the ideas and proposals put forward in this paper, and commit to achieving Real Change for Autistic People and their Families.**

# Annex – Components of the Reform Programme



- This Annex provides additional detail on how a Real Change programme could be established and operate across Government.
- Implementation of a Real Change programme would be led by a **single accountable Minister**, ideally a Secretary of State, who would be accountable for delivering the programme and securing better outcomes and reduced inequalities for autistic people.
- New powers in education and care could be taken as part of the planned legislation following publication of the current Government’s SEND and Alternative Provision Improvement Plan.
- The Real Change programme would have two phases: an initial **task and finish** phase, to build and deploy key components of system reform, followed by a **sustained change** phase, to bed down reform, and monitor and assure progress in delivering Real Change.
- Both phases of the programme would be led by a **cross-departmental team** reporting into the accountable Minister. The cross-departmental team would cover the services impacted by the programme, drawing together officials from the Department for Education, Department for Health and Social Care, Department for Work and Pensions, and the Ministry of Justice.
- Government would be held to account for delivery through an **Autistic People’s Forum**, chaired by an autistic person and before which the accountable Minister would appear each year. The Forum would publish a record of each of its meetings.
- Co-production would be at the heart of programme delivery. The cross-departmental programme team would work hand-in-hand with a **Real Change Co-Production Group**, chaired by an autistic person and involving the accountable Minister; and autistic people would be involved from the start in all piloting of service reform at a local level.
- Following the task and finish phase, the set of interventions covered by the programme would be **tested in a range of local areas** prior to scaling nationally. Interventions developed by the programme would adopt the most direct approach to addressing underlying barriers to change, on the basis that with the right support from decision-makers, the most direct route is often the most straightforward.



- To succeed, the programme would need a **compact** agreed across the participating Departments, opening up permission to enact reform through the operating model and services of each part of the system. It would also need a **local test bed framework**, enabling changes to be piloted through local channels of the system, including Integrated Care Boards (reflecting the Hewitt Review), local authorities, schools and other educational settings, prisons and the police. This is particularly important for changes to the funding system, which are not straightforward and will require:
  - A full appreciation of the reasons for taking a new approach to funding, together with a desire to think boldly about the art of the possible;
  - A commitment to focus on outcomes, to engage with new approaches, and to embrace the management of risk as an opportunity;
  - Trust and collaboration between local commissioners and all players in the market, whether education, health or care, informed by open and transparent data;
  - An iterative approach to reform focused on learning and improving.
- Across both the task and finish phase and the delivery phase, the programme would be delivered through its three core workstreams:
  - The **accountability** workstream would sit as an overarching component of the programme. It would take a cross-system-view, piloting changes to the accountability framework at all relevant levels, mainstreaming successful changes across the system, and using data to measure progress in achieving Real Change and to push learning back into the system.
  - Underneath this, the **funding reform** and **culture change** workstreams would be delivered as sub-programmes. Each would be responsible for defining, piloting, evaluating and scaling reforms across relevant parts of the system – for example, funding reform would apply particularly to education, health and care – and would work with local channels of the system through both task and finish and delivery phases. These workstreams would also host, and be informed by, the two major independent reviews carried out as part of the programme: A Review to End Cruelty in Care, and A Task Force to End Long Term Confinement in Inpatient Care.



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