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# Doing the right thing

What the next government can do to drive real change for autistic people

Autism Alliance, April 2024



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Front cover illustration: A concept and composition created by Rachel Jarvis incorporating *Embracing Differences* and *Seeing the Positive* by Charlotte Crawford – The Autistic Artist.

Charlotte is an abstract artist from Berkshire. She loves to work with lots of colour and texture, combining materials and themes to create unique abstract work.

*"I see the world in a slightly different way because I am autistic. This is something I only discovered in the beginning of 2021 at the age of 21. Throughout my life I have struggled with mental health difficulties and in 2020 ended up in hospital because of these struggles. Art and anything creative has always been something I've been incredibly passionate about. Its been my safety net when I am feeling down or lost.*

*My work is a translation of how I see the world and how I communicate when words can't. I want to create work that makes people feel joy and freedom."*

Charlotte thoroughly enjoys creating artworks to sell, but particularly likes working on commissions. She loves to work with people to create something personal and meaningful for their homes. Visit [www.theautisticartist.com](http://www.theautisticartist.com)



# Summary

In 2023, the Autism Alliance published **Real Change for Autistic People and their Families**<sup>1</sup>. This ‘manifesto for change’ set out to establish two simple points: that despite dedicated legislation, successive Government strategies and many commitments, autistic people’s outcomes have not changed; and that this is because policy has not focused on the whole system and the underlying barriers that hold back progress. To achieve Real Change, we will need system level reform.

This paper follows on from Real Change, and proposes a set of policy measures that can be adopted by the Government and by all political parties. The measures focus on two of the three system-level enablers identified in Real Change: **strengthening accountability** and **changing culture**.

They are designed to be implementable within current financial plans, and to start improving autistic people’s outcomes as wider challenges around funding are explored and addressed. All policy measures could be adopted across the UK, noting that steps have been taken towards some of the measures in Northern Ireland and Scotland.

Alongside this, the paper notes the fundamental importance of addressing shortfalls in funding across education for children and young people with Special Educational Needs and Disabilities, and across adult social care, and that the

Autism Alliance is ready to work with Government and Parliamentarians on solutions.

**The Autism Alliance urges all political parties to adopt the measures set out in this paper.**

The Alliance also invites parties to engage with a powerful idea; that a system which works for autistic people and their families **will work better for everyone**; and that putting autistic people’s voices at the heart of policy thinking can help shape a future model of public services to meet the challenges our country faces: one based on valuing difference, identifying strengths and meeting needs.

With continuing global uncertainty and significant pressure on resources, doing things differently has to be a top priority.



*In 2022 only 20% of autistic children achieved grades 5 or above in English and Mathematics GCSEs, compared to almost 52% of all pupils.\**

# Policy proposals

## STRONGER ACCOUNTABILITY



- A Ministerial role for autistic people, so that accountability is clear and not diffuse across different Ministerial posts.



- Co-produced national targets for improving autistic people's outcomes, and a statutory duty on public bodies to report consistently on progress.



- National Panel for Autism, chaired by an autistic person and holding the Government to account.



- A Commissioner for Autistic People, championing rights and holding public bodies to account.



- The Accountability List, showing clearly who is accountable for autistic people's outcomes at a local level.



- Mandatory Autism Partnership Boards, ensuring the consistent involvement of autistic people in local decision making.

### Alongside these measures:



- A statutory direction from Government to Ofsted to make quality of support for SEND a limiting judgement at inspection for schools and education settings.



- A high profile Review to End Cruelty in Care, reporting directly to the Prime Minister.

# ACCELERATING CULTURE CHANGE



- Government leading the way in adopting positive and well-informed attitudes to autism, assessing impact and co-producing policy.



- A National Autism Champion, to promote a positive and balanced public perception of autism.



- Mandatory autism training across public services, promoting acceptance and addressing misunderstanding.



- National action on autism acceptance and understanding, delivered through grassroots organisations across the country.



- Accessible public education, increasing knowledge of autism through short video content for TV and social media.



- A media/tech partnership for good, working with the media and tech sectors to create clear, balanced and positive content on autism.



- Autism peer education in primary schools, to reflect together, understand others' perspectives and create content about autism.



# Introduction

Autistic people comprise between 1% and 2% of the population<sup>2</sup>, but face some of the greatest inequalities of any group in society. Despite increases in autism awareness<sup>3</sup>, there is continuing discrimination, and barriers are evident everywhere in the system and across wider society.

The figures are stark, and show the unacceptable extent of inequality that autistic people face. Life expectancy is between 6 and 11 years lower than the rest of the population<sup>4</sup>. 79% of autistic adults will experience poor mental health<sup>5</sup>, significantly higher than other marginalised groups, and 42% of autistic children experience anxiety compared to 3% of non-autistic children<sup>6</sup>. Educational outcomes for autistic children are persistently worse than for pupils in most other groups<sup>7</sup>. Autistic people have one of the lowest employment rates of any group<sup>8</sup>, and experience a gap in pay with non-disabled employees of almost 34%<sup>9</sup>. These effects are compounded for autistic women and autistic people from Black, Asian and minority ethnic communities<sup>10</sup>.

There is commitment to address these inequalities at a national level. Following successive national strategies for autistic adults, the Government in England launched a National Strategy for Autistic Children, Young People and Adults in 2021 (the 'National Strategy') committing to improve outcomes for autistic people of all ages, and their families. Government has also legislated in ways which should support better outcomes for autistic people, both directly and indirectly. This legislation includes:

- **The Autism Act 2009** (England and Wales), which requires Government to publish a strategy and issue guidance to local authorities and NHS services on services and support for autistic people.
- **The Equality Act 2010** (England, Scotland and Wales), which tackles discrimination and inequality, and requires all organisations to make reasonable adjustments for people with a disability. Autism is covered by the definition of disability set out in the Act.
- **The Care Act 2014** (England), which provides the framework for social care services and requires local authorities to assess and meet eligible needs for social care.
- **The Children and Families Act 2014** (England, some provisions apply to Wales), which requires education, health and social care to work together on identification, assessment, and meeting needs for children and young people with Special Education Needs and Disabilities and their families.

However, despite the National Strategy, the duties in these Acts, and commitments from Government, outcomes for autistic children, young people and adults are not improving in the ways they should. Across the system, autistic people and their families cannot access the services and support they need, with profound consequences for their lives. The Autism Alliance highlighted this lack of progress in **Real Change for Autistic People and their Families**, published in 2023, and with a specific focus on adult social care, in the **Breaking Point** campaign.

Research<sup>11</sup> has continually demonstrated the overwhelming barriers faced by autistic people and their families in every area of the system. The Autism Alliance's Real Change report showed that the lack of progress in improving outcomes and reducing inequalities is systemic, and has been driven by three underlying factors:

- **A lack of accountability.** Although laws are clear about what should happen, and the Government's National Autism Strategy sets clear objectives for policy, there is little accountability if the law is not followed or if policy objectives are not met. Most often, families are forced to challenge decisions, working through exhausting and costly processes with no guarantee of success, and the consequences for commissioners or professionals who do not follow legal duties are unclear. Equally, it is difficult to hold the Government to account for delivery of its National Strategy because the Strategy does not contain outcome targets or a clear model of change, and there is little data on the experiences and outcomes of autistic people.
- **A lack of funding.** A combination of political decision-making and economic conditions has seen funding for public services fall dramatically in the past decade, most clearly across SEND education and adult social care, and at the present time it is clear that the system is hugely under-resourced: unable to meet need, or to recruit and retain the specialist workforce required to provide support for autistic people and their families. This applies equally for other groups with specific needs, including people with a learning disability. Underfunding has driven cost cutting through the system, with disastrous consequences.

- **A lack of inclusive culture.** Although awareness of autism has increased substantially in the past two decades and is now almost universal, autism acceptance and understanding have not seen similar increases, and autistic people continue to experience stigma and discrimination. Society is not inclusive or accessible for autistic people, creating continual barriers and distress that have a damaging impact on their health, wellbeing and opportunities. The values and beliefs held by people at all levels of the system, and the decisions they take ‘in the moment’ have huge impact on autistic people’s lives, all too often holding back access to the support and services autistic people and their families need.

Of these underlying factors, funding has the greatest impact because it affects directly the availability of services and support for autistic people and their families. However, the Autism Alliance recognises that the need for economy is locked in at a political level for the foreseeable future.

The Autism Alliance will continue to advocate strongly for system-level reform and sustainable funding settlements, particularly in SEND education and adult social care. We believe that reform of system design and funding models could be powered by a key principle: **that a system which works for autistic people and their families will work better for everyone**; and that putting autistic people’s

voices at the heart of policy thinking can help shape a future model of public services to meet the challenges our country faces: one based on valuing difference, identifying strengths and meeting needs. With continuing global uncertainty and significant pressure on resources, doing things differently has to be a top priority.

In the meantime, this paper proposes a range of policy measures that could be introduced now: showing intent and starting the process of improving outcomes for autistic people, while wider reform and new funding arrangements are scoped, tested and put in place. We hope that the measures are capable of securing cross-party support, and with the right agreement could be taken forward by any or all parties in the next term of Government. The policy measures proposed in this paper would:

- **Strengthen accountability** for improving autistic people’s outcomes and reducing inequalities: by ensuring that current law, which protects autistic people’s right to live happy, healthy and fulfilled lives is proactively and fully applied in the way intended.
- **Drive faster progress towards an inclusive culture** across public services and wider society, so that there is greater acceptance and understanding of autism and autistic people, supporting better outcomes and reduced inequalities. In turn, this would support the development of skills in supporting autistic people effectively, across the public service workforce.





# Assumptions

In developing policy measures that can strengthen accountability and drive faster progress towards an inclusive culture, we have made a core set of assumptions.

We have assumed that **action is needed specifically to improve outcomes for autistic people and their families.**

This recognises the unacceptable inequalities autistic people face, the significant proportion of the population likely to be autistic, and the specific barriers that prevent autistic people's voices from being heard. However, as with the measures set out in Real Change for Autistic People and their Families<sup>12</sup>, and in Breaking Point<sup>13</sup>, we believe strongly that the characteristics of a system that worked for autistic people would help create a better system for everyone.

We have assumed that at all levels of the system, from Government Ministers to individual teachers and care workers, **there are people who carry a deep commitment to improving autistic people's lives, and want to do the very best they can.** This has been our experience in working with senior party politicians, Government officials, local authorities, the NHS, education and care providers, and those in the justice system. In proposing new policy measures, we take a positive view: that further strengthening accountability and accelerating culture change is not an unwelcome additional burden, but is in line with the way most people would like to act.

Finally, we have recognised **the importance of sustaining public services** in what is in every sense a challenging period for commissioners and practitioners. Although stronger accountability and a more supportive culture may initially increase the loading on already stretched public services, over time this will deliver better outcomes and better value for money. We therefore recommend that the measures proposed in this paper are **introduced as part of a managed programme of reform, with regular assessment of their impact.** We have also applied 'five tests' to ensure that the measures we propose have the greatest chance of being adopted and implemented. The measures are designed to be:

- **Targeted** – addressing identified barriers in the system that prevent or constrain the delivery of better outcomes for autistic people and their families.
- **Low cost** – recognising that large new spending commitments are unlikely in the next Parliament, although the Autism Alliance will continue to advocate

for wider funding reform across SEND education and adult social care, and funding settlements which can meet needs.

- **Straightforward** – easy to put in place, working within existing public structures and processes, without requiring new infrastructure or complex new systems.
- **Proportionate** – any additional work required to implement the measure should be in proportion to the potential impact of the measure.
- **Aligned** – as far as possible, fitting broadly into the anticipated policy programmes and known priorities of the political parties, without creating tension that weakens other aspects of these policy programmes.

In the rest of this paper, we set out the factors in the system that lead to weak accountability for autistic people's outcomes, and hold back autism acceptance and understanding: and in each case propose measures that could start the process of improving outcomes for autistic people and their families.

## Ensuring the voices of autistic people and their families are heard and acted on

Although levels of autism awareness are now high, knowledge, acceptance and understanding of autism is at a much lower level amongst policymakers, public services and wider society. To ensure policies are effective in achieving better outcomes and reducing inequalities, it is vital that autistic people and their families are fully involved in development, implementation and evaluation, and that their voices are heard and acted on at every stage. The measures set forward in this paper were developed in workshops with autistic people and parents/carers of autistic people and reflect their ideas and experiences. The implementation and evaluation of any or all of these measures should follow a similar approach.



## The UK context

Although the measures proposed in this paper relate directly to England, the principles behind the measures could be applied in other parts of the UK.

In Scotland, Northern Ireland and Wales, legislation establishes clear duties that, if fulfilled can secure better outcomes for autistic people and their families: but as in England, the true barriers are systemic, and Real Change will require action on accountability, funding and culture.

- In Scotland, relevant legislation includes the Education (Additional Support for Learning) (Scotland) Act 2004, Community Care and Health (Scotland) Act 2002, Public Bodies (Joint Working) (Scotland) Act 2014, Carers (Scotland) Act 2016. The Scottish Government is also consulting on a Learning Disabilities, Autism and Neurodivergence Bill.
- In Northern Ireland, the Autism Act (NI) 2011 provided a comprehensive and progressive legislative basis for action to support autistic people and their families. It was followed by the Autism (Amendment) Act (NI) 2022, which creates a range of key services, measurable outcome targets, and an independent scrutiny body to oversee implementation.
- In Wales, the Welsh Government has published a Code of Practice on the Delivery of Autism Services, developed under the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006. The Well-being of Future Generations (Wales) Act (2015) is also relevant.
- In addition, the Scottish Government is consulting on a proposed Learning Disabilities, Autism and Neurodivergence Bill, including consideration of a Commissioner role, and in Northern Ireland the recruitment of an Autism Reviewer to scrutinise policy and services is awaiting completion following the return of Government.

The measures proposed in this paper are relevant to governments in Scotland, Northern Ireland and Wales, and the Autism Alliance recommends that all governments consider action on accountability and culture change – as well as funding – in their continuing programmes of policy development and implementation.



# Accountability

The Autism Alliance's paper **Real Change for Autistic People and their Families** identifies weak accountability for autistic people's outcomes at all levels of the system. This is due to a number of factors:

- Despite the significance of autism, it is not clear who in Government is ultimately accountable for improving autistic people's outcomes. Although the Minister for Mental Health and Women currently leads Government meetings on the National Strategy for Autistic Children, Young People and Adults, there is no 'Minister for Autistic People', and accountability for policies that impact autistic people's lives rests in different parts of Government, across education, health and social care, employment and justice.
  - Although there is a National Strategy for Autistic Children, People and Adults, it does not include metrics that show how autistic people's outcomes are improving, and there is no model of change linking the activities in the Strategy to the outcomes the Government intends. Alongside this, at a national and local level, despite some improvement there remains a lack of data that allows autistic people's outcomes to be measured, and progress in improving these outcomes to be tracked.
  - Although there is legislation in place to protect autistic people's human rights and ensure appropriate service provision – including the Autism Act 2009, Equality Act 2010, Children and Families Act 2014 and Care Act 2014 – the consequences for public bodies failing to meet legal duties are hard to identify, and typically the only people seeking to hold local authorities, local NHS bodies and other public services to account are the families affected. Moreover, the processes of recourse for families appealing decisions – which cases show are often unlawful, driven by a lack of funding – are complex, time consuming and exhausting.
  - Outside of prosecution, the specific consequences for those who are involved in the abuse of autistic people and people with a learning disability, and for the organisations they represent, are not clear.
- effect of legitimising decisions that pull against, or in some cases contravene the law: pushing the impact down onto autistic people and their families, rather than pushing up responsibility to the Government to address.
- Ironically, this also leads to poorer long term value for money, as funding that should support better lives is drawn instead into crisis response. Examples include autistic pupils being excluded from mainstream schools and placed in more expensive alternative provision when they may not need or want this provision; and autistic adults not receiving specialist social care provision, leading to deterioration in mental health, the onset of crisis, and confinement in costly mental health hospitals.
  - If people who are required or expected to carry out an action do not carry it out, perceptions and behaviours arise which gradually undermine the system as a whole. It becomes easier and more 'acceptable' to avoid carrying out actions, and breaking the law becomes normalised.
  - This, in turn, undermines trust between commissioners, professionals and the people they serve, and reduces potential for the collaboration and co-production that is vital to understand needs and put in place the right support.
  - Coming full circle, a lack of accountability encourages decision-makers to be less transparent about their decisions, and it becomes harder to know whether progress is being made.
  - The appalling abuse of autistic people and people with a learning disability continues to recur. Since the exposure of Winterbourne View in 2011 there have been other similar cases, including at Whorlton Hall, Cawston Park and the Edenfield Centre. Despite repeated promises of 'never again' from Government, regulators and local councils, these cases have continued.

This weak accountability has a number of important consequences:

- At a time when budgets are under intense pressure due to long term underfunding, service commissioners are understandably concerned to control costs. In this context, a lack of accountability can have the

The Government is taking some steps to clarify accountability: for example, statutory guidance for local authorities and NHS services, issued in 2015 under the Autism Act 2009 is being revised and strengthened. This is positive: and again, legislation and guidance which intends to improve autistic

people's outcomes should be strongly welcomed. But by itself, the revised statutory guidance is unlikely to drive the step change in outcomes autistic people and their families need to see. Action will be required at a system level.

Fundamentally, accountability should be coherent across all levels of the system. It makes no sense to hold local authority commissioners accountable for sufficient investment in SEND education or adult social care when there is no national accountability for ensuring overall funding levels are in line with expected need; and it is incoherent to hold local areas to account against measures of impact that are out of step with other areas.

Equally, accountability should not place demands on the system that are impossible to meet, but should be strong enough to create the conditions in which the right actions and behaviours are clearly preferable to the consequences of the wrong actions and behaviours. As well as starting to improve outcomes, this can spotlight the clearly evident and substantial gap between funding and need more clearly at a national level, encouraging a stronger Government response. In turn, strong accountability reinforces culture change, because those with power and responsibility are seen to be leading by example, and because more people being seen to take the right decisions increases the likelihood that others will also take the right decisions.



*Autistic children continue to be failed by the system. 2021 figures showed that only 26% of autistic pupils feel happy in school.\**

# Measures to strengthen accountability

Following workshops with autistic people and parents/carers of autistic people, the Autism Alliance proposes the following measures are adopted by the Government and all political parties. All should be fully impact assessed, as it is important to avoid measures that either fail to achieve their purpose or drive unintended behaviours. However, we are confident that these measures would strike the right balance. Although the measures focus specifically on autistic people, reflecting the assumptions set out earlier in this paper, they would have impact for autistic people with a learning disability, and in some cases for non-autistic people with a learning disability.



## A Ministerial role for Autistic People

The Government should vest in an existing Ministerial role true accountability for improving autistic people's outcomes and reducing inequalities, and the powers required to lead and enforce delivery of the Autism Act 2009 and the National Strategy for Autistic Children, Young People and Adults. The Minister would have an explicit cross-Government role with a civil service team brought together from across Departments. The right role could be at the Department for Health and Social Care, linked to the Autism Act 2009, or at the centre of Government.



## Co-produced national targets and a statutory duty to report

The Government should co-produce with autistic people and their families a set of national targets for improvement in autistic people's outcomes, covering education, employment, health, social care and justice. The targets would be stretching but achievable, and calibrated to drive year on year improvements. A new data framework would ensure the timely and accurate collection of data allowing progress towards the targets to be measured. The targets could be cascaded and applied appropriately at a local level, and there would be a new statutory duty on local authorities and Integrated Care Boards to report publicly each year on progress. The duty would be an amendment to the Health and Care Act 2022, and should be accompanied by a monitoring approach based on the Self-Assessment Framework used to monitor implementation of previous adult autism strategies in England.



## A National Panel for Autism

A vital new structure to strengthen accountability, the National Panel would comprise a range of autistic people, including those with a learning disability and those who speak few or no words. Chaired by an autistic person, the panel would meet four times a year, holding the responsible Minister to account for progress against the national targets for improvement in autistic people's outcomes. Secretariat for the Panel would be provided by Parliament, minutes of the Panel's meetings would be publicly available, and some meetings could be held publicly. The Minister would have to appear before the Panel as it would be a core part of their role – in exceptional circumstances, due to unavoidable Ministerial commitments, a meeting could be rescheduled for the next available opportunity.



## A Commissioner for Autistic People

Providing a vital source of energy in the system of accountability, and tackling head on the barriers families face in upholding the law, a Commissioner for Autistic People would champion the rights of autistic people and their families and hold public bodies to account for their compliance with the law: this would include schools and other education settings, local authorities, local NHS bodies, police forces, prison and probation services, and courts and tribunals. Established in statute, they would:

- Have powers to commission legal support for autistic adults and children/families challenging decisions, with a small budget to commission this support;

- Publish an annual ‘state of the nation’ report on compliance with the law, informed by survey data from public bodies and autistic people and their families;
- Commission an annual independent audit of progress towards national targets for autistic people’s outcomes in each local authority/local NHS area;
- Meet with the Minister accountable for autistic people’s outcomes twice yearly to discuss findings from the independent audit and progress in responding to these findings.



### The Accountability List

Addressing an important and frequent gap in information, local public bodies would be required to create an online, always up-to-date register of the single person in each local authority and each Integrated Care Board with responsibility for improving outcomes for autistic people, with contact details. This would make it easier for autistic people and families to hold those with responsibility to account. An extension of this measure could be a ‘duties board’ in each public place – schools, GP surgeries, care homes, hospitals – setting out clearly and in easy read language what duties relevant for autistic people the organisation must fulfil under the law.



### Mandatory Autism Partnership Boards

Autism Partnership Boards, bringing together local decision makers and autistic people, are already recommended in statutory guidance<sup>14</sup> and present in many areas. Making these Boards mandatory would ensure there is a local panel, co-chaired by an autistic person, involved in all key decision-making that affects autistic people’s outcomes, and providing an additional mechanism to hold local commissioners and professionals to account. It would also allow Government to mandate consistent processes for how Boards are established and run, and the role they are expected to play in local decision making and accountability. Currently, the term ‘meaningful partnership arrangement’, included in the autism statutory guidance published in 2015, is interpreted differently in different areas, leading to different levels of transparency and accountability.

Alongside these measures, the Autism Alliance also proposes the following changes, included in its policy paper Real Change for Autistic People and their Families:



A statutory direction from Government to Ofsted to make quality of support for Special Educational Needs and Disabilities a limiting judgement at inspection for schools and education settings. This will increase the education system’s focus on recognising, understanding and meeting the individual needs of pupils, in the context of wellbeing, attendance and attainment.



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 a learning disability in mental health hospitals, and to propose tough new measures to strengthen collective accountability across the NHS, local government and regulators.





# Culture

The Autism Alliance's paper **Real Change for Autistic People and their Families** identifies a lack of acceptance and understanding of autism at all levels of the system and across society, which contributes to poorer outcomes for autistic people and their families. 91% of autistic people in the UK feel that society does not accept or only sometimes accepts them<sup>15</sup>. Fundamental misconceptions about autism persist: nearly 30% of adults in Britain are unsure whether autism can be cured, 39% believe autistic people 'lack empathy', and over a third (35%) still believe that autism is a learning disability<sup>16</sup>. This is due to a number of factors:

- A continuing and persistent negative stereotyping of autistic people. This creates the wrong type of expectation about behaviour, leading to wariness and even fear. It also reinforces the assumption that autism is somehow 'wrong', leading to a lack of empathy.
- A lack of reliable, consistent and accessible information about autism and autistic people. This makes it harder for families, professionals and public servants to learn about autism and increase their understanding.
- The predominance of the 'medical model' of autism in public discourse, both across public services and in the media. In this model, autism is still seen by many as a 'disorder' or something to be 'treated' – again reinforcing the assumption that autism is a problem, rather than a natural part of human diversity.

This lack of acceptance and understanding has a number of important consequences:

- At the most granular level of behaviour, decisions both large and small – whether advocating for increases in Government spending, agreeing the right social care package, or putting in place additional support for a pupil at school – are more likely to go against autistic people because of discrimination. Without acceptance and understanding of autism and awareness of the unacceptable inequalities autistic people face, the motivation to prioritise, make adjustments and meet needs is weaker.
- Most public discourse about autism maintains the status quo rather than challenging stereotyping. Unfortunately this is true even in parts of the media advocating for autistic people's human rights, where autistic people are still described as having a 'condition' or find it hard to 'seek treatment'.
- The instinctive approach of many in society is to

limit or move away from contact with autistic people, because of their differences and because they perceive that autism is 'difficult' – this prevents development of the familiarity which is essential to break down barriers and increase understanding.

- In some circumstances, autistic people – and others who are 'different', including people with a learning disability – can be mistreated or abused, with tragic consequences.

The Government is taking some steps to increase acceptance and understanding of autism, and develop the skills required across public services to support autistic people effectively. These include:

- The **Oliver McGowan Mandatory Training** for health and care staff, which is increasing specific knowledge of autism amongst health and care professionals across England.
- The **National Autism Trainer Programme** for mental health professionals and other relevant NHS staff across England, again increasing knowledge and understanding.
- **Autism Central**, a new 'peer education' service for England commissioned by the NHS, helping parents and carers of autistic people learn about autism and providing help to navigate the system.
- Plans to develop new 'practitioner standards' for autism for education professionals in mainstream schools and settings in England, alongside continuing support for the **Autism Education Trust**.

As a minimum, the Government should invest in high quality evaluation of the impact of the interventions listed above, assessing the extent to which sustainable changes in behaviour are delivered; and should continue to invest in activities that increase acceptance, understanding and skills.

However, although these interventions are welcome and will undoubtedly help to increase knowledge, acceptance

and understanding of autism, there is an opportunity for action that targets culture, beliefs and values more directly. The key to this is by engaging with social change: the process through which cultures develop and move forward.

Social change is a powerful force. Over time, it reshapes values and beliefs, and lays the ground for public opinion. Generally, social change is beyond the control of policy, and in many cases policy responds to social change – as seen in the ban on smoking in public places in England in 2007, which followed growing public support.

Evidence suggests that social change relating to autism is underway. Awareness of autism is at an all-time high, autistic people are visible in the media far more than they were 10 or 20 years ago<sup>17</sup>, and there is a strong self-advocacy movement amongst the autistic community in the UK<sup>18</sup>. However, social change takes time, and while discrimination and a lack of understanding persist, there will continue to be a negative impact on outcomes for autistic people and their families.

While policy cannot control social change, it can reinforce and accelerate it. Encouraging positive beliefs and values, and increasing access to reliable and accurate information,

can add energy to social change, extending its reach to more people and changing more minds.

One of the keys to changing beliefs and values is by increasing familiarity: recognising that the more familiar something is, the more accepting we are towards it. Because autistic people represent a minority – albeit a significant minority – of the population, they are relatively less visible than other groups in society. Added to this, the ways in which autistic people are different are not always present, or can be harder for non-autistic people to identify. This includes masking, a suppression of the natural self in order to ‘fit in’.

Research has shown that greater contact with autistic people increases acceptance, and concludes that “in addition to public awareness campaigns to raise knowledge of autism, it may be important to increase contact between autistic and non-autistic people to improve public attitudes towards autistic people.”<sup>19</sup> Acceptance and understanding is frequently stronger in families with autistic children, young people and adults; and it seems likely that increases in public awareness of autism have been driven in part by more frequent coverage in the media.



# Measures to accelerate culture change

Following workshops with autistic people and parents/carers of autistic people, the Autism Alliance proposes the following measures are adopted by the Government and all political parties. As with the measures relating to accountability, all should be fully impact assessed. As part of implementation, the Government should put in place a national survey to monitor regularly changes in acceptance and understanding of autism, and gather evidence on the causes for these changes. Autistica, the UK's autism research charity, is developing an Autism Attitudes Index, and this could be the model for such an approach.



## Government leading the way

Current activity to increase autism awareness amongst Ministers and Parliamentarians is welcome. But Government could, and should go even further. Reflecting the commitment made by passing the Autism Act 2009 and publishing a National Strategy for Autistic Children, Young People and Adults in 2021, Government Departments should lead from the front in adopting and championing positive and well-informed attitudes to autism. Autistic people should be considered a core group for public policy, and the Government and MPs should work together to model the highest standards in language, awareness and attitudes; should proactively and transparently assess the impact of policy on autistic people and their families; and should ensure that co-production with autistic people is adopted wherever possible as part of policy development and implementation.



## A National Autism Champion

Government should appoint a well-known public figure with lived experience of autism as a National Autism Champion. Their function would be to promote a positive, accurate and balanced public perception and understanding of autistic people: enabling them to tell their stories, helping to demonstrate their strengths, and promoting a clear understanding of the support and adaptations that autistic people need. The Champion would have access to a small amount of funding drawn from Departmental communications budgets, to commission content, run campaigns, and engage with the public and the media. The Champion could also recruit and support a network of Regional Autism Champions, who would work with Combined Authorities, local authorities and Integrated Care Boards, using resources funded by the National Champion, to further increase impact.



## Mandatory autism training across public services

The Oliver McGowan Mandatory Training for health and care staff establishes a crucial benchmark that – within health and social care – all staff must have knowledge of autism and learning disability. This reflects the increasing awareness of autism across society, and the frequency with which autism continues to be misunderstood, sometimes with tragic consequences. Government should build on its commitment in healthcare by introducing mandatory autism and learning disability training across all public services, recognising the gaps and inconsistencies that currently exist and reflecting the importance of supported pathways across all services. In some sectors, such as education and justice, this would formalise and strengthen good practice already underway, so would not mean introducing an entirely new requirement. The mandatory training requirement should be established in statute, and like the Oliver McGowan Mandatory Training should be based on the principles of co-production and co-delivery with autistic people and people with a learning disability. Importantly, the training should focus on the ways in which autistic people are different, the ways in which this can be missed or misunderstood, and the practical ways in which autistic people can be supported. It should comprise a programme of knowledge building and 'learning through doing', targeting culture



change at the level of the organisation providing the service. In the case of education, the training should draw on the resources and models already in place through the Autism Education Trust. In some areas of public service, the training could be incorporated within existing inclusion and equality programmes, avoiding the need for a substantial additional investment.



### **National action on acceptance and understanding, delivered locally**

As part of the National Strategy for Autistic Children, Young People and Adults, the Government pledged to “develop and test an autism public understanding and acceptance initiative, working with autistic people, their families and the voluntary sector.” This was a positive commitment, but so far has not happened. The investment earmarked for this initiative could be used to bring charities and autistic people and their families together to co-produce a clear set of messages around acceptance and understanding. These messages could then be delivered at a grassroots level through small charities and not for profit organisations in communities across the country, with national content together with micro-grants for community organisations to deploy this content as part of their local activity. The model could be administered by the Autism Central programme currently supported by NHS England. It would include a strong focus on building acceptance and understanding through greater familiarity, by increasing contact between autistic people and their families, and non-autistic people and families in the same community.



### **Accessible public education**

The Government would work with media companies to explore the case for developing short pieces of video content for TV and social media, increasing knowledge of different aspects of autism and how to support autistic people. These would share common ground with public information films about ‘how to recognise when someone is having a stroke’, or ‘how to administer CPR’, but would have a positive, balanced and non-medical focus. Examples could include: ‘what to do if an autistic person is experiencing a meltdown or shutdown’, ‘understanding that autistic people may communicate differently’, ‘understanding that many autistic people can work, but that some autistic people may not be able to’. Every piece of content would be co-produced and tested with a range of autistic people with different interests and experiences, and with a sample of the wider public.



### **Media/tech partnership for good**

The Government could build a multi-year partnership with national media and tech companies to develop a progressive, non-political programme to increase familiarity with autism in ways that encourage and celebrate inclusive values and behaviours. The programme would focus on creating content – TV, radio, online – that is clear, balanced and positive, and making this accessible and entertaining. This could include:

- Bringing together autistic people and non-autistic people who don't know each other, following their journey of discovery and building friendships.
- An online autism toolkit, to help any organisation or person use inclusive, balanced language when speaking or writing about autistic people. There are some current examples, including from Autistica<sup>20</sup>.



### **Autism peer education**

Recognising the crucial importance of building inclusive values and beliefs at an early age as the basis for acceptance and understanding, the Government would fund an autism peer education programme for primary schools. With input from the Autism Education Trust and autism charities, the programme would include content co-produced with autistic children and young people, and opportunities to reflect, understand others' perspectives and create their own content about autism. There would also be guidelines for involving autistic pupils in this learning in ways that are positive and affirming, building connections and strengthening friendships.

# Doing the right thing

The Autism Alliance is calling for real change for autistic people and their families, so that we see sustained, substantial improvements in outcomes across education, health, care and justice, and reductions in the stark inequalities that autistic people face. The underlying barriers holding back progress are systemic, and achieving real change will require system-level reform across accountability, funding and culture.

Increased investment across education, health and social care is essential, and the Autism Alliance urges the Government, and all political parties, to consider as a top priority the best ways of securing this investment. There is significant scope to rebalance existing funding flows, for example between health and social care, but additional investment will make the single biggest difference. This may require radical solutions.

Alongside increases in investment, the measures proposed in this paper would make a significant contribution to system-level change, and crucially would set out a 'signal of intent' from any or all parties committing: the leading edge of a wider programme of reform and investment that could deliver better

outcomes for autistic people and their families, and better outcomes for everyone.

The Autism Alliance encourages the Government, and all political parties, to consider these proposals and incorporate them into policy work, both now and following the next General Election. The Alliance and its partners, including autistic people and their families, would be pleased to work with officials and advisers to take this forward.

This paper also demonstrates that charities, autistic people and parents/carers are thinking hard about solutions to the problems faced across the system for autistic people and their families, and bringing forward those we believe have the greatest chance of success.



- <sup>1</sup> <https://www.autism-alliance.org.uk/real-change>
- <sup>2</sup> Autism prevalence, UK, 2020, ONS; also studies by Baird et al., 2006; Tomans et al., 2018; McConkey, 2020; Roman-Urrestarazu et al, 2021, O'Nions et al, 2023
- <sup>3</sup> Too Much Information: [https://nen.press/wpcontent/uploads/2016/04/TMI\\_Campaign\\_Report\\_FINAL\\_290316-1.pdf](https://nen.press/wpcontent/uploads/2016/04/TMI_Campaign_Report_FINAL_290316-1.pdf)
- <sup>4</sup> Elizabeth O'Nions, Dan Lewer, Irene Petersen, Jude Brown, Joshua E.J. Buckman, Rebecca Charlton, Claudia Cooper, Céline El Baou, Francesca Happé, Jill Manthorpe, Douglas G.J. McKechnie, Marcus Richards, Rob Saunders, Cathy Zanker, Will Mandy, Joshua Stott, Estimating life expectancy and years of life lost for autistic people in the UK: a matched cohort study, *The Lancet Regional Health - Europe*, Volume 36, 2024, 100776, ISSN 2666-7762, <https://doi.org/10.1016/j.lanepe.2023.100776>.
- <sup>5</sup> Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *J Autism Dev Disord*. 2016;46(6):1916–1930.
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- <sup>7</sup> GCSE and equivalent attainment by pupil characteristics in England, Department for Education, 2022
- <sup>8</sup> Outcomes for disabled people in the UK: 2021, ONS, February 2022
- <sup>9</sup> Office for National Statistics. 'Disability Pay Gaps in the UK - Office for National Statistics'. Office for National Statistics, 25 April 2022. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilitypaygapsintheuk/2021>
- <sup>10</sup> Bishop-Fitzpatrick, Lauren, and Amy J. H. Kind. 'A Scoping Review of Health Disparities in Autism Spectrum Disorder'. *Journal of Autism and Developmental Disorders* 47, no. 11 (1 November 2017): 3380–91.
- <sup>11</sup> Grant A & Williams K (2023) 'Dehumanising policies' leave autistic people struggling to access health, education and housing – new review [online]. Available at: <https://nation.cymru/news/dehumanising-policies-leave-autistic-people-struggling-to-access-health-education-and-housing-new-review/> (accessed March 2024).
- <sup>12</sup> <https://www.autism-alliance.org.uk/real-change>
- <sup>13</sup> <https://www.autism-alliance.org.uk/breaking-point>
- <sup>14</sup> Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, Department of Health, 2015
- <sup>15</sup> Keating CT, Hickman L, Geelhand P, Takahashi T, Leung J, Schuster B, Rybicki A, Girolamo TM, Clin E, Papastamou F, Belenger M, Eigsti IM, Cook JL, Kosaka H, Osu R, Okamoto Y, Sowden S. Global perspectives on autism acceptance, camouflaging behaviours and mental health in autism spectrum disorder: A registered report protocol. *PLoS One*. 2021 Dec 30;16(12):e0261774. doi: 10.1371/journal.pone.0261774. PMID: 34969045; PMCID: PMC8718008.
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- <sup>18</sup> <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2021.635690/full>
- <sup>19</sup> [https://www.cambridge.org/core/services/aop-cambridge-core/content/view/C637DA76663363D3B4C5435017A73782/S2516712X20000465a.pdf/greater\\_autism\\_knowledge\\_and\\_contact\\_with\\_autistic\\_people\\_are\\_independently\\_associated\\_with\\_favourable\\_attitudes\\_towards\\_autistic\\_people.pdf](https://www.cambridge.org/core/services/aop-cambridge-core/content/view/C637DA76663363D3B4C5435017A73782/S2516712X20000465a.pdf/greater_autism_knowledge_and_contact_with_autistic_people_are_independently_associated_with_favourable_attitudes_towards_autistic_people.pdf)
- <sup>20</sup> <https://www.autistica.org.uk/about-us/media-communications-guide>

\* References for the information provided in photo captions could be found on our website at: <https://www.autism-alliance.org.uk/references>

# About the Autism Alliance UK

**The Autism Alliance UK** is a national partnership of not-for-profit organisations that support autistic people and their families. Our members represent a range of sectors, including adult social care, education, and community support. Together, they support thousands of autistic children, young people and adults across the UK.

Autism Alliance members work together to share their knowledge, skills and experience in ways which can improve outcomes and reduce inequalities for autistic people, and to achieve our vision of: **a world where autistic people can thrive.**

As well as campaigning and influencing, we regularly commission new evidence to support our mission. Key to our approach is our belief that: **a society that works for autistic people will work for everyone.**

In 2023 we launched our campaign, **Real Change** for Autistic People and their Families: our manifesto for systemic change across the UK.

Later that year we ran our **Breaking Point** campaign which highlighted the gap in social care for autistic adults in England.

**Doing the Right Thing** is a clear call to action for the next Government, and provides them with meaningful changes that could be made as a signal of intent for the systemic Real Change that is needed in the longer term.



*Awareness of autism may be high, but amongst adults in Britain 30% are unsure whether autism can be cured; 39% believe autistic people lack empathy; and 35% still believe that autism is a learning disability.\**

# AUTISM ALLIANCE UK

Making a world where  
autistic people can thrive.

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