



# The *Autism Act*, 10 Years On:

A report from the All Party Parliamentary Group on Autism  
on understanding, services and support for autistic people  
and their families in England



APPGA  
All Party Parliamentary Group on Autism



# Foreword

## Rt Hon Dame Cheryl Gillan DBE MP

Ten years ago, I was incredibly proud to campaign alongside autistic people, their families, and autism charities for the introduction of an *Autism Act* to make new legal duties to provide adult autism services. We were successful, and the *Autism Act* was introduced in 2009. It remains the only Act dedicated to improving support and services for a specific group of disabled people.

A decade later, there has been significant progress. Awareness of autism has increased hugely. Every council now has an adult autism diagnosis pathway, whereas fewer than half did before the *Autism Act*. Today, all but a very few councils now have a lead commissioner for autism. Autism is also a cross-party priority and, significantly, was mentioned in the vast majority of parties' manifestos in the 2017 general election.

However, every day, I and my MP colleagues are contacted by autistic constituents or their family members who struggle to get a diagnosis, or have to wait several years for one. Too often, they cannot get support from social care or in school. It is clear that there is still much to be done.

This inquiry set out to find out what actions the Government, health and care organisations, businesses and society as a whole must take to improve autistic people's lives. Specifically, it looked at what needs to be included in the Government's revised autism strategy. I am delighted that for the first time the Government strategy will include children as well as adults.

I am honoured to chair the All Party Parliamentary Group on Autism (APPGA). It is a truly cross-party group, among the most active in Parliament, and I am proud to have worked with colleagues from across the House of Commons and the House of Lords on this inquiry. Working together, I am confident we can build on our achievements to ensure the *Autism Act* can live up to its promise.



Rt Hon Dame Cheryl Gillan DBE MP



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# What is the APPGA?

The APPGA is a formal cross-party backbench group of Members of the House of Commons (MPs) and Members of the House of Lords who campaign in Parliament for greater awareness of autism, and improved services for autistic people and their families. We have also offered autism training for MPs and their staff to improve understanding of autism in Parliament.

## Introduction

The *Autism Act* was a landmark moment in the campaign to improve the lives of autistic adults and their families in England. It requires the Government to have an adult autism strategy, setting out how autistic adults should be better supported. And it says that this must be underpinned by guidance, placing duties on councils and the NHS to take action.

Ten years after the Act's introduction, the APPGA wanted to gauge the impact this legislation has made, as well as finding out more about the state of support and services for autistic people in England. This report is the result of a wide-ranging inquiry across all the areas the autism strategy covers and the issues autistic people and their families told us matter most to them.

It is informed by the views of over 11,000 autistic people and their families, alongside many professional experts. It is the most in-depth analysis of the autism strategy that has been undertaken.

Our research uncovered that the Act has led to welcome improvements in some areas of support. Over the last decade, there has been an increasing recognition of autism among commissioners and the public. However, the overwhelming picture that emerged is one of deeply concerning unmet need. Many thousands of autistic people who need support in the classroom, at home, at work and in every aspect of everyday life, simply are not getting it.

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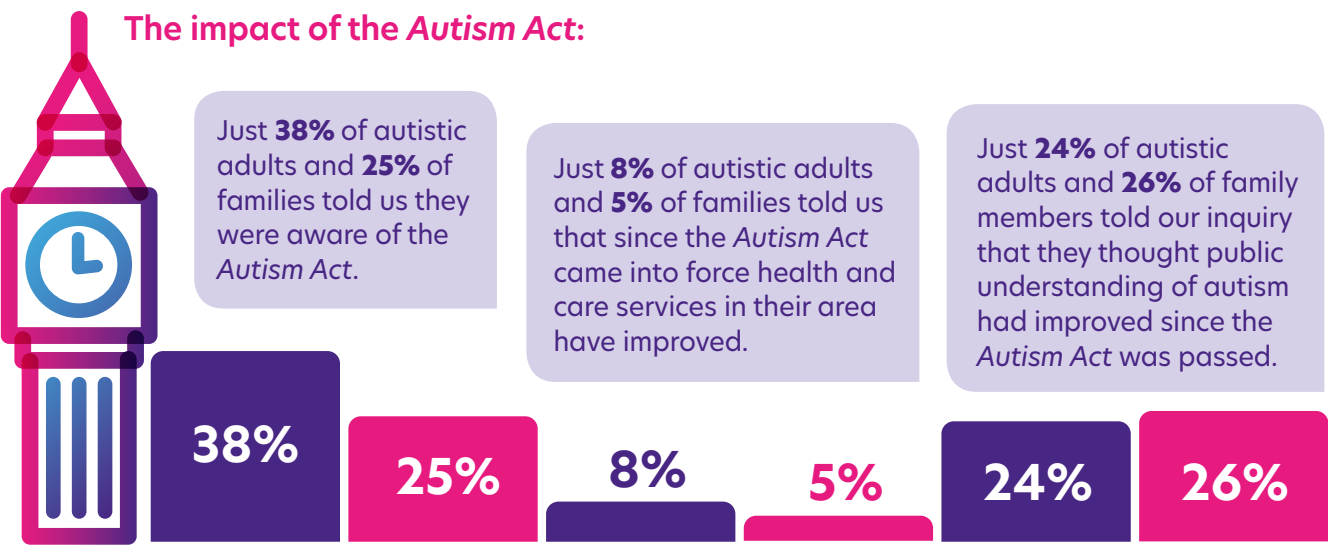
These unmet needs stem from poor autism understanding by professionals and low awareness of the duties that are included in the *Autism Act*. But, given the evidence we have seen and heard, it is also undeniable that allocation of funding has affected the ability to provide autistic people and their families with the services they need.

Combined, these factors are having a profoundly negative impact on the lives of the 600,000 autistic people in England and their families. Too many are facing unacceptable health inequalities, and are at risk of falling into mental health crisis or social isolation and of dying early.

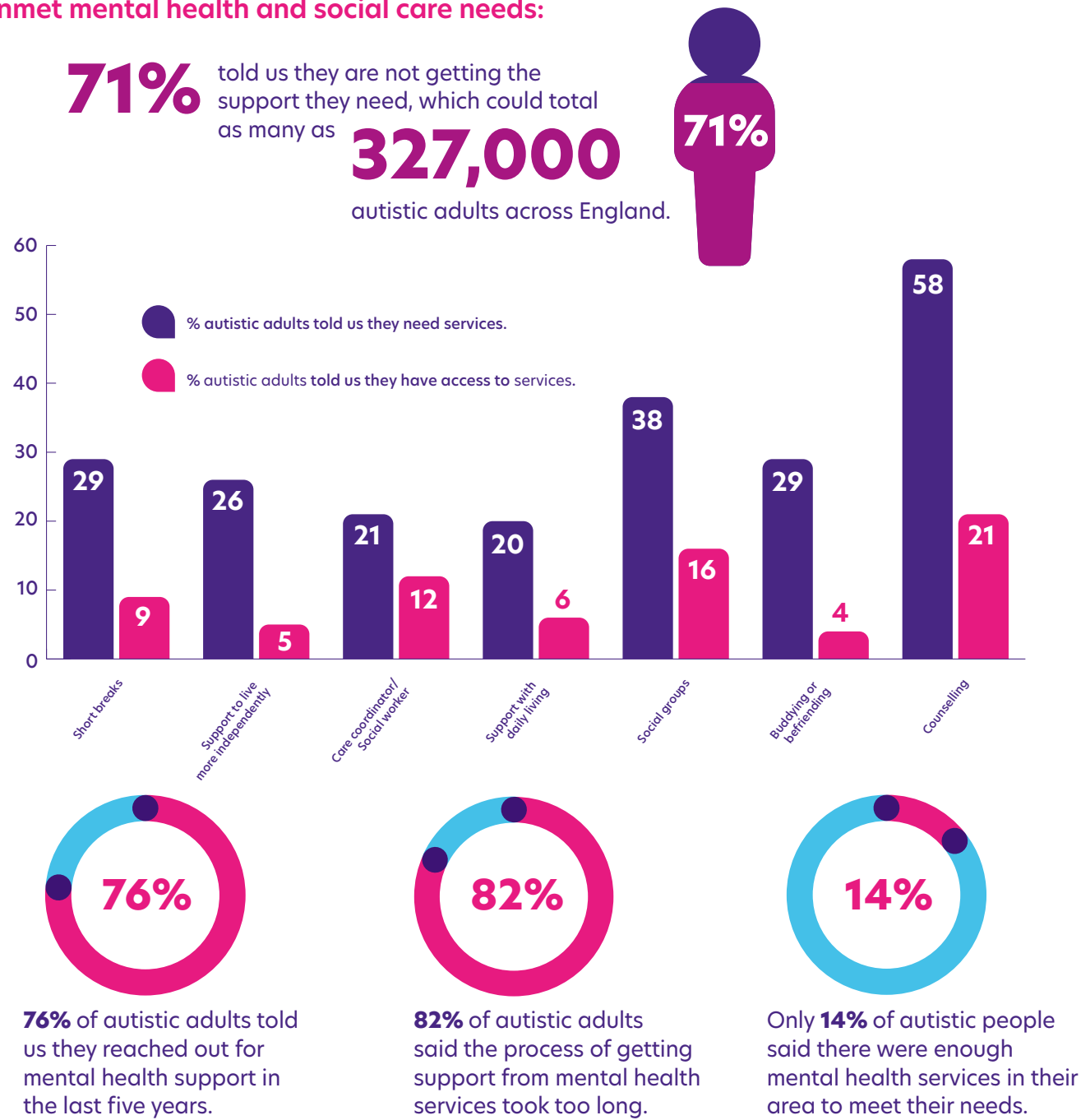
This must change. This year is our best opportunity to make that happen, as the Government will refresh its autism strategy and extend it to children and young people for the first time. To make a difference, this strategy must set out concrete actions so that autistic people and their families can live fulfilling and rewarding lives. This report sets out what the APPGA has heard and what the Government must include in the next autism strategy. It is now for the Government to lead the way.



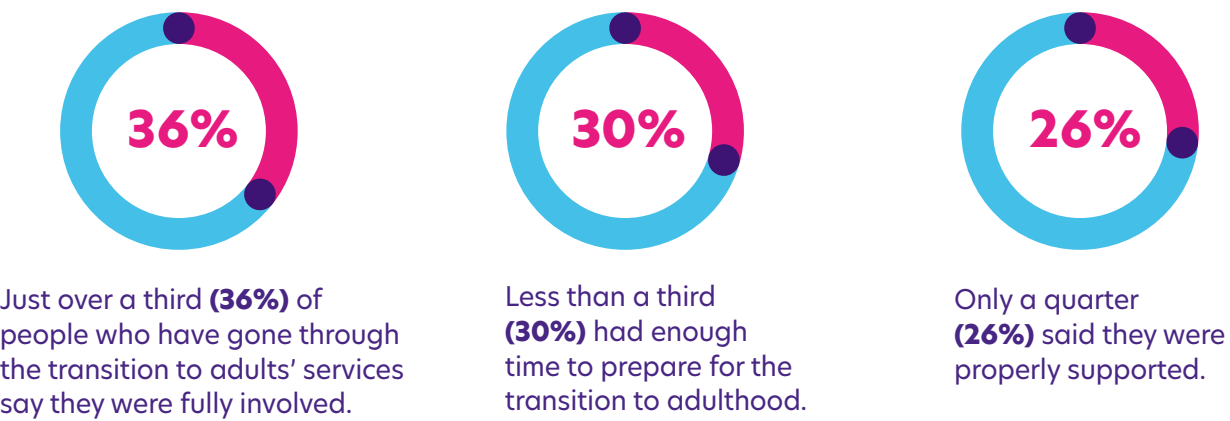
# Our survey findings



### Unmet mental health and social care needs:



### Access to wider support:



### Benefits assessments:



### Professional understanding:





# Our key recommendations

- Create and fund a long-term, properly funded **national autism understanding campaign**, aiming to shift the attitudes and behaviour of millions of people.
- Undertake a cross-Government review on where autism is recorded in Government **data collections** to identify where improved information could lead to better support.
- Commit to establishing well-resourced **specialist autism teams** in every local authority in England.
- Establish an autism **social care commissioning fund** for councils to use to set up and run new autism services and support.
- Include a requirement in contracts for benefits assessment providers to provide all frontline assessors with **autism training**, and regularly monitor compliance.
- Establish and report on a new **waiting time standard** from referral to diagnosis, involving autistic people and their families to identify an appropriate benchmark wait.
- Clarify legal duties on local health and social care bodies, and as part of their plans to develop a **mandatory autism training programme**, establish a mechanism for monitoring implementation and holding providers to account. This should also make sure that training is at an appropriate level for each staff member, based on the Autism Capabilities Framework and statutory guidance.
- Commission an **independent review** of the definition of autism as a 'mental disorder' under the *Mental Health Act*, consulting with autistic people and their families, charities and mental health professionals.
- Set out clear requirements to NHS England and local health commissioners on the need to commission **community mental health services** that meet the needs of autistic people, and ensure that this is implemented.
- Set out and deliver an ambitious plan to move autistic people out of hospital into the community – succeeding where *Transforming Care* has failed. The Government should establish an **inter-ministerial group** to ensure cross-Government accountability on the delivery of this programme.
- Commission a review **tracking the journey of autistic people** in mental health hospitals and prisons to develop a better understanding of why they end up in these environments. It must set out how national and local Government can address the issues that come out of this review.
- Commit to underpinning commitments in the autism strategy for children and young people with **statutory guidance**.
- Require autism training to be included in professional development for all teachers, including head teachers.
- Develop clear guidance for schools and commissioners on what good education provision for children and young people on the autism spectrum looks like.
- Make **autism training compulsory for all Jobcentre Plus staff**, making sure staff have the level of training that reflects their interaction with autistic people.
- Commit to making **autism training mandatory for all police officers**, by working with the College of Policing to require all new police recruits to undergo autism-specific training, as well as creating a programme for all existing officers to receive this training.

## Chapter one – Public understanding

### Introduction

#### Rt Hon Dame Cheryl Gillan DBE MP

Awareness of autism has come a long way over recent decades. The last autism strategy, *Think Autism*, made raising awareness and acceptance its top objective. More recently, an increasing number of popular portrayals of autistic people across the autism spectrum have raised many of the issues that autistic people face into the public's consciousness. Our inquiry wanted to hear about whether enough has been done and whether awareness alone would improve the lives of autistic people.

Polling from the National Autistic Society in 2015 suggests that 99.5% of people have heard of autism.<sup>1</sup> But the charity's research also found that just 16% autistic people and their families feel the public understand what it means to be autistic. Around a half said that they sometimes do not go out, and 28% said that they have been asked to leave a public space because of their autism.<sup>2</sup>

This tells us that poor public understanding of autism has profound consequences for autistic people and their families. We were particularly concerned to hear National Autistic Society research showed that 79% of autistic people and 70% of families felt socially isolated because of this lack of public understanding of autism.<sup>3</sup> Just 24% of autistic adults and 26% of family members told our inquiry they thought public understanding of autism had improved since the *Autism Act* was passed.

In our inquiry evidence session, we heard more from autistic people and families and a number of organisations that have been involved in awareness raising. We wanted to know what had been tried, what had worked and what still needs to be done to improve understanding. We also wanted to find out from autistic people and their families what 'understanding autism' means to them.



<sup>1</sup>National Autistic Society (2015), *Too Much Information*. London, UK.

<sup>2</sup>Ibid. <sup>3</sup>Ibid.

# What does 'understanding' autism mean?

## 1. Awareness is not understanding and understanding is what matters

Awareness and understanding are not the same thing and to make a difference to autistic people's lives, it is better public understanding of autism that we need to see.

The people who gave evidence felt that, as well as knowing that autism exists, the public needs to know more about what it means to be autistic and some of the ways that they might be able to support autistic people – particularly at times of difficulty. The National Autistic Society's *Too Much Information* campaign highlighted the five things autistic people have told the public they would like them to know about what it is like to be autistic:

- needing extra time to process information
- experiencing anxiety in social situations
- experiencing anxiety with unexpected changes
- finding noise, smells and bright lights painful and distressing
- becoming overwhelmed and experiencing a 'meltdown' or 'shutdown'.

Max, an autistic man who was one of our witnesses, highlighted that as an autistic person, he constantly has to adapt to the world around him instead of the world adapting to him. With more understanding, members of the public would know better what they can do. This could be knowing not to ask lots of questions at once, to remove things that cause sensory overload, or what to do if an autistic person is experiencing a meltdown. One parent explained that, while care and support is vital, society gaining a better understanding of autism is what can help many people on a day-to-day basis.

**Awareness and understanding are not the same thing and to make a difference to autistic people's lives, it is better public understanding of autism that we need to see**

Understanding helps counter misconceptions and myths about autism, which sadly are still common. Stereotypes can be hard to change, but the way to do this is to tackle the misinformation from which they stem. Part of this can be achieved through exposure, including in the media. Recently, two national soap operas have introduced autistic characters, and autistic people are also presenting shows such as *The Autistic Gardener*. Primetime dramas, including *The A Word*, have provided a greater insight into people's strengths, as well as the challenges autistic people and their families face across their lives. This improving representation is encouraging, but the Government has a role to play in making sure this greater understanding of autism is transmitted from our screens to everyday life.



## 2. Autism is a spectrum

Our witnesses told us they wanted the public to understand that autism is a spectrum condition. This means that, although autistic people will share many of the same characteristics, each and every autistic person is different. Some will go through life with very little support, while others will need a lifetime of care and support. Witnesses wanted to ensure the full range of experiences and needs is understood and represented in the media and public life.

Lack of understanding often leads to misconceptions. Some autistic people can communicate with speech, while others cannot – and some can only speak some of the time. Our witnesses told us that people make wrong

assumptions in each of these situations; either that someone does not need any support, that someone can be 'written off' and not listened to, or failing to realise that not being able to verbalise can be a sign of anxiety and someone needing support. Each of these assumptions can be very damaging in their own way.

It is also important that the public understands that being autistic does not mean you might not have other conditions that mean you need care and support – like a learning disability or a mental health condition. But these need to be recognised as distinct from autism.



### 3. Identity

Being autistic does not strip you of your individuality. Autistic people may be of any gender, faith, ethnicity or sexuality. However, witnesses told us that too often, in terms of public understanding as well as services, people's different identities are not well understood or taken into account. One witness described a system where people are 'put in a box' and if you do not fit into that 'box' you can end up feeling very isolated.

One witness, Venessa Bobb, also highlighted that awareness and understanding of autism in some communities (eg BAME communities) falls behind that of wider society. This means that autistic people can be doubly isolated – from mainstream support that does not reach into their community, as well as from their community itself.

Witnesses talked about how important it is to improve understanding of how different identities intersect, for example, what it means to be an autistic woman, autistic and black, or Muslim, gay, or non-binary. This needs to be part of the public's understanding, and must also be acknowledged by care and support services.

### 4. Autistic people are all ages

Ten years ago, when the *Autism Act* was going through Parliament, the goal was to tackle the assumption in statutory services that autism only affects children. The last decade has seen a lot of progress, but our witnesses (a mix of autistic adults, parents and family members) believed that public understanding still largely focused on children, or younger adults. Initiatives like autism-friendly screenings, for example, are often based on children's films.

Autistic people are also getting older. Those who received their diagnosis in childhood in the 1960s and 70s are approaching older age. Meanwhile, more adults are now being diagnosed. Over time, we will see more older autistic people. While public depictions of autistic people are increasingly showing autistic adults, there is an under-representation of older autistic adults.

## Ways to improve autism understanding

### 1. Role of business

We heard from the National Autistic Society, which has launched an Autism Friendly Award and the more recent Autism Hour initiative. Both are aimed at encouraging shops and public spaces to become more accessible to autistic people. We also heard from Autism Together who have worked across Liverpool to open up many spaces in the city to autistic people.

Last year's Autism Hour saw 30,000 designated quiet hours across 11,000 businesses.<sup>4</sup> This is very welcome and we hope participation continues to increase. But we want this to be reflected in long-term change – not just an hour, but all year round.

Several large businesses have led the way in becoming more accessible to autistic people. We heard from Gatwick Airport, which has received the National Autistic Society's Autism

Friendly Award. They are providing staff training, information for autistic visitors and routes through the airport that can avoid overwhelming situations like duty free and security. Likewise, Workman Retail and Leisure have also gained this Award in 11 of their shopping centres that have made changes to their environments. Closer to home, the UK Parliament has also achieved the Award for its work to improve access for autistic visitors. However, there is a lot of work to be done to make sure that the whole Parliamentary Estate is autism-friendly – not only to visitors but staff and Members of Parliament too. It is really encouraging to see so many businesses taking steps that often do not require huge changes or significant investment – but can make a big difference to autistic people and their families' experiences.

<sup>4</sup>National Autistic Society, Autism Hour Highlights. Available at: <https://www.autism.org.uk/get-involved/media-centre/news2018-10-16-autism-hour-highlights.aspx> (Accessed: 16 July 2019)





## 2. Role of Government

There have been national autism awareness campaigns; both the National Autistic Society and the Autism Alliance have developed models, while countless local organisations work in their own communities every day. Some of these have had significant results. We heard that the National Autistic Society's *Too Much Information* campaign had a reach totalling 70 million views, and resulted in a 17% change in public understanding.<sup>5</sup> But even with achievements like this, individual organisations' reach can only go so far.

We heard strong views from our witnesses that the Government has an important role to play in improving autism understanding. The success of the Dementia Friends programme, which the Government funded, led to significant improvements in public understanding of dementia. Autism needs similar levels of improvement and we feel there is a lot to be learned from its approach. Our witnesses were keen to highlight that to be as impactful as possible, an understanding campaign should be empowering to autistic people, and should focus on improving understanding of the breadth of the spectrum and the full range of people's needs.

There was agreement that Government has a reach and resources that individual organisations do not have, meaning that a programme could be larger and longer-term. Our witnesses were also keen to highlight that any autism understanding campaign must include and involve autistic people and their families, and be rooted in their experiences. Public understanding campaigns are no substitute for professional understanding and we heard evidence from witnesses, making clear that professionals working with autistic people need specific and more in-depth training.

<sup>5</sup>Don't Panic, Too Much Information. London, UK. Available at: <https://www.dontpaniclondon.com/project/too-much-information/> (Accessed: 15 July 2019)

## What needs to be done

In its new autism strategy, the Government should:

- create and fund a long-term, properly funded national autism understanding campaign, aiming to shift the attitudes and behaviour of millions of people
- outline a plan for ensuring that all public buildings are autism-friendly, or are taking steps towards becoming autism-friendly, and meet duties under the *Equality Act* for autistic people by 2024
- develop guidance for councils on how to use their roles in economic development to promote autism-friendly initiatives (and their benefits) to businesses
- commission research into the additional barriers faced by autistic people from diverse backgrounds and with a range of needs, and set out an action plan for how to tackle the specific barriers they face.

In addition, as parliamentarians, we believe there is more that Parliament itself can do to be more accessible and welcoming to autistic people. As part of the renovation of the Parliamentary Estate, Parliament should commit to becoming fully autism-friendly. Parliament should consult with autistic people and their families about designs for renovations of the Parliamentary Estate to guarantee the environment is more inclusive to autistic visitors, staff members and MPs.



## Chapter two – Support in adulthood

### Introduction - Catherine West MP

Autistic adults may need a wide range of support to live as independently and happily as possible, either from social care services, from benefits or from housing. Before the *Autism Act*, national autism strategy and statutory guidance were introduced, research from the National Autistic Society's *I Exist* campaign in 2008 found autistic adults were being ignored and isolated. While the introduction of the Act, and the *Care Act* in 2014, should have improved autistic adults' entitlement to support, we know that ten years later many still do not get the support they need to live the lives they want.

Our research has found that ten years after the introduction of the *Autism Act*, thousands of autistic adults are living without the range of support they may need from social care, benefits or housing because care staff do not understand their needs and the right specialist and lower level services are not available. Many do not get any help until they reach crisis point.



### What our research tells us

For many autistic people, social care is the difference between being able to leave the house or not, being able to wash, dress and eat or not, or work or volunteer or not. Social workers make decisions every year about whether thousands of autistic people are able to get this support, under the *Care Act*. Our inquiry has found that support for autistic adults has actually got worse, particularly for those who need social care, over the last 10 years. We have found alarming levels of unmet need, with 71% of autistic adults telling us they are living without the support they need. In particular, those who need 'preventative' support are not getting it because the services all too often are not available.

It has also uncovered that part of the reason autistic people cannot access the care or benefits they need to live well is down to difficulties with assessments. We heard in the inquiry session about the impact of lacking understanding amongst assessors on assessments, as well as the processes not being autism-friendly.

Just **10%** of autistic adults said the social workers they have come into contact with had a good understanding of autism or autistic people's needs,

while just **19%** thought this for support workers.

To ensure autistic adults are able to live well, the Government must address this unmet need with more and better services as well as improved professional understanding.



1. Deeply concerning levels of unmet need in adult social care

Over the last 10 years, funding for public sector services has been stretched by the need to make savings in the context of increasing demand for support. Our research, including interviews with council staff, suggests that these reductions have meant a decrease in the range of services councils can provide, from preventative or lower level services, to specialist support.<sup>6</sup> The Local Government Association estimates that without additional funding for social care, there will be a £3.5 billion gap by 2024/2025.<sup>7</sup>

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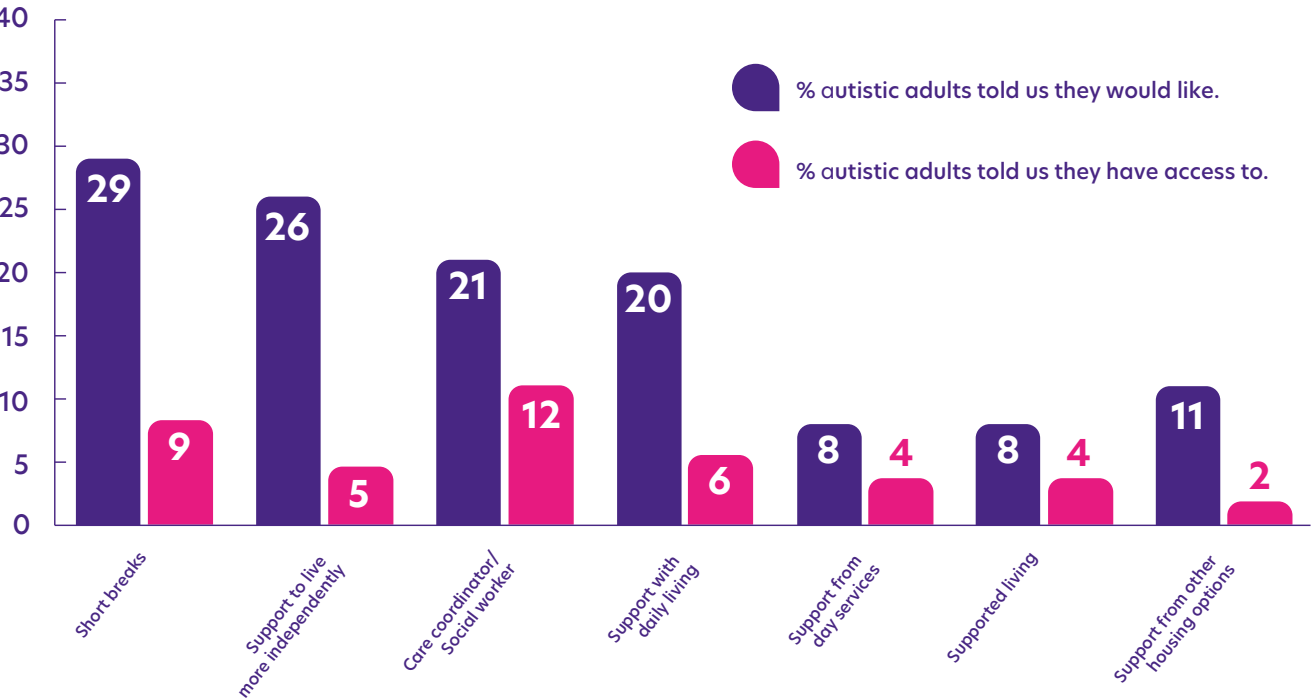
The impact on support for autistic adults has been profound. In our survey we asked autistic adults about the support they need – and what they get. The number of autistic people who are not getting the support they need has actually increased over the lifetime of the Act. Today, as many as 327,000 autistic adults could be living with unmet needs across England.<sup>8</sup>

46% of autistic adults told us that with more support they would be more independent. We heard throughout the inquiry about the devastating impact of this widespread unmet need. People who lack the care they need often have no choice but to rely on family members or the health service, and can end up in crisis.

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A recent report by Carers UK showed the extent to which family carers are plugging the gap in support and the impact on their wellbeing, with 81% of all carers reporting feeling lonely or isolated as a result of their caring role.<sup>9</sup> We also heard that without the care they need, too many autistic people end up in mental health hospitals, because there is nowhere else to get support.

An unacceptably low number of autistic adults and families who need support are getting it:



<sup>6</sup>National Audit Office (2018). *Financial sustainability of local authorities 2018*. London.  
<sup>7</sup>Local Government Association (2018). *The lives we want to lead: the LGA green paper for adult social care and wellbeing*. London, UK.  
<sup>8</sup>Calculated using the prevalence of over 18s in England, The NHS Information Centre, Community and Mental Health Team, Brugha, et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adults Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care.  
<sup>9</sup>Carers UK (2019). *State of Caring: A snapshot of unpaid care in the UK*. London, UK.

“I rely on my parents who are 71 and 82 years old. I go out once a week with Shared Lives. I could not cope on my own so have been back with my parents for two months. It is not easy as my father is ill. I have had help with cookery lessons in the past - but nothing consistent. Nothing is consistent - things keep changing. What is to happen to me when my parents are dead? Who will help me?” - Anonymous



2. Insufficient services for autistic people

Autistic people may need a wide range of support, from a little help to organise and keep on top of things, to intensive packages of personal care. But our inquiry has found that for people across the autism spectrum of all ages, those services are not there. We found that in two areas in particular there was a worrying lack of services.

Access to preventative and lower-level support

Some low-level support can stop people needing more help later on. This is often called ‘preventative’ support, because it prevents people needing more intensive support. It can include things such as social groups and befriending services. Our witnesses told us that this support plays a crucial role in reducing loneliness and social isolation. Councils should be providing a range of preventative services, including for autistic adults, but we heard that too often this is not happening.



In our survey, 38% of autistic adults told us they need access to social groups but only 16% have access to this support, while 29% said they need buddying or befriending but just 4% access this.

In our interviews with council commissioners and during our inquiry session, we heard that in many cases preventative services have closed because councils had to prioritise available funding for people with more complex needs. Councils must be encouraged and supported to increase investment into these services, which are cheaper in the long-term, because they stop people’s needs from escalating. We also need a greater understanding of which models of low-level support are most effective for autistic people.

One commissioner told us: “Some really good services have been lost”.

## Access to specialist support

Autistic adults, families and witnesses at the inquiry session told us they need support from services that really understand autism and are tailored to autistic people's needs, but that these services are not widely available – in part due to pressures on councils. Witnesses said there is an increasing 'one size fits all' form of support that doesn't always take autistic people's needs into account. Often, autistic people can only access generic or learning disability care that doesn't meet their needs.

Professor Bryony Beresford from the University of York told us about her research into Specialist Autism Teams (SATs), which is known as the SHAPE project. These teams were recommended by the National Institute for Health and Care Excellence (NICE) and in the *Autism Act* statutory guidance. NICE defined SATs as specialist community-based, multi-disciplinary services providing or coordinating diagnosis and assessments, holistic care and support (addressing health, social care, housing, welfare or employment needs), support to family members and carers, and supporting mainstream services caring for autistic adults. This research found that few local areas in England currently have these teams. Where they do exist, they are specifically for autistic adults without learning disabilities (LD), and this is because commissioners and practitioners feel there is no provision for this particular group. The research followed over 250 autistic individuals who had access to a SAT, and found the following:

- Twelve months after first using a SAT, there was evidence of a positive impact on people's mental health and ability to manage their daily lives.
- It also found evidence that people benefit most from SATs when these are made up of staff with diverse skills and professional backgrounds.
- It also found differences between people who were diagnosed by a SAT, and therefore offered high quality information and advice about autism and support to address presenting needs, and those who only accessed a diagnostic assessment service.

## Other findings from the SHAPE project

Senior SAT professionals were all highly committed to this model of provision for autistic adults without LD, but did also report there needs to be adequate investment and resource as referrals were higher than expected. These professionals reported benefits of partnering with local autism groups, for instance in planning and evaluating their provision, designing information resources and jointly running groups for people who were newly diagnosed. They reported that some autistic people valued joining such groups or communities, whether local or online. However, and very importantly, the study also found that only a minority of people were in contact with such groups.

Professionals believed several elements were key to ensuring sustainable improvements in support for autistic adults without learning difficulties. In addition to providing autism-specialist interventions and support, SATs should have greater resource and capacity to upskill and support mainstream services to deliver care and support for autistic people. SATs should work in ways that promote self-management skills and capacity, and should have the resources to provide drop-in services and other forms of low intensity, ongoing support.

We heard overwhelming support for these teams from all our witnesses and others who attended our inquiry. We strongly believe the Government's next strategy must ensure that more autistic adults are able to benefit from them, with a SAT in every area.

## Adult Autism Service (Tower Hamlets)

This service was developed directly in response to NICE guidance and the *Autism Act's* statutory guidance. It is jointly commissioned by the CCG and council. It offers autism assessments, diagnosis and support. The team develop a support plan to help the autistic person with any difficulties they may have after diagnosis.

The service provides up to 12 sessions to address these difficulties, and runs an informal support group for its users, autism-awareness events across the area and autism-specialist consultancy to mainstream services. The multi-disciplinary team includes a consultant psychiatrist, clinical psychologist, occupational therapist, speech and language therapist and a social worker. For those with needs around accessing or staying in employment, the team works in partnership with a local specialist supported employment service for young people and adults.

## 3. Professionals who do not understand autism

### Why autism training has not been embedded

The *Autism Act* statutory guidance requires councils to train all social care staff in autism to an appropriate level, meaning staff carrying out assessments need specialist training. But the Government's latest survey of councils on *Autism Act* implementation shows only 21% of councils say they are fully complying with the commitment to provide autism training to all health and care staff, and this has only marginally improved in two years (from 18%).<sup>10</sup>

To make matters worse, over 43% of councils said they do not have specialist autism training for professionals carrying out care assessments, and this unfortunately represents a decrease since 2016.<sup>11</sup> If staff carrying out assessments do not understand autism, they are much less likely to properly identify people's needs.

Autistic adults responding to our survey also told us there is still a considerable lack of understanding in social care more broadly. Just 10% of autistic adults said the social workers they have come into contact with had a good understanding of autism or autistic people's needs and 19% thought this for support workers. Specialist autism teams have a key role to play here. We heard from witnesses that specialist teams need to be resourced to train other services, such as generic social care teams.

Professionals told us that training is often relegated on the list of priorities, particularly because of a lack of monitoring and enforcement. The high turnover of social care staff and prevalence of agency workers also makes implementation of autism training difficult. One commissioner said that "professionals have to prioritise the direct business of the day, so training is never at the top of their priority list."

It is vital that whenever an autistic adult comes into contact with a care professional, they understand how to meet their individual needs. They may be making very important decisions about people's care, or mental capacity. In the long term, support from care professionals who understand autism can make the difference between someone living well in their community and falling into crisis.

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## 4. Social care assessments

The evidence session and survey have highlighted that in spite of the *Autism Act*, autistic adults still face barriers in getting assessments of their care and support needs. But for many, this is a vital part of being able to live a fulfilling and rewarding life.

The latest Government survey of councils showed that 61% of councils do not automatically offer care assessments when someone is diagnosed with autism, and this figure has increased from 50% in 2016.<sup>12</sup> Around a fifth of councils (22%) also said that they do not have a pathway for care assessments for autistic adults without a learning disability.<sup>13</sup> This is concerning, as we heard from our witnesses that this particular group struggle to get care assessments – and are often refused them. This is despite it being clear in the *Autism Act* statutory guidance that people should not be denied a care assessment based on whether they have a learning disability.

Witnesses also told us about challenges with the assessment process itself. Many said assessments are anxiety-inducing and not autism-friendly, particularly when carried out by professionals who do not understand autism. Melissa McAuliffe, a social worker from London, revealed some of the difficulties she has seen autistic adults face, which include:

- difficulties with being able to communicate their needs and knowing to ask for the right type of support
- not sharing potentially relevant information with assessors that may factor into the outcome of the assessment
- the structure and content of the assessment not being autism-friendly.

These barriers can, and do, result in autistic adults losing out on vital support. Witnesses at the inquiry session also said how important it is for there to be more flexibility in how assessments are carried out (which could be giving people more time, or making sure that questions are autism-friendly) and that assessors have a proper understanding of autism when making decisions.

## 5. Autistic adults' challenges with benefits assessments

Accessing benefits can make a substantial difference to autistic adults' lives, whether or not someone is in work. However, the inquiry session revealed that too many are having negative experiences with benefits assessments.

A key issue, as with social care, was the lack of understanding among assessors. Unlike in social care, there are currently no statutory requirements for benefits assessors to have autism training. In the inquiry session, Dr Ian Gargan from Capita acknowledged that assessors struggle with assessing autistic adults.

There are also issues with the benefits assessment process itself. Autistic adults have told us they face many different barriers:



**60% told us the forms to apply for benefits were difficult to complete.**

**Just 19% told us the location of the assessment was suitable.**

**Just 14% told us they were satisfied with the length of time it took for their claim to be processed.**

As a result, too many autistic adults miss out on benefits and the support they offer.

## What needs to be done

### Social care

**In the new autism strategy, the Government must:**

- commit to establishing well-resourced specialist autism teams in every local authority in England
- establish an autism social care commissioning fund for councils to use to set up and run new autism services and support.
- set out how it plans to improve social care services for autistic people across England, making sure that upcoming commissioning guidance is used and that services are properly resourced
- restate to councils their duty to assess people's needs regardless of whether they have a co-occurring learning disability, and hold areas that are found not to follow this duty to account
- make clear how they are going to ensure that the mandatory health and care training programme consulted on in early 2019 is going to be taken forward for all social care staff, including how it will be resourced and monitored
- require autism to be recorded in all key social care data sets including Short and Long-Term Support and Adult Social Care Finance returns
- set out plans to increase and improve social care and preventative services for older autistic people, including those with nursing care needs
- extend and strengthen councils' responsibilities around providing preventative services under the *Care Act*, and provide the support to make this a reality locally
- commission research into what care and support options work well for autistic people and act to embed the results across councils in England.

Underpinning this, the Government needs to set out how it is going to place the social care system on a sustainable footing in the longer term. It must ensure that the needs of autistic people and their families are properly included in plans for a reformed system.

**To better implement the *Autism Act* at a local level, councils must:**

- use upcoming commissioning guidance and the autism population calculator, being developed by Skills for Care and the National Autistic Society, to plan and commission services
- nominate an elected member to be an autism champion for the area. This champion should regularly report on training and work with the council's autism lead to improve services. The Government should require this in the new autism strategy
- include a requirement in contracts with social care providers to demonstrate that they are implementing mandatory autism training
- prioritise investment into preventative services, such as buddying or befriending, to improve early intervention and reduce the number of autistic people ending up in crisis.

### Benefits

**In the new autism strategy, the Government must:**

- include a requirement in contracts for benefits assessment providers to provide all frontline assessors with autism training, and regularly monitor compliance
- the Government should develop guidance – working with autistic people and their families – to be disseminated to all providers carrying out benefits assessments on how to properly identify autistic people's needs and ensure assessments truly capture their circumstances.

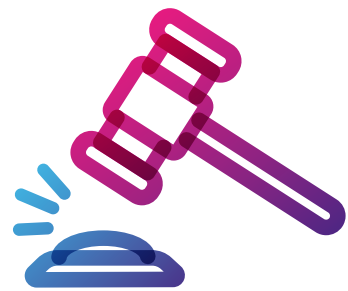


# Chapter three – Physical health inequality

## Introduction - Rt Hon Sir Norman Lamb MP

After several years of highlighting the issues autistic people face in getting a diagnosis or accessing physical health services, it is now well-documented that autistic people face an utterly unacceptable health inequality. As Autistica's *Happier, healthier, longer lives* briefings found, autistic people face many barriers in accessing healthcare and experience poorer physical health and life expectancy.<sup>14</sup> The Government recognised this, and included autism in the NHS's new Long Term Plan as a clinical priority. While this is a big step in the right direction, there is much left to do.

It is clear there have been certain important improvements since the introduction of the Act and the last review of the autism strategy. For instance, every English council now reports having an adult autism diagnosis pathway, up from fewer than half before the *Autism Act*, which means many more adults are receiving an important diagnosis.



**However, just 8% of autistic adults and 5% of families told us that since the *Autism Act* came into force health and care services in their area have improved,**

while only 14% of autistic adults said the support they received helped them to have good physical health. Many of these issues appear to stem from continued poor autism understanding among health professionals, despite clear duties to provide training in the *Autism Act* statutory guidance. As a result, autistic people's needs are missed and important reasonable adjustments are not made.

## What our research tells us

The inquiry highlighted the range of difficulties autistic people and their families face in accessing healthcare, including challenges in getting a diagnosis. Both autistic people and their families told us that getting a diagnosis is vital to them, but that they have to wait far too long to be able to get it. Our survey has also shown that people still lack support after diagnosis, with just 4% of autistic adults and families telling us they were fully supported in the 12 months after their diagnosis.

There are also clear difficulties for autistic people in accessing the health service when they need it more generally. In large part, this inequality is down to healthcare professionals' lack of training in autism. Hospital doctors and nurses in particular were found to have low understanding of autism, with just 11% and 13%

**Our survey has also shown that people still lack support after diagnosis, with just 4% of autistic adults and families telling us they were fully supported in the 12 months after their diagnosis.**

of autistic adults saying these professionals have a good understanding of autism respectively. This, as well as lack of access to reasonable adjustments, means that autistic people are often not engaging with the NHS when they need to. And this is having a knock-on impact on people's physical health and life expectancy.



## 1. Trouble getting an autism diagnosis

Although every area now has an adult diagnosis pathway, this is not clear for children. Both autistic adults and children still face long waiting times – sometimes running into several years. Alongside this, a lack of information, advice and signposting onto other support means that this process can be incredibly stressful. For autistic people and their families, improving access to diagnosis was a top priority in our survey.

The NICE Quality Standard on autism states that the wait between referral and first diagnosis appointment should be no more than 13 weeks, but just 18% of councils reported meeting this target for adults in a recent Government survey.<sup>15</sup> Moreover, reported waiting times for adults appear to have almost doubled since 2016, with average waits now standing at 30 weeks, compared to 16 weeks in 2016.<sup>16</sup> The longest waits in England were reported in Greenwich, Tameside and Bradford – standing at over two years.<sup>17</sup> The increase in waiting times could in part be attributed to the increasing number of people being diagnosed, with 62% of councils reporting a rise, but also budget pressures on the NHS.<sup>18,19</sup>

A Freedom of Information request last year uncovered a similarly concerning waiting times postcode lottery for children, with many waiting more than two years.<sup>20</sup> At our inquiry session, National Learning Disability Director at NHS England, Ray James, recognised this, saying there is a need to “incentivise and bear down on variability”.

As awareness of autism increases, more people are identifying that they might be autistic and seeking a diagnosis. A diagnosis can be a crucial step in getting the right support, stopping people from struggling and helping people to better understand their own needs. But services are not keeping up with this demand.

**The NICE Quality Standard on autism states that the wait between referral and first diagnosis appointment should be no more than 13 weeks, but just 18% of councils reported meeting this target for adults in a recent Government survey.**

<sup>15</sup>Public Health England (2019), *Self-assessment exercise 2018: overview of results*. London, UK. <sup>16</sup>Ibid. <sup>17</sup>Ibid. <sup>18</sup>Ibid.

<sup>19</sup>National Autistic Society, *New report shows adult diagnosis waiting times have almost doubled in the last two years*. Available at: [www.autism.org.uk/get-involved/media-centre/news/2019-06-20-new-report-adult-diagnosis-waiting-times.aspx](http://www.autism.org.uk/get-involved/media-centre/news/2019-06-20-new-report-adult-diagnosis-waiting-times.aspx) (Accessed on: 16 July 2019)

<sup>20</sup>The All Party Parliamentary Group on Autism and Lamb, Norman (2018), *The autism diagnosis crisis*. London, UK.



The NHS Long Term Plan recognised long waiting times for diagnoses, and committed to reducing these for children. This is a welcome step, but the Government must also act to reduce waits for adults.

Following extensive campaigning from the APPGA, the National Autistic Society and others, new national waiting time data will be published from autumn 2019, reporting on the average wait between referral and first appointment. The Government must ensure this data is used to make sure local services keep up with demand and meet NICE guidance. But this measure is only one part of people’s diagnosis journey. After what we heard from our witnesses, we believe a standard should be put in place for diagnosis

**“I asked my GP for proper diagnosis as she and other professionals have agreed I am extremely likely to be autistic and I have children who have all been diagnosed as on spectrum. My GP said no point in getting diagnosis and waiting lists were closed.”**

waiting times, and that more data should be recorded to show the overall wait – from initial referral to the stage of a diagnosis being given.

2. The lack of support after diagnosis

As well as trouble getting an autism diagnosis, autistic people and their families said they struggle to navigate often complex diagnostic pathways, as well as not knowing where to turn after a diagnosis. Getting a diagnosis is a crucial step, but it should include providing autistic people with the information and knowledge they need to understand what their diagnosis means, as well as leading to the provision of support if they need it. The *Autism Act* statutory guidance makes it clear that they should be offered services, such as care assessments.

We heard from our witnesses and survey respondents that this information and follow-up support is not being provided. This means that autistic people and their families often rely on self-research after receiving a diagnosis to understand what their autism means and the support they could be entitled to. As a result, they are at risk of missing out on support. Autistic people and their families told us they needed healthcare professionals to give them clear information about what support they could get following a diagnosis and what process to follow.

People told us they want to see the diagnostic pathway include follow-up conversations with healthcare professionals to review their needs after diagnosis, as well as provide information and referrals on to other support. While the statutory guidance already states that NHSE and CCGs should be providing appropriate post-diagnostic advice and support, the majority of autistic people told us this is not happening. This is where specialist autism teams can play a role.

3. The lack of professional understanding

One of the major barriers to autistic people having full and equal access to healthcare (and other support where appropriate) is the pervasive lack of autism training. Having a proper understanding of autism, how autism affects a person, and the adaptations professionals may need to make, is central in ensuring people receive the care they need. This is true for specialist autism services and for all other health services, like GP surgeries and hospitals.

Back in 2013, the National Autistic Society called on the Government to meet outstanding strategy and statutory guidance commitments on training. However, our inquiry findings show that training is not being provided to all healthcare professionals, as it should. We asked autistic people and their families to tell us how good they thought the autism understanding of health professionals was.

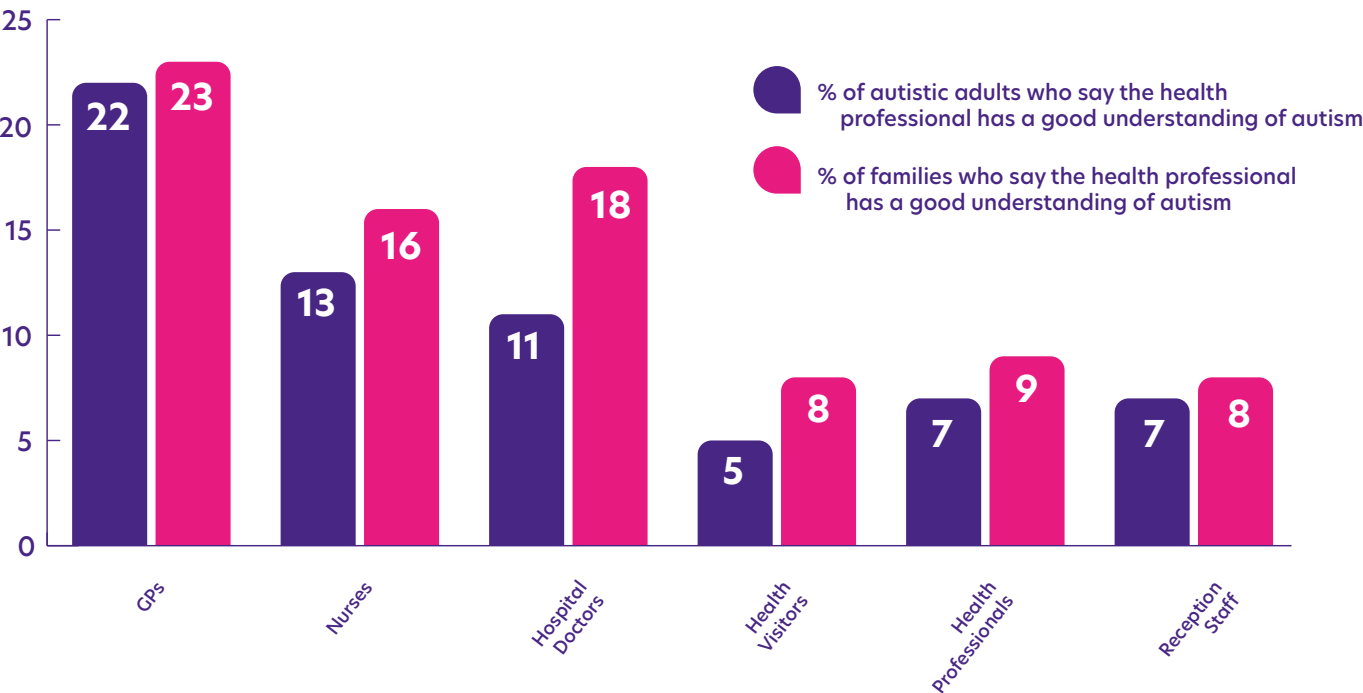
During our inquiry session, witnesses discussed why there has been such varied implementation of autism training across the NHS. Some felt that legal duties are unclear - that statutory guidance is expressed as things that ‘should’ (rather than ‘must’) be done, despite case law clarifying that it is a legal obligation - and that there was low awareness of the *Autism Act* across the NHS, and a lack of monitoring and enforcement.

The Government has committed to mandatory training, following the tragic case of a young autistic man, Oliver McGowan, dying in hospital. This is clearly a vital step and the Government must also take bold action in the review of the strategy to ensure all NHS bodies know their duties. In addition, it should guarantee that proper monitoring and enforcement mechanisms are put into place to ensure local areas are held to account. This is crucial in guaranteeing better implementation in the future, so that autistic people receive support from professionals who understand their needs.

4. Improving access to health services

Autistic people do not always come into contact with the health service because of their autism, but because of physical health needs or co-occurring disabilities. However, our inquiry has shown that they often struggle to access health services, and that many have negative interactions with the NHS because reasonable adjustments are not made to the support they receive. This can result in distress and anxiety, or not seeking health support at all.

Autism understanding among healthcare professionals:



The statutory guidance 2015 states that

- local authorities, NHS bodies and Foundation Trusts must comply with all the duties which apply to them under the *Equality Act 2010*, including the duty to make reasonable adjustments to their services whether they provide these services directly or outsource them for disabled people (such as autistic people)

- NHS England CCGs must under the *National Health Service Act 2006* have regard to the need to reduce inequalities between patients with respect to their abilities to access health services and reduce the inequalities between patients with respect to outcomes achieved for them by health services being provided. This should positively affect the way that these bodies exercise their functions in respect of autistic people.

The *Autism Act* statutory guidance confirms the NHS has a duty to provide reasonable adjustments. In spite of this, people told us they struggle with the physical environment not being autism-friendly, have problems with booking appointments and a lack of understanding of the communication or sensory difficulties people might have. In the last autism strategy, the use of hospital passports was recommended. These have since been introduced and have been found to be useful to those who have accessed them. As technology in the NHS has progressed, the NHS Long Term Plan has also committed to including autism in new electronic reasonable adjustment ‘flags’ that will go on a database for health professionals, so people’s communication and sensory needs can be recorded. This is a positive step and we recommend it should be rolled out at the earliest opportunity.

We have seen sobering research from Autistica that suggests autistic people are at risk of dying prematurely, with evidence pointing to the fact that autistic people are more than twice as likely to die early than the general population.<sup>21</sup> It is imperative that the Government takes urgent action to address this difference in life expectancy, starting by undertaking an autism mortality review and developing a better understanding of the issues behind it and how to tackle it. A similar mortality review exists of people with learning disabilities. We recommend that it should look at whether particular groups of autistic people are at greater risk of ill health than others.

It is also important that potential health issues are picked up more systematically. As part of our inquiry, we referred to Autistica and the National Autistic Society’s research into annual health checks for autistic people. This could help make sure that health symptoms are identified and treated earlier, which in turn could help improve or save the lives of many autistic people, particularly those who struggle to communicate feeling unwell. The charities agreed that health checks should be rolled out across the country – and we welcome the pilot proposed in the NHS Long Term Plan. In order to make this a reality, NHSE will need to improve recording of autism in primary care to ensure doctors know who to invite for health checks.

<sup>21</sup> Autistica (2016). *Personal tragedies, public crisis: the urgent need for a national response to early death in autism*. London, UK.

## What needs to be done

### In the new autism strategy, the Government should:

- commit to establishing well-resourced specialist autism teams in every area in England, providing diagnosis, support and information immediately after diagnosis, and training to staff in other local services
- commission a comprehensive review into the suspected gap in life expectancy for autistic people, and put forward plans for how it will reduce this gap
- establish and report on a new waiting time standard from referral to diagnosis, involving autistic people and their families to identify an appropriate benchmark wait
- clarify legal duties on local health bodies, and as part of their plans to develop a mandatory autism training programme, establish a mechanism for monitoring implementation and holding providers to account. This should also make sure that training is at an appropriate level for each staff member, based on the Autism Capabilities Framework and statutory guidance
- commit (specifically the Healthcare Quality Improvement Partnership) to commissioning an annual mortality review to better understand and reduce premature mortality and health inequalities among autistic adults
- commission a wide-ranging review of the data that needs to be collected across health and social care to inform and improve health interventions for autistic people, and then commit to making sure this is collected
- commit to establishing and funding an autism research strategy to underpin future commissioned autism and learning disability research.

### NHS England should:

- ensure there is clear leadership for autism within NHSE, by either expanding the current role of Director of Learning Disability to Director of Learning Disability and Autism or establishing a separate leadership role at Director level
- work with the Government to ensure that specialist autism teams are established in every area
- establish a formal structure to hold each area to account on diagnosis waiting times (eg the CCG Improvement and Assessment Framework) for both children and adults
- record autism in Local Health and Care Records, to ensure autistic people can be identified and appropriately supported locally
- roll out the inclusion of autism in reasonable adjustment ‘flags’ on Summary Care Records by the end of 2020. While waiting for this, NHS England should share best practice about hospital passports amongst NHS providers and CCGs. This will then help with inputting the correct information to the flags
- ensure that the Long Term Plan’s commitments on health checks, embedding reasonable adjustments (including ‘digital flags’) and better training are taken forward and fully funded

- commit to reducing autism diagnosis waiting times for adults, building on the commitment in the Long Term Plan to make this happen for children
- provide local commissioners with support to commission accessible autism-friendly services.

### Local health services should:

- ensure they are following the NICE Quality Standard on autism and each of the Clinical Guidelines in full
- provide all autistic people with the information they need to understand what their autism means at the point of diagnosis, as well as the option of a post-diagnostic review, and ensure referrals onto other support happen systematically
- be clear of their duty to provide anticipatory reasonable adjustments and to act on that duty.





# Chapter four – Mental health

## Introduction - Rt Hon Sir Norman Lamb MP

Autism is not a mental health condition, but many autistic people develop mental health problems – often avoidably and because of a lack of support. In the worst cases, autistic people find themselves in crisis, without appropriate support and end up in mental health hospitals. During our inquiry, we heard about the devastating experiences autistic people can have in these services, and the need to overhaul the system for autistic people.

Addressing the problems with mental health support was identified as a key challenge for autistic people, families and professionals across the inquiry. So many experience difficulties in getting the support they need and are routinely being let down by the system. Unfortunately, the Government's commitments over the last several years to ensure autistic people are able to live in their community have not delivered the required improvements. We now have an NHS Long Term Plan, which commits to improving community mental health support and driving down the number of autistic people in inpatient settings. To make this a reality, the Government needs to take urgent action to reduce the widespread unmet need at every level in mental health services and in social care.



## What our research tells us

In spite of Government efforts over the last ten years to move towards a community-based model of mental health support, our research tells us that autistic people are being failed by the mental health system. Thousands are developing avoidable mental health problems because they cannot access the support they need early on – from preventative services to social care.

**An overwhelming majority (76%) of autistic adults told us they reached out for mental health support in the last five years, but far too many were not able to access this crucial support.**



**Thousands are developing avoidable mental health problems because they cannot access the support they need early on – from preventative services to social care.**

58% of autistic adults told us they needed counselling, but less than half (21%) are accessing this support. Sometimes people are told that their mental health problems are 'due to their autism' and they cannot therefore receive any help from mental health teams. This demonstrates deeply concerning levels of unmet need.



People can end up unnecessarily in inpatient mental healthcare, even when they do not need this form of care. Witnesses told us that when people do not get the social care support they need and they reach crisis point, inpatient mental health services are often the only care that people can access. And, this spiralling unmet need, as well as issues with legislation, means that a growing number of autistic people are ending up in mental health hospitals against their and their families' will.<sup>22</sup>

So, when people ask for mental health support early on, they are too often turned away because they are autistic. But equally when people do not require mental health services, many are forced into them – also because they are autistic.

IAM Health, which is a research programme funded by the National Institute of Health aimed at improving mental health outcomes for autistic people. This will report in 2019.

Our inquiry has found that three-quarters of adults have tried to access mental health services, and that significant numbers want to access counselling or talking therapies. However, the survey and our inquiry also shows that many are not able to access this support. One of the main difficulties autistic people faced in getting mental health support was referral. Many reported challenges with self-referring, saying they found the process stressful and difficult to navigate. Others felt they were overlooked by healthcare professionals who often failed to identify or even ignored their mental health needs because they were autistic

## 1. Primary mental healthcare

Research shows that 71% of autistic children have mental health problems, such as depression, anxiety or obsessive compulsive disorder, while 40% have two or more conditions.<sup>23</sup> Meanwhile, research by Autistica shows that almost 8 in 10 autistic adults experience mental health problems during their lifetime.<sup>24</sup> While there could be many causes for this, our discussions with autistic people and their families have demonstrated that the lack of understanding across society as well as the absence of support to live, work and take part in their community contribute to poor mental health outcomes.

Poor mental health should not be an inevitable part of being autistic, and the Government must act to improve people's mental health. To do so, they must take into account the findings from

**82%**  
of autistic adults  
and 86% of families  
told us the process  
of getting support  
from mental health  
services took  
too long,

while  
only **14%**  
of autistic adults  
and 11% of families  
said there were  
enough mental  
health services in  
their area to meet  
their needs

which is contributing to long waits for support. Many told us the only form of support on offer is medication, and that this often does not meet their needs.

<sup>22</sup>NHS Digital, *Assuring Transformation*. Available at: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/assuring-transformation/content>, (Accessed: 3 July 2019)

<sup>23</sup>2 Simonoff E. et al (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample, *Journal of American Academy of Child and Adolescent Psychiatry* 47(4): pp921-929

<sup>24</sup>Harper, G et al (2019). *Autistica Action Briefing: Adult Mental Health*. London, UK.



For those autistic people who had managed to get mental health support, many told us that what they ended up getting was not appropriate for their needs as an autistic person. Often, counselling was not adapted and sometimes people's autistic behaviour was misinterpreted. Professionals must recognise autistic people's needs and behaviour, and acknowledge that for some autistic people general talking therapies may need to be adapted or could be inappropriate. In our survey, 32% of autistic adults rated mental health professionals as having a good or very good understanding of autism, which indicates more needs to be done to ensure they are having proper training.

***"I was unable to access autism-specific mental health help on the NHS in my area, so I've had to go private. My therapist is absolutely amazing and has helped me so much, but I worry for people who cannot afford to pay."***  
Anonymous

***"We need support faster than it is given. Having to wait months for help with PTSD alongside the autism. CBT is a long wait too. So parents are being left to struggle. So many areas do not even understand autism."***  
Anonymous

The Autism Act statutory guidance says local areas have to ensure autistic people have equal access to local therapy services, including Improving Access to Psychological Therapies (IAPT). This is clearly not the case and is having a devastating impact on autistic people and their families' lives – with many being driven to crisis point.

## 2. Crisis support

We heard from many people who said it was only when crisis hit that they got any support – but sadly even then the support is often still inadequate. Research in 2018 found that 66% of autistic adults have thought about taking their own life, while 35% have attempted suicide, demonstrating why it is so important we get these services right.<sup>25</sup> At that stage, many need timely access to crisis services in the community, to prevent them from being sectioned and ending up in mental health hospitals. A recent Government survey shows that, concerningly, only 11% of local areas have mental health crisis services that support autistic people without learning disabilities.<sup>26</sup>

**Research in 2018 found that 66% of autistic adults have thought about taking their own life, while 35% have attempted suicide, demonstrating why it is so important we get these services right.**

Witnesses at our inquiry session, autistic people and their families, reported that crisis services are not widely available when they need them. They also told us autistic people often find it difficult to navigate the mental health system at crisis point and that self-referral into services can be particularly challenging when people find communication difficult. The inquiry session also highlighted particular challenges for women and girls, who seem to be more likely to be identified and diagnosed at crisis point or in hospital.

For many of the autistic people who took part in our inquiry who have reached crisis point, the only form of support offered was being admitted to A&E. The stressful environment can compound their situation, and often results in people being sectioned due to behaviour that can be perceived as challenging.

<sup>25</sup>Cassidy, S and Rodgers, J (2017). *Understanding and prevention of suicide in autism*. London: The Lancet.

<sup>26</sup>Public Health England (2019). *Self-assessment exercise 2018: overview of results*. London, UK.

***"Early intervention, particularly in schools for children and young women as early as possible, and having the services available to support them in the community is really important. Ensuring that we have sufficient crisis response services, when we can see a crisis escalating for both children and adults."***

*Moira Wilson from the Association of Directors of Adult Social Services*

There was a resounding call for greater investment in community-based interventions such as Safe Spaces, which autistic people say would be beneficial to their wellbeing in crisis situations and have also been found to be helpful to people with mental health conditions more broadly. Specialist autism teams must train and work with mental health crisis teams to guarantee autistic people can access these types of services, ensuring an understanding of the adjustments that need to be made so that services are fully accessible.

## 3. Reducing inappropriate inpatient care

Too many autistic people are ending up in mental health hospitals – often far away from their home, because they have fallen into crisis or are being sectioned due to behaviours that could be perceived as challenging. Research shows that women and girls in particular are at risk of being sectioned, often not being diagnosed until they are in inpatient care. Often, they are in these services due to eating disorders or because they are self-harming, and are only referred for a diagnosis at that point. Many women mask their autism and go overlooked until they reach crisis point. This is the result of an absence of support from services such as community mental health and social care. This fact is acknowledged, and both the Government and NHS England have tried

to address it through the *Transforming Care* programme. But this programme has failed autistic people.

Recent research highlighted by the National Autistic Society in their *Beyond Transforming Care* report shows an overall increase between 2015 and 2018 in the number of autistic people in mental health hospitals and in particular a 24% rise in reported autistic people without a learning disability.<sup>27</sup> One in four of the inpatients had been in these hospitals for five years or more.<sup>28</sup> For many, these admissions stem from a failure of wider care and support, often starting very early in life, which could have been prevented (for instance being excluded from school).

### Ending inappropriate admissions and speeding up discharge

The *Mental Health Act Code of Practice* sets out that hospitalisation is rarely likely to be helpful.<sup>29</sup> During the inquiry session, witnesses agreed we need concerted action to reduce the number of autistic people who are detained in mental health hospitals. To meet the NHS Long Term Plan commitment of halving the number of autistic people and people with learning disabilities in these services by 2023/2024, we need to see a significant investment in community services, including preventative services, social care and mental health support.

***"There is definitely much more that we need to learn – what can we change about community services so there is a better skillset, understanding and more appropriate response to autistic children and families. The data suggests that while we have made some progress, of all the areas where we need to focus we need to learn and do more around autistic people with no LD."***  
*Ray James, National Learning Disability Director at NHS England*

<sup>27</sup>The National Autistic Society (2018). *Beyond Transforming Care*. London, UK. <sup>28</sup>Ibid.

<sup>29</sup>Department of Health and Social Care (2017). *Code of Practice: Mental Health Act 1983*. London: UK.



The inquiry session highlighted that one of the barriers to reducing the number of people in inpatient care are funding disincentives. This is because councils, whose budgets are under considerable pressure, fund care in the community while the NHS funds mental health hospitals. Although community-based social care is much less expensive than inpatient mental healthcare, it still means councils have to spend more money – and many of them do not have this. Our witnesses told us that this can be avoided by pooling health and social care budgets, but not enough areas are actually doing this. It also needs professionals to work together to create high quality packages of care with support from staff who understand autism.

Another barrier is the law. As it stands, autism is defined as a ‘mental disorder’ under the *Mental Health Act*. This contrasts with neurological conditions like stroke or epilepsy, which can put people at risk and yet are not included in the definition. This means autistic people who do not have a co-occurring mental health condition can be forced to accept treatment and live in inpatient facilities against their will – and often against their families’ wishes. We also heard some concern that it could be adding to the disincentive to create new community services, as there is always the ‘backstop’ of admitting someone if lower level support is not in place.

There is considerable debate about how to change the law. Some mental health professionals are concerned that a change to the definition could lead to more autistic people ending up in prison, as admission to hospital can be used to ‘divert’ people away from the criminal justice system. At the same time, many held a strong belief that this definition is inappropriate. This is clearly a very complex issue and of the highest importance. We believe it needs very careful consideration from the Government.

‘Homes, not hospitals’ is a phrase we often hear. It is a good one and we have heard clear evidence that it should be what we are aiming for. But sadly it is also clear evidence that without concerted action from Government and NHS England, it will not be a reality.

## Improving inpatient care for those who need it

For a small number of autistic people who also have a mental health condition, short-term assessment and treatment might be necessary for the purposes of treating that mental health condition. When that is the case, care and treatment should be of the highest quality. But the horrifying scenes uncovered by BBC’s *Panorama* at Whorlton Hall and the excessive use of seclusion reported in the CQC’s Thematic Review in 2019 leave us seriously concerned about the quality of care for autistic people in mental health hospitals.<sup>30</sup> We have heard convincing evidence that this is also symptomatic of a broken system, which needs to be fixed urgently. This is key if we are to create the responsive, understanding and compassionate mental health system that autistic people in England so desperately need.

## What needs to be done

### The Government should:

- consider the recommendations from IAM Health research into how autistic people’s mental health outcomes can be improved when this is published
- commission an independent review of the definition of autism as a ‘mental disorder’ under the *Mental Health Act*, consulting with autistic people and their families, charities and mental health professionals
- set out clear requirements to NHS England, local health commissioners and Sustainability Transformation Partnerships (STPs) on the need to commission community mental health services that meet the needs of autistic people, and ensure that this is implemented
- commission a review tracking the journey of autistic people in mental health hospitals and prisons to develop a better understanding of why they end up in these environments. It must set out how national and local Government can address the issues that come out of this review
- accept the recommendations from the Wessely review of the *Mental Health Act* in relation to learning disability and autism in full

- implement the recommendations made by the CQC in its Thematic Review on restraint and seclusion
- consider the development of pathways for particular groups of autistic people, eg for women and girls with eating disorders. This could involve screening for autism in eating disorder services.

### NHS England should:

- commission community-based mental health services that meet the needs of autistic people, including autism-adapted and accessible counselling and low-level psychological therapy. These should work closely with specialist autism teams in the area
- make clear mental health services’ legal duty to provide anticipatory reasonable adjustments, and share best practice amongst local services
- commission community-based crisis services that meet the needs of autistic people
- set out to Child and Adolescent Mental Health Services (CAMHS) and Community Mental Health Services that they cannot use autism as an excluding factor when making decisions about whether to support people with mental health conditions

- work with local STPs and Integrated Care Systems (ICSs) to ensure every area has prepared clear pathways for young autistic people to access mental health support that begin at referral for an autism diagnosis. This should be focused on preventing the escalation of need
- set out and deliver an ambitious plan to move autistic people out of hospital into the community – succeeding where *Transforming Care* has failed. The Government should establish an inter-ministerial group to ensure cross-Government accountability on the delivery of this programme
- require health bodies and local authorities as part of the development of local plans to pool budgets when commissioning care for autistic people with mental health problems or behaviour that challenges
- improve practice around Care and Treatment Reviews (CTRs) by providing professionals with greater clarity on people’s rights to CTRs. Autistic people and their families should be provided with more information on their rights and entitlements to CTRs too
- ensure sufficient advocacy workers with specialist training in autism and learning disability to meet local demand.





# Chapter five – Education and preparation for adulthood

## Introduction - Huw Merriman MP

In 2017, we carried out an inquiry into autism and the education system, which found that many autistic young people were missing out on the opportunities they require. Too often, they were being held back from achieving their potential, because they were not getting the support they need to succeed at school.

We concluded that autistic children face particular challenges that need to be addressed by the Government, schools and local authorities if the SEND reforms set out in the *Children and Families Act 2014* are to work as policymakers intended. We said that the Government needed to create a strategy, similar to the one that already exists for adults, to make sure that the gap in support for autistic children is closed.

The Government accepted this recommendation, committing to extend the adult autism strategy to include children and young people for the first time. Our last inquiry shed light on many of the challenges autistic children and their families face in the education system, and made a number of recommendations that still apply today, based on the following findings:



- **Fewer than half of children** and young people on the autism spectrum said they were happy at school.
- **42% of parents** said their child was refused an assessment of their special educational needs the first time it was requested.
- **50% of parents** said their child waited more than a year for support to be provided at school.
- **40% of parents** said their child's school place did not fully meet their needs.
- **Fewer than 5 in 10 teachers** said they were confident about supporting a child on the autism spectrum.
- **Six in 10 young people** said that the main thing that would make school better for them was having a teacher who would understand autism.

As we approached the review of the strategy, we wanted to highlight all of the areas that matter most to young autistic people and their families. Many told us a specific area of concern was the lack of support available to prepare them for life after school. In this inquiry, we wanted to investigate why people are having particularly difficult experiences during this stage in life and what more the Government can do in the strategy to better support autistic young people into adulthood.



## What our research tells us

Our inquiry session showed that transition points are of particular concern to autistic people and their families. This is because the move from primary to secondary school, from secondary school to college, and then from college onwards, are all times of heightened uncertainty for autistic young people and their families.

It was clear from witnesses that autistic young people face many challenges in their move to adulthood, and that the transitions process often let them down. Many are not being properly involved in decisions about their future, do not have enough time to prepare for adulthood and are not being supported as they should. We also heard from witnesses that professionals often overlook autistic young people's aspirations and ambitions, as well as the wider non-academic support they may need to succeed and thrive in adulthood. This must be addressed in the extended strategy.

### 1. Low aspirations and limited options

One of the main problems identified in the inquiry session is a widespread 'poverty of expectations' around what young people on

the autism spectrum can achieve. This is despite the statement in the SEND Code of Practice that "high aspirations are crucial to success".<sup>31</sup> A better understanding is needed of what a good life looks like for autistic people with all types of needs, and how young people can be encouraged and supported to pursue their interests and live the life they want.

Members of the National Autistic Society's Young Ambassadors Group told us how important it is that they received tailored rather than 'one size fits all' support, and that this helps them pursue their interests into adulthood. It is vital that professionals understand that autism affects individuals in many different ways, and are prepared to provide flexible, practical support.

Some autistic children become 'looked after children', for example because they live in a children's home or residential school. This means that councils have specific duties to keep those children safe, promote their wellbeing, and provide them with services (this is known as the council being a 'corporate parent'). It is vital that any autistic looked after child, just like any other autistic child, gets the care and support they need to prepare them for adult life.

<sup>31</sup> Department for Education and Department of Health (2015). *Special Educational Needs and Disability Code of Practice: 0 to 25 years*. London.



## 2. Inadequate preparation for independent living

**“There is a lot of focus on exams, but nothing really about living on your own or socialising.”**

*Member of National Autistic Society Young Ambassadors Group*

One of the most important functions of education is to prepare young people for adult life. But there is a mixed picture in how effectively this is done for autistic young people. Our inquiry heard from witnesses that services often lack ambition, particularly for young people with the most complex needs, who may not receive the support they need to develop necessary self-care skills. To illustrate: learning self-care skills (such as learning how to use the toilet) is central to a young person developing independence and gaining employment, exploring hobbies and engaging in their community. It can take a while for a child to embed skills, so it needs to start as early as possible. But we heard from one parent who had been told self-care skills were not a priority for her son, because he would always need a high level of care. His options for independence are limited as a result.

**One of the most important functions of education is to prepare young people for adult life. But there is a mixed picture in how effectively this is done for autistic young people.**

The SEND Code of Practice states that preparing for adulthood should begin early, and for young people who have an EHC plan, there should be a formal focus on life after school from

Year 9 onwards. We heard from witnesses that planning does not always begin even in Year 9, let alone at an earlier stage. Planning to leave secondary school can be a long and difficult process, and autistic young people often struggle to effectively communicate their views on what is happening next in their lives.<sup>32</sup>

Doing this effectively requires time and a holistic approach. Despite the existence of EHC plans, and despite detailed statutory guidance in the SEND Code of Practice on joint working for joint outcomes,<sup>33</sup> we heard from witnesses that education, health and care services too often do not work together.

For example, when a young person moves from school to college, they may have a shorter week than at school, leaving them with ‘blank days’. These blank days could be filled with activities that are productive and enjoyable, but often the days are left empty because services are not working together to design a holistic week-long programme.

### People’s experience of transition to adults’ services:



**Just over a third (36%) of people who have gone through the transition to adults’ services say they were fully involved.**



**Just over a quarter (26%) received enough information.**



**Just over a quarter (26%) felt properly supported.**



**Less than a third (30%) had enough time to prepare for the transition to adulthood.**

## 3. Low priority for emotional health and wellbeing

Children and young people on the autism spectrum are at high risk of mental health problems, with research suggesting that 71% of autistic children have a mental health problem.<sup>34</sup> This can be exacerbated by a failure to put the right support in place – even if, on the face of it, an autistic child is doing well academically.

Witnesses told us that young people who are academically able can nonetheless have very high needs in relation to social communication, and these needs are not always well recognised.

We also heard that for young people leaving special schools outside their home area, there is a risk of becoming alienated from the community. Unless they receive support services to help them participate in their (possibly new) local community, their world can shrink and they will become isolated. Good social care has a vital role to play in this. Witnesses told the inquiry that there is not a good enough understanding of what good social care looks like for autistic children and young people, beyond the narrow remit of statute.

## 4. Lack of support leading to crisis

Families told us there is a lack of community services to prepare and support their children into adulthood. Some even told us that while they may receive direct payments to help them care for their child or young person, there are not services available to spend it on. Young people also say that there are not enough group activities and that they do not have enough opportunities to participate socially.

**“The Transition Support Service answers questions from families of young people aged 20-25 that should have been answered 10 years earlier.”**  
*Rachel Babbidge, Transition Support Manager, National Autistic Society*

One of the main issues to emerge from this part of the inquiry was the perception that some autistic children are ‘too able’ – that is, perceived as ‘not disabled enough’ – to be entitled to support. But this impression can ignore very significant underlying needs. Focus group participants told us that if children are doing well academically, their wider social needs may be overlooked. This can result in them becoming socially isolated and vulnerable to bullying, which can then exacerbate mental health problems.

We heard from the National Autistic Society’s Transition Support Service that this lack of support means too many families and young people have to hit crisis before they get any help. Families also report a lack of information on where to go for support, with a heavy reliance on word of mouth.

## 5. Commissioning is the key

**“Commissioning means local acceptance of responsibility.”**  
*Dame Christine Lenehan, Director, Council for Disabled Children*

Getting commissioning right is the solution to many of the problems this inquiry has identified. Providing the support that autistic children and young people need depends on collecting accurate data on the needs of local populations and using this to plan all the education, health and care services they will need in the future. But many local authorities do not have a good enough understanding of what good commissioning looks like.

For many young autistic people, their education, health and care plan remains the best option for putting in place everything that is needed for them to achieve good outcomes. An EHC plan should be about a young person’s whole life, not just their school day. But the fact that education is the only statutory part of an EHC plan means a child’s health and care needs can be overlooked. One witness said that in practice it becomes “just an E plan”. And for those children without an EHC plan, we heard very concerning evidence that support is just not available. SEN Support is often inadequate,

leading to a steady rise in the number of requests for EHC assessments as the only way for children's needs to be met.

The SEND Local Offer that every area is required to have was supposed to improve transparency and access to services and support, but it is not working well in all areas. The Local Offer should be a tool for identifying where the gaps in provision are, not simply a directory of all the services that may (or may not) be available in a particular area. Families do not always find the support they are looking for, and many say they do not find the local offer easy to navigate.

What needs to be done

**In our last inquiry, we set out a number of things that need to be included in the extended autism strategy for children and young people:**

- Autism training should be explicitly included in professional development for all teachers, including head teachers.
- A specialist curriculum should be provided for all pupils on the autism spectrum who need this.
- The types of reasonable adjustments that autistic children may need in schools should be clearly explained.
- Strategies should be in place to improve autism awareness and understanding in all schools, to help reduce bullying and improve inclusion.
- There should be guidance on how special schools and mainstream schools can support each other and transfer good practice.

- There should be guidance for schools and commissioners on what good educational provision for children and young people on the autism spectrum looks like, based on the large volume of existing evidence.
- Modelling should be available for local authorities to help them commission educational provision that meets the full range of needs of children on the autism spectrum.
- Schools should be required to work with local mental health services to ensure that children on the autism spectrum get any mental health support they need before their problems become severe.

These all still apply. In addition to this, from the evidence we have heard in this inquiry, in the new autism strategy, the Government should:

- commit to underpinning commitments in the autism strategy for children and young people with statutory guidance
- require schools and councils to provide information for all families with a child on the autism spectrum on the rights and entitlements of both the young person and the family as the young person reaches adulthood

Witnesses and our survey respondents told us that too often it appears to be a “dump of information”, with no guidance on what an individual family can access for their individual child.

The extension of the national autism strategy to children and young people is an unprecedented opportunity to address these issues, and spell out clearly what support autistic children and young people are entitled to at school and as they move into adulthood.

- set out schools’ legal duties to provide reasonable adjustments in school for autistic children whose behaviour may challenge schools, following a court case last summer,<sup>35</sup> and provide schools with guidance on how to do this
- require schools to teach children and young people on the autism spectrum about relationships and sexual health in an accessible way (eg providing clear and direct information), recognising that for these young people this is a ‘hidden curriculum’ and they may not learn from their peer group
- commission the development of a model of what good social care looks like for children and young people on the autism spectrum
- make clear that the development of self-care, life skills and social skills should be written into a child’s EHC plan, without rigid boundaries between what is considered to be ‘education’ and what is ‘health’
- set out clear ‘transition protocols’ to support young people at the point when they move from school to college and when they leave college. This should apply to autistic children with EHC plans as well as those receiving SEN Support
- set out that transition planning should begin earlier than Year 9
- extend supported internships to young people who have significant needs but who do not have an EHC plan, rather than limiting them to young people with EHC plans as at present
- commission a review of how support is provided to autistic looked after children across England and act on its findings
- set out in guidance to councils that their Corporate Parenting Boards should report to local autism partnership boards on their performance for autistic children, and attend partnership board meetings
- work with universities to gather and share best practice on supporting autistic people moving into higher education.

- commit to ongoing support for staff in all schools to put good policy into practice from the Autism Education Trust.
- include guidance on how to make classrooms and the wider school or college environment more supportive for children and young people on the autism spectrum
- commission guidance on what good SEN Support in schools and colleges looks like for autistic children and young people





# Chapter six – Employment

## Introduction - Thangam Debbonaire MP

According to the National Autistic Society's *Autism Employment Gap* report, the proportion of autistic people in full-time work is 16%, with a further 16% in part-time work.<sup>36</sup> Meanwhile, data from the Labour Force Survey shows just over 51% of all disabled people are in paid work, suggesting that the autism employment gap is significantly wider than the disability employment gap.<sup>37</sup> The figure has not changed much over the decade since the *Autism Act 2009*. Whatever other improvements have taken place – and they have – employment does not seem to be one of them.

We would like to think of Parliament as a beacon of equality and accessibility for autism but it is not yet. As an employer of autistic staff members myself, I understand the need for information and guidance to support people into employment and provide autistic staff members with positive experiences. Unfortunately, this is often lacking, and much more must be done for Parliament to become an example of best practice for employers across the UK.

Autistic people told us that one of the key barriers for getting into and staying in employment is employers' poor understanding of autism. This, we heard, often affects people's ability to access crucial reasonable adjustments across their employment journey, from the application stage to thinking about career progression. We believe particular attention must be drawn to guaranteeing that employers, and those who provide employment support to autistic people, understand autism and their duties to provide reasonable adjustments.

The inquiry showed employers want to do more to recruit, train, employ and promote autistic people but also that they lack the confidence to do so. Government has a key role to play here, both by showing what can be done across the civil service and in providing employers with more support. We hope that the recommendations to Government, to Parliament and to employers in this chapter can help to bring about long overdue improvements in recruitment and retention of autistic people.



## What our research tells us

There have been small improvements in awareness among employers since 2016. A YouGov poll in March 2019 of 601 employers found that 27% thought an autistic person would be unlikely to fit in their team – down from 34% in a similar poll in 2016.<sup>38</sup> Those thinking an autistic person required too much support was also down to 31% from 38%.<sup>39</sup> However, while employers appear more confident that an autistic person might fit in, the number that worry they may not get the support right for an autistic person has increased, as has the number of employers who do not know where to turn for advice. The same poll shows a large majority of employers think Government has a key role to play in making sure that advice and information is available.<sup>40</sup>

In terms of support from councils, we have seen a fall in the number reporting they are following the examples of good practice set out in the autism strategy and statutory guidance. What is particularly concerning is the clear fall in the number of councils reporting that support from school to adult services has an employment focus, from 42% to 33%.

It was also clear throughout the inquiry that unemployment or underemployment can have a significant knock-on impact on other areas of people's lives, as it can reduce independence and confidence, and leave people at greater risk of loneliness and/or social isolation. Through our survey and inquiry sessions, we heard more about what employers, support providers, and the Government can do to help remove these barriers.

## 1. Barriers to and opportunities for getting into employment

As in other parts of the inquiry, people told us there is a lack of services to meet their needs.



**42% of autistic adults told us they need employment support, but just 12% receive it, meaning that the majority who need it do not get it.**

Our inquiry also found that getting the right social care, benefits or other support affects people's ability to get into and stay in work.



**Just 13% said that the care and support they currently get helps them find – or stay in – work.**

**Meanwhile, 37% said more support would help them find work.**

When asked about autism understanding among a range of professionals, Jobcentre Plus staff were reported as being among the worst for understanding autism.



**Only 4% of autistic adults said Jobcentre Plus staff have a good understanding of autism.**

This is a shockingly low number and translates into poor experiences, inappropriate placements for work or not putting in place the right support for people to be able to work. It is really important Jobcentres have the knowledge and understanding required to adequately support autistic people and provide them with opportunities that meet their aspirations and skills.

<sup>36</sup>The National Autistic Society (2016). *The Autism Employment Gap - Too Much Information in the workplace*. London, UK.

<sup>37</sup>Office for National Statistics, *The Labour Force Survey*, Available at: <https://www.ons.gov.uk/surveys/informationforhouseholdsandindividuals/householdsandindividualsurveys/labourforcesurvey> (Accessed: 17 July 2019)

<sup>38</sup>The National Autistic Society (2019). *Auto Trader leads drive for businesses to be autism friendly*. Available at: <https://www.autism.org.uk/get-involved/media-centre/news/2019-04-03-autotrader.aspx> (Accessed: 3 July 2019)

<sup>39</sup>Ibid. <sup>40</sup>Ibid. <sup>41</sup>Public Health England (2019), *Self-assessment exercise 2018: overview of results*. London, UK.



In both the survey and inquiry session, autistic people and professionals underlined the challenges identified in the *Autism Employment Gap* report. Several professionals involved in job and skills training identified inconsistent support from Access to Work providers as a problem, particularly delays in the Access to Work process. Judith Kerem, Development Director at Care Trade UK, said this can be a problem in ensuring adjustments are in place from the beginning of the employment process:

**“One thing that is very common is inaccessibility of Access to Work. A lot of employers are not even aware of it so they can feel they are on their own, or the advice they get is often not right.”**  
Judith Kerem at Care Trade

Some of our witnesses highlighted examples of good practice, including “quiet and calm” Jobcentres. However, this has only been piloted in a few Jobcentres so far, meaning that its impact has been limited and support is varied across the country.

Supported internships also provide a great opportunity for young autistic people to try work, but again, we heard these schemes are still few in number and often not resourced to be sustained in the long term. But autistic people in the session also identified specific barriers to getting a job in the application and interview process. Interviews are particularly challenging, as people have to deal with new surroundings and questions that are often unanticipated or not autism-friendly.

It is important to remember that while not all autistic people will be able to work, the *Autism Employment Gap* report found that 77% of unemployed autistic people want to work.<sup>42</sup> Both autistic people and professionals made clear that with the right support people with varying needs could work. James Cusack, Director of Research at Autistica, said:

**“The biggest challenge is that we still do not know enough about what sort of employment works for autistic people. We need to ask how they can meaningfully contribute to society and in a way that enhances their wellbeing.”**

James Cusack, Director of Research at Autistica

He also said it was crucial that we collect data through the Labour Force Survey to monitor factors like career progression and under-employment.

## 2.Support for employers in recruiting and retaining autistic people

A key area of discussion in the inquiry session was the idea of an online information hub, which both the National Autistic Society and other disability charities have been calling for. This would provide employers with information and support in one place about best practice and financial support available.

Polling of employers showed support for the establishment of a hub. However, our witnesses highlighted that to be effective, this should contain more than just basic information, incorporating the active support employers need – including ways to find specialist support if needed and how to help employers support their autistic employees reach their career ambitions. Emma Kearns from the National Autistic Society, who helps support employers in employing autistic people, also said that she supported the hub, but that it needed to bring services like benefits and schemes like Access to Work together to help coordinate support.

## Online information hubs

The internet offers opportunities for autistic jobseekers, as well as employers. Richmond upon Thames developed an online peer support hub for autistic people to support access to skills and employment, secured through government funding in 2014. This is designed to build autistic people’s confidence and allow them to gain access to necessary skills for job applications.

Lewisham has also converted its Work Programme centres into Shaw Trust community hubs that link up employment support and other services. This includes counselling, health and wellbeing support, and skills training such as practising mock interviews. This allows for support focused on the ‘distance travelled’ towards employment rather than targets on employment itself. Work Foundation analysis found this increased participant engagement and staff satisfaction.<sup>43</sup>

While these hubs focus on supporting autistic people looking for work, they show how services could be coordinated and provide a single place where employers could access support, training, or more information to support autistic people.



Some employers have recognised autistic people’s potential and have taken steps to actively seek out employment options. Christos Tsaprounis from Auto Trader said at the time of the inquiry session that 7% of its employees identify as neurodiverse, and talked about the wider adjustments they have made to the

workplace, as well as support in the form of peer networks and mentoring. Roxanne Hobbs, an employment consultant, said that having workplace Neurodiversity Champions could be a way of embedding these wider adjustments and support for employers.



<sup>42</sup> The National Autistic Society (2016). *The Autism Employment Gap - Too Much Information in the workplace*. London, UK.

<sup>43</sup> The Work Foundation (2016). *Is welfare to work, working well? Improving employment rates for people with disabilities and long-term conditions*.



## Case study: Auto Trader

In April 2019, the National Autistic Society launched the Autism Friendly Employer Award. Auto Trader was the first organisation in the world to achieve this award, as a result of having implemented specialist standards across recruitment as well as improving awareness of autism and support for autistic employees.

Christos Tsaprounis spoke in our inquiry session about the changes they have made at all stages of the employment process and across the company. This includes encouraging people to disclose before the application process. Christos told us: “What seems to have the most positive results is making sure it is clear in all our communications that we are autism-friendly, and ensuring that it is autistic people who are helping to deliver this message. People will respond better if they feel it is authentic.”

He also spoke about the importance of mentoring support from other autistic people in the company: “Having something where everyone at all levels of management can help support autistic people really helps the autistic person to flourish and is important for changing the culture of the company.”

## 3.Reasonable adjustments and disclosure

Disclosure was also seen as a barrier throughout the session. While 58% of autistic adults in work have disclosed their autism according to the *Autism Employment Gap* report, many autistic people and professionals spoke about the stigma that is still attached to autism.<sup>44</sup>

Helen Ellis of the National Autistic Society told us disclosure should be one part of normalising adjustments in the workplace for everyone: “Autistic people are not the only people with needs; parents with school runs have needs, people suffering bereavement have needs. We need to normalise it so that it does not need to be disclosed like a top secret.”

A consistent theme throughout the session was workplace culture as a whole. “Reasonable adjustments are Plan B,” witness Janine Booth said. As identified with Auto Trader, adjustments that can be embedded in the workplace as a whole make it easier to hire and retain autistic people, as well as reducing the stigma of asking for adjustments. To be effective, it is important for employees to have a good assessment of what their needs in the workplace might be. This will also help employers know exactly what they should do, in a manageable way.

There was strong support in the inquiry session for more quiet workspaces or making flexible working the default. At the same time, there was a view that reasonable adjustments still need to be tailored to individual needs, and that a ‘one size fits all’ approach should not be taken. There was also a feeling that some of the elements of flexible working, such as hot desking, could be very challenging to autistic people, which is why taking into account individual strengths and challenges is so important.

One autistic person said that one of the key barriers with reasonable adjustments is that it can cause resentment if non-autistic people assume it is a specific adjustment just for them. Jonathan Andrews said that adjustments to the application process, such as allowing all people to have access to interview questions beforehand, not just autistic people, would remove stigma from these adjustments.

Judith Kerem of Care Trade spoke about “unwritten workplace rules”, such as birthday card collections or after work drinks, which are “rules that we do not learn, but it is assumed we know about them.” As such, she felt it was important that any adjustments made concerned ongoing support to ensure people stay in work. She said that “an autistic person needs longer-term support. It is not just a question of a trial. Things change over not just days but weeks and months.”

## What needs to be done

In the new autism strategy, the Government must:

- make autism training compulsory for all Jobcentre Plus staff, making sure staff have the level of training that reflects their interaction with autistic people
- appoint an Autism Employment Champion in each Government department to promote the benefits of employing autistic people
- make inclusive apprenticeships and supported internships available for young people without EHC plans
- create an online autism information hub for employers, with resources, advice, and clear information on how to get more support. It should be developed in partnership with employers (including businesses of different sizes and across industries), autistic people and their families
- implement the recording of autism in the Labour Force Survey, following the commitment in July 2019 to make this happen, and draw on the findings from the data to develop services and specific interventions for autistic people across the UK, including as part of the country’s ongoing industrial strategy
- commit to independently monitor autistic people’s outcomes on the Work and Health Programme, and people’s access to Jobcentre Plus support
- commit to independently monitor the effectiveness of supported internships in helping autistic people into work
- make autism training compulsory for all Access to Work advisers
- commit to ensuring support is available for autistic people through Access to Work
- encourage employers to work towards schemes to improve autism employment, like the Autism Friendly Employers Award
- review the automatic disbarment of autistic people from positions in certain professions, for instance the armed forces
- commission research into the barriers autistic people face in career progression, including looking at the support required to support people to fulfil their ambitions
- commission research on outcomes for people who have reasonable adjustments, and promote good practice on the provision of reasonable adjustments amongst employers.





To make sure the *Autism Act* statutory guidance is making a difference, councils should:

- commission social care services to support autistic adults to work, where this is something the person can and wants to do
- ensure Jobcentre Plus representatives attend Autism Partnership Boards
- ensure guidance about reasonable adjustments and the employer hub is shared throughout their area, so local employers are aware of their responsibilities and good practice.

To close the autism employment gap, employers and representative bodies should:

- provide the option of flexible working from the start of a person's employment
- encourage managers and employees to undertake autism training and to make their workplace autism-friendly

- work towards schemes to improve autism employment, like the Autism Friendly Employers Award.
- trades unions should have autism or neurodiversity representatives in the workplace, who can represent autistic people and also inform of their rights to support or to join a trade union.
- the Federation of Small Businesses (FSB) and the Confederation of British Industry should produce guidance for employers and develop autism training packages to be disseminated with their members.

The UK Parliament should also lead by example, making its recruitment and employment practices autism-friendly.



# Chapter seven – Access to justice

## Introduction - Anne-Marie Trevelyan MP



The vast majority of autistic people are law abiding citizens. In spite of this, autistic people may come into contact with the justice system for a number of reasons, as a victim, a witness or defendant. Some autistic people may be more vulnerable to criminal acts against them or become unwitting accomplices to criminal activity. Whichever of these situations apply, autistic people have a right to be understood by the justice system.

Our inquiry sought to uncover some of the issues autistic people face when they interact with the police, the courts and the prison system. While the Government and other agencies have taken a number of steps since the autism strategy was last reviewed to try and make the justice system work better for autistic people, many issues remain. These can have a profoundly damaging effect on autistic people. In the most serious cases, these problems may lead to potential miscarriages of justice.

### What our research tells us

At our inquiry session, and throughout our survey, we heard from autistic people and their families about the different experiences autistic people are having in the justice system. As in other areas of this report, we found a clear lack of understanding amongst professionals in the system.

This absence of understanding, many told us, can have deeply negative consequences, for example in misinterpreting signs of distress as suspicious behaviour.

In the inquiry session, we also heard about the importance of ensuring liaison and diversion services, appropriate adults, and intermediaries are in place in preventing people from ending up in the system and in supporting those who are (for whatever reason). Too often, though, this is not the case.



**Only 6% of autistic adults and 5% of families feel that police officers have a good understanding of autism.**



**Just 3% of autistic adults and 1% of families feel that criminal justice professionals other than the police, such as courts and prison staff, have a good understanding of autism.**



## 1. Contact with the police

Considering that autistic people make up over 1% of the population, the chances of police coming into contact with autistic people or their families, is high. Initial contact often comes at a time of heightened anxiety - whether an autistic person is a victim, witness or suspect. It is important that police officers have a good understanding of autism so they are equipped with the skills required to support autistic people and prevent situations from escalating.

However, our survey has found particularly low understanding of autism amongst police officers, in spite of the *Autism Act* statutory guidance stating that training should be available to the police. Encouragingly, the College of Policing have included information about autism in their Authorised Professional Practice on Mental Health, but this clearly has not yet delivered necessary improvements to understanding.

During our inquiry session, we heard about research from 2016 that found just 42% of police officers surveyed were satisfied with how they worked with autistic people, while just 37% of respondents said they had autism training.<sup>45</sup> Of those who had not, 92% of officers reported this would be useful, with many saying it would help with communication and minimising distress.<sup>46</sup> The impact of lacking autism understanding was evident in the responses to our survey. Many autistic people and their families told us they got into more trouble after an initial encounter with a police officer who did not understand their autism.

***"I can't emphasise this enough; autistic people are being criminalised through lack of awareness."***

*Anonymous*

We heard clear evidence from witnesses that all, including new recruits and existing police officers, should have autism training. Currently, the College of Policing encourages training to take place, but it is not reaching enough officers, which is why many said training should be made compulsory. The Metropolitan Police

has also recently launched an autism alert card and communication passport, which helps police officers to identify people's needs and support them properly.

## 2. Liaison and diversion services

Witnesses raised that liaison and diversion services can play a vital role in identifying people who may be autistic when they first come into contact with the police and in diverting them away from the criminal justice system. While these services can be very beneficial, witnesses said they are not widely available and that the Government should ensure there are liaison and diversion services in every area of England. Staff working in these services must also have a proper understanding of autism so they can refer people onto the right services and support.

***"Taking him into the criminal justice system would have been catastrophic for someone so vulnerable. Never a day goes by without us being so grateful for the common sense and care shown by those police officers."***

*Anonymous*

## 3. Access to 'Appropriate Adults'

The Police and Criminal Evidence Act Code of Practice states autistic people should have access to an Appropriate Adult - someone who ensures a suspect is treated fairly by police and is able to take part in interviews - due to their vulnerability. However, we were concerned to hear from witnesses that this does not always happen. There are incidents of autistic people making it all the way to prison without the support of an Appropriate Adult. Professionals told us making the provision of Appropriate Adults mandatory in all cases where autism is known or suspected, as Avon and Somerset Police have done, is the best way to address this. It is also vital that Appropriate Adults have a good understanding of autism.

***"I am an Appropriate Adult and assist autistic people at police stations. I would like to see the police given more training on how to deal with people on the autistic spectrum, especially in interviews re criminal offences. At present I notice that the police have little understanding of the issues involved."***

*Anonymous*



## 4. Experiences of courts

Once an autistic person is in the justice system, the nature of their difficulties may not be recognised or may be misunderstood. This inquiry heard that this puts autistic people at an increased risk of miscarriages of justice. It is therefore vital that legal professionals are familiar with autism. Some steps have been taken to make courtrooms less intimidating for autistic people. For example, the Equal Treatment Bench Book now includes information about autism and reasonable adjustments that can be put in place for autistic people. In addition, the Crown Prosecution Service has developed an autism guide for prosecutors. While these are positive steps, more must be done to improve understanding across the courts system, so autistic people can be properly supported.

During our inquiry, we heard from some experts who believed intermediaries (communication facilitators) have the biggest beneficial impact on people's experience in the courts system, but that they are currently not widely available. They are currently only available for witnesses, not defendants.<sup>47</sup> Witnesses advocated for intermediaries to be available for defendants too, to ensure they understand questions and are able to fully convey their case.

Witnesses also told us about the importance of professionals working in courts having a good understanding of autism and access to high quality, role-specific training. However, only very few autistic adults and families responding to our survey felt criminal justice professionals other than the police, such as judges and prison staff, had a good understanding of autism. Improving autism understanding amongst these professionals would help to identify whether someone may be autistic and needs adjustments.

## 5. Experiences in prison

Autistic people can end up in prison, just like anyone else. We currently do not know how many autistic people are in prisons in England, as this information is not routinely collected, although work in one Young Offenders' Institute suggested that 4.5% of inmates there were autistic.<sup>48</sup> Having a better idea of the number of autistic inmates across the prison estate would help plan support services in prisons. This could be recorded through the UK Prison Population Statistics.

<sup>47</sup> Wurtzel, D. and Marchant, R. (2017). Intermediaries. In Cooper, P., & Norton, H. (Eds.), *Vulnerable People and the Criminal Justice System - A Guide to Law and Practice*, Oxford, England: Oxford University Press, pp388.

<sup>48</sup> The National Autistic Society (2016). Award-winning Accreditation programme in the prison service. Available at: <https://www.autism.org.uk/professionals/accreditation/events/cjs-award.aspx> (Accessed: 26 June 2019)

Autistic prisoners can be particularly vulnerable due to their social and communication difficulties, which puts them at risk of being bullied or manipulated by fellow prisoners. Many prison buildings are noisy and brightly lit, which can be overwhelming for autistic inmates. The evidence we heard suggests that many autistic people have profoundly negative and damaging experiences in prison, which can impact their chances of being released and re-joining their community.

**“He was sent to prison where he spent six months. He was sexually abused in prison and also physically abused which has left terrible scars on him.”**  
Anonymous

One of the major problems identified was a lack of understanding amongst staff working in prisons, and professionals making decisions

about autistic prisoners. This can lead to significant problems with the identification and wider support of autistic prisoners. Early identification and assessment of autistic prisoners’ needs is crucial, but unfortunately we heard that getting an autism diagnosis in prison is often incredibly difficult and that the pathway for getting a diagnosis can be unclear.

During the inquiry session, several witnesses highlighted the benefits of prisons going through the National Autistic Society’s Autism Accreditation scheme. Many prisons and probation services are taking part, including HMP Wakefield, HMP Parc, HMYOI Feltham and the National Probation Service in Lancashire. Accreditation is aimed at improving their autism practice. So far, four prisons and a probation service have achieved the accreditation, with a further three working towards this. Training is key to gaining accreditation, helping staff to understand the different ways autism can affect prisoners and how to support them. We believe this model could be beneficial to many other prisons.

## Case study - National Probation Service (NPS) in Lancashire

Kathryn Bruderer told us, **“We were delighted to be the first NPS division to achieve Autism Accreditation 2018. For several years, we have been working closely with the National Autistic Society and other partners to develop our approach for offenders on the spectrum and those with learning disabilities. This has helped us identify the specific issues faced by autistic people in the criminal justice system as early as possible, and improve the experiences of autistic people in our service. Some of the actions we took were:**

- **set up and trained a network of autism and learning disability champions in all our North West offices and areas of work**
- **designed a development programme for staff including face-to-face training, e-learning, and reflective practice sessions**
- **successfully lobbied for a change to case management databases to better record reasonable adjustments for autistic people**
- **improved our local partnership working with health and social care and local authority autism leads**
- **worked as part of the Ministry of Justice’s Autism working group to identify and contribute to national developments of its work.”**

<sup>49</sup> Public Health England (2019). *Self-assessment exercise 2018: overview of results*, London.

<sup>50</sup> Ibid.

## 6. Being a victim of hate crime

We heard serious concerns about a perceived increase in the number of autistic people who are the victims of hate crimes. In a recent Government survey of councils, only 6% of those responding said they record autism in their local hate crime statistics.<sup>49</sup> This is because police forces are only required to record crimes against autistic people as “disability hate crime”, which is one of the five mandatory strands stipulated by the Home Office. However, from June 2019, Avon and Somerset Police will be the first force to record crimes against autistic people separately. The Government should monitor this, and consider rolling this out across all police forces.

## 7. Representation on autism partnership boards

One of the challenges raised in making the justice system work better for autistic people is the lack of meaningful representation of justice professionals in local autism partnership boards. Recent data has suggested that the number of councils where CJS representatives are actively engaged on their partnership boards has halved from 11% in 2016 to 6% in 2018. This is an important local relationship as councils and justice services are encouraged to work together in providing autism training.<sup>50</sup>

### What needs to be done

In the new autism strategy, the Government should:

- commit to making autism training mandatory for all police officers, by working with the College of Policing to require all new police recruits to undergo autism-specific training, as well as creating a programme for all existing officers to receive this training
- consider how best to roll out initiatives, such as the Metropolitan Police’s autism alert cards, which can help to improve interactions between autistic people and the police
- commit to making the availability of Appropriate Adults mandatory in all cases where autism is known or suspected for all police services in England

- work with relevant agencies to make good quality, role-specific training in autism mandatory for other CJS professionals, such as legal professionals and prison staff
- promote best practice guides and toolkits aimed at CJS professionals
- ensure that contact with the justice system, as a suspect or victim, is considered an indication that an autistic person may have social care needs and offer them an assessment as appropriate. This should be included in updated *Autism Act* statutory guidance
- consider extending the Registered Intermediaries programme to cover defendants as well as witnesses
- encourage more justice services to take part in autism partnership boards
- record and report on the number of people in prison who are autistic through the UK Prison Population Statistics
- require all prisons to improve their autism practice, for example through encouraging them to work towards Autism Accreditation.

In addition to this, NHS England should establish a national autism diagnosis pathway for prisons.





# Summary of recommendations

## Public understanding

**In its new autism strategy, the Government should:**

- create and fund a long-term, properly funded national autism understanding campaign, aiming to shift the attitudes and behaviour of millions of people
- outline a plan for ensuring that all public buildings are autism-friendly, or are taking steps towards becoming autism-friendly, and meet duties under the *Equality Act* for autistic people by 2024
- develop guidance for councils on how to use their roles in economic development to promote autism-friendly initiatives (and their benefits) to businesses
- commission research into the additional barriers faced by autistic people from diverse backgrounds and with a range of needs, and set out an action plan for how to tackle the specific barriers they face.

In addition, as parliamentarians, we believe there is more that Parliament itself can do to be more accessible and welcoming to autistic people. As part of the renovation of the Parliamentary Estate, Parliament should commit to becoming fully autism-friendly. Parliament should consult with autistic people and their families about designs for renovations of the Parliamentary Estate to guarantee the environment is more inclusive to autistic visitors, staff members and MPs.

## Support in adulthood

### Social care

**In the new autism strategy, the Government must:**

- commit to establishing well-resourced specialist autism teams in every local authority in England
- establish an autism social care commissioning fund for councils to use to set up and run new autism services and support

- set out how it plans to improve social care services for autistic people across England, making sure that upcoming commissioning guidance is used and that services are properly resourced
- restate to councils their duty to assess people's needs regardless of whether they have a co-occurring learning disability, and hold areas that are found not to follow this duty to account
- make clear how they are going to ensure that the mandatory health and care training programme consulted on in early 2019 is going to be taken forward for all social care staff, including how it will be resourced and monitored
- require autism to be recorded in all key social care data sets including Short and Long-Term Support and Adult Social Care Finance returns
- set out plans to increase and improve social care and preventative services for older autistic people, including those with nursing care needs
- extend and strengthen councils' responsibilities around providing preventative services under the *Care Act*, and provide the support to make this a reality locally
- commission research into what care and support options work well for autistic people and act to embed the results across councils in England.

Underpinning this, the Government needs to set out how it is going to place the social care system on a sustainable footing in the longer term. It must ensure that the needs of autistic people and their families are properly included in plans for a reformed system.

**To better implement the *Autism Act* at a local level, councils must:**

- use upcoming commissioning guidance and the autism population calculator, being developed by Skills for Care and the National Autistic Society, to plan and commission services

- nominate an elected member to be an autism champion for the area. This champion should regularly report on training and work with the council's autism lead to improve services. The Government should require this in the new autism strategy
- include a requirement in contracts with social care providers to demonstrate that they are implementing mandatory autism training
- increase investment into preventative services, such as buddying or befriending, to improve early intervention and reduce the number of autistic people ending up in crisis.

## Benefits

**In the new autism strategy, the Government must:**

- include a requirement in contracts for benefits assessment providers to provide all frontline assessors with autism training, and regularly monitor compliance.
- the Government should develop guidance – working with autistic people and their families – to be disseminated to all providers carrying out benefits assessments on how to properly identify autistic people's needs and ensure assessments truly capture their circumstances.

## Physical health inequality

**In the new autism strategy, the Government should:**

- commit to establishing well-resourced specialist autism teams in every area in England, providing diagnosis, support and information immediately after diagnosis, and training to staff in other local services
- commission a comprehensive review into the suspected gap in life expectancy for autistic people, and put forward plans for how it will reduce this gap
- establish and report on a new waiting time standard from referral to diagnosis, involving autistic people and their families to identify an appropriate benchmark wait

- clarify legal duties on local health bodies, and as part of their plans to develop a mandatory autism training programme, establish a mechanism for monitoring implementation and holding providers to account. This should also make sure that training is at an appropriate level for each staff member, based on the Autism Capabilities Framework and statutory guidance
- government (specifically the Healthcare Quality Improvement Partnership) must commit to commissioning an annual mortality review to better understand and reduce premature mortality and health inequalities among autistic adults
- commission a wide-ranging review of the data that needs to be collected across health and social care to inform and improve health interventions for autistic people, and then commit to making sure this is collected
- commit to establishing and funding an autism research strategy to underpin future commissioned autism and learning disability research.

**NHS England should:**

- ensure there is clear leadership for autism within NHSE, by either expanding the current role of Director of Learning Disability to Director of Learning Disability and Autism or establishing a separate leadership role at Director level
- work with the Government to ensure that specialist autism teams are established in every area
- establish a formal structure to hold each area to account on diagnosis waiting times (eg the CCG Improvement and Assessment Framework) for both children and adults
- record autism in Local Health and Care Records, to ensure autistic people can be identified and appropriately supported locally
- roll out the inclusion of autism in reasonable adjustment 'flags' on Summary Care Records by the end of 2020. While waiting for this, NHS England should share best practice about hospital passports amongst NHS providers and CCGs. This will then help with inputting the correct information to the flags

- ensure that the Long Term Plan’s commitments on health checks, embedding reasonable adjustments (including ‘digital flags’) and better training are taken forward and fully funded
- commit to reducing autism diagnosis waiting times for adults, building on the commitment in the Long Term Plan to make this happen for children
- provide local commissioners with support to commission accessible autism-friendly services.

#### Local health services should:

- ensure they are following the NICE Quality Standard on autism and each of the Clinical Guidelines in full
- provide all autistic people with the information they need to understand what their autism means at the point of diagnosis, as well as the option of a post-diagnostic review, and ensure referrals onto other support happen systematically
- be clear of their duty to provide anticipatory reasonable adjustments and to act on that duty.

## Mental health

#### The Government should:

- consider the recommendations from IAM Health research into how autistic people’s mental health outcomes can be improved when this is published
- commission an independent review of the definition of autism as a ‘mental disorder’ under the *Mental Health Act*, consulting with autistic people and their families, charities and mental health professionals
- set out clear requirements to NHS England, local health commissioners and Sustainability Transformation Partnerships (STPs) on the need to commission community mental health services that meet the needs of autistic people, and ensure that this is implemented
- commission a review tracking the journey of autistic people in mental health hospitals and prisons to develop a better understanding of why they end up in these environments. It must set out how national and local Government can address the issues that come out of this review

- accept the recommendations from the Wessely review of the *Mental Health Act* in relation to learning disability and autism in full
- implement the recommendations made by the CQC in its Thematic Review on restraint and seclusion
- consider the development of pathways for particular groups of autistic people, eg for women and girls with eating disorders. This could involve screening for autism in eating disorder services.

#### NHS England should:

- commission community-based mental health services that meet the needs of autistic people, including autism-adapted and accessible counselling and low-level psychological therapy. These should work closely with specialist autism teams in the area
- make clear mental health services’ legal duty to provide anticipatory reasonable adjustments, and share best practice amongst local services
- commission community-based crisis services that meet the needs of autistic people
- set out to Child and Adolescent Mental Health Services (CAMHS) and Community Mental Health Services that they cannot use autism as an excluding factor when making decisions about whether to support people with mental health conditions
- work with local STPs and Integrated Care Systems (ICSs) to ensure every area has prepared clear pathways for young autistic people to access mental health support that begin at referral for an autism diagnosis. This should be focused on preventing the escalation of need
- set out and deliver an ambitious plan to move autistic people out of hospital into the community – succeeding where *Transforming Care* has failed. The Government should establish an inter-ministerial group to ensure cross-Government accountability on the delivery of this programme.
- require health bodies and local authorities, as part of the development of local plans, to pool budgets when commissioning care for autistic people with mental health problems or behaviour that challenges

- improve practice around Care and Treatment Reviews (CTRs) by providing professionals with greater clarity on people’s rights to CTRs. Autistic people and their families should be provided with more information on their rights and entitlements to CTRs too.

- ensure sufficient advocacy workers with specialist training in autism and learning disability to meet local demand.

## Education and preparation for adulthood

### In our last inquiry, we set out a number of things that need to be included in the extended autism strategy for children and young people:

- Autism training should be explicitly included in professional development for all teachers, including head teachers.
- A specialist curriculum should be provided for all pupils on the autism spectrum who need this.
- The types of reasonable adjustments that autistic children may need in schools should be clearly explained.
- Strategies should be in place to improve autism awareness and understanding in all schools, to help reduce bullying and improve inclusion.
- There should be guidance on how special schools and mainstream schools can support each other and transfer good practice.
- There should be guidance for schools and commissioners on what good educational provision for children and young people on the autism spectrum looks like, based on the large volume of existing evidence.
- Modelling should be available for local authorities to help them commission educational provision that meets the full range of needs of children on the autism spectrum.
- Schools should be required to work with local mental health services to ensure that children on the autism spectrum get any mental health support they need before their problems become severe.

### These all still apply. In addition to this, from the evidence we have heard in this inquiry, in the new autism strategy, the Government should:

- commit to underpinning commitments in the autism strategy for children and young people with statutory guidance
- require schools and councils to provide information for all families with a child on the autism spectrum on the rights and entitlements of both the young person and the family as the young person reaches adulthood
- commit to ongoing support for staff in all schools to put good policy into practice from the Autism Education Trust
- include guidance on how to make classrooms and the wider school or college environment more supportive for children and young people on the autism spectrum
- commission guidance on what good SEN Support in schools and colleges looks like for autistic children and young people
- set out schools’ legal duties to provide reasonable adjustments in school for autistic children whose behaviour may challenge schools, following a court case last summer,<sup>51</sup> and provide schools with guidance on how to do this



- require schools to teach children and young people on the autism spectrum about relationships and sexual health in an accessible way (eg providing clear and direct information), recognising that for these young people this is a 'hidden curriculum' and they may not learn from their peer group
- commission the development of a model of what good social care looks like for children and young people on the autism spectrum
- make clear that the development of self-care, life skills and social skills should be written into a child's EHC plan, without rigid boundaries between what is considered to be 'education' and what is 'health'
- set out clear 'transition protocols' to support young people at the point when they move from school to college and when they leave college. This should apply to autistic children with EHC plans as well as those receiving SEN Support
- set out that transition planning should begin earlier than Year 9
- extend supported internships to young people who have significant needs but who do not have an EHC plan, rather than limiting them to young people with EHC plans as at present
- commission a review of how support is provided to autistic looked after children across England and act on its findings
- set out in guidance to councils that their Corporate Parenting Boards should report to local autism partnership boards on their performance for autistic children, and attend partnership board meetings
- work with universities to gather and share best practice on supporting autistic people moving into higher education.

## Employment

**In the new autism strategy, the Government must:**

- make autism training compulsory for all Jobcentre Plus staff, making sure staff have the level of training that reflects their interaction with autistic people

- appoint an Autism Employment Champion in each Government department to promote the benefits of employing autistic people
- make inclusive apprenticeships and supported internships available for young people without EHC plans
- create an online autism information hub for employers, with resources, advice and clear information on how to get more support. It should be developed in partnership with employers (including businesses of different sizes and across industries), autistic people and their families
- implement the recording of autism in the Labour Force Survey, following the commitment in July 2019 to make this happen, and draw on the findings from the data to develop services and specific interventions for autistic people across the UK, including as part of the country's ongoing industrial strategy
- commit to independently monitor autistic people's outcomes on the Work and Health Programme, and people's access to Jobcentre Plus support
- commit to independently monitor the effectiveness of supported internships in helping autistic people into work
- make autism training compulsory for all Access to Work advisers
- commit to ensuring support is available for autistic people through Access to Work
- encourage employers to work towards schemes to improve autism employment, like the Autism Friendly Employers Award
- review the automatic disbarment of autistic people from positions in certain professions, for instance the armed forces
- commission research into the barriers autistic people face in career progression, including looking at the support required to help people to fulfil their ambitions
- commission research on outcomes for people who have reasonable adjustments, and promote good practice on the provision of reasonable adjustments amongst employers.

**To make sure the *Autism Act* statutory guidance is making a difference, councils should:**

- commission social care services to support autistic adults into work, where this is something the person can and wants to do
- ensure Jobcentre Plus representatives attend Autism Partnership Boards
- ensure guidance about reasonable adjustments and the employer hub is shared throughout their area, so local employers are aware of their responsibilities and good practice.

**To close the autism employment gap, employers and representative bodies should:**

- provide the option of flexible working from the start of a person's employment
- encourage managers and employees to undertake autism training and to make their workplace autism-friendly
- work towards schemes to improve autism employment, like the Autism Friendly Employers Award.
- Trade unions should have autism or neurodiversity representatives in the workplace, who can represent autistic people and also inform them of their rights to support or to join a trade union.
- The Federation of Small Businesses (FSB) and the Confederation of British Industry should produce guidance for employers and develop autism training packages to be disseminated with their members.

The UK Parliament should also lead by example, making its recruitment and employment practices autism-friendly.

## Access to justice

**In the new autism strategy, the Government should:**

- commit to making autism training mandatory for all police officers, by working with the College of Policing to require all new police recruits to undergo autism-specific training, as well as creating a programme for all existing officers to receive this training
- consider how best to roll out initiatives, such as the Metropolitan Police's autism alert cards, which can help to improve interactions between autistic people and the police
- commit to making the availability of Appropriate Adults mandatory in all cases where autism is known or suspected for all police services in England
- work with relevant agencies to make good quality, role-specific training in autism mandatory for other CJS professionals, such as legal professionals and prison staff
- promote best practice guides and toolkits aimed at CJS professionals
- ensure that contact with the justice system, as a suspect or victim, is considered an indication that an autistic person may have social care needs and offer them an assessment as appropriate. This should be included in updated *Autism Act* statutory guidance. Consider extending the Registered Intermediaries programme to cover defendants as well as witnesses
- encourage more justice services to take part in autism partnership boards
- record and report on the number of people in prison who are autistic through the UK Prison Population Statistics
- require all prisons to improve their autism practice, for example through encouraging them to work towards Autism Accreditation.

In addition to this, NHS England should establish a national autism diagnosis pathway for prisons.

## About this report

The report is based on an inquiry conducted by the APPGA between March and May 2019. This included an online self-selecting survey, completed by 12,500 people, including 8,210 family members and 2,974 autistic adults in England.

We also held six evidence sessions at the House of Commons, which involved MPs and Peers hearing from autistic people, family members and professionals working in the field of autism. In addition to the sessions, we held a focus group with local authority representatives during this inquiry, and had a call for evidence – which received 72 submissions.

## Evidence sessions

- **Health and mental health, 14 March 2019**
- **Public understanding, 1 April 2019**
- **Access to justice, 7 May 2019**
- **Support in adulthood, 8 May 2019**
- **Employment, 16 May 2019**
- **Education and preparation for adulthood, 20 May 2019**

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- all the members of the All Party Parliamentary Group on Autism (APPGA)
- the National Autistic Society, who provide the secretariat to the APPGA
- the **12,500** people who completed the survey which has provided invaluable insight into the lives and experiences of autistic people and their families across England
- everyone who sent us submissions as part of the call for evidence.
- The Chairs of our inquiry sessions:
  - Rt Hon Dame Cheryl Gillan MP
  - Thangam Debbonaire MP
  - Rt Hon Sir Norman Lamb MP
  - Huw Merriman MP
  - Catherine West MP
  - Anne-Marie Trevelyan MP

- members of the APPGA:
  - Baroness Angela Browning, Vice President of the National Autistic Society
  - Alex Burghart MP
  - Helen Hayes MP
  - Louise Haigh MP
  - Lord Sterling of Plaistow
  - Dr Paul Williams MP
  - Lord Bradley of Withington

**The panellists and witnesses who took part in our inquiry sessions, listed below, as well as everyone who attended the sessions:**

- Jonathan Andrews, Self-advocate
- Penny Andrews, Self-advocate
- Rachel Babbidge, National Autistic Society
- Laura Bennett, Carers Trust
- Bryony Beresford, University of York
- Venessa Bobb, Parent
- Janine Booth, Trade Unionist
- Peter Bowker, Author
- Adam Bradford, National Autistic Society
- Kathryn Bruderer, National Probation Service
- Robin Bush, Autism Together

- Matthew Bushell, The British Association of Social Workers
- Leo Capella, National Autistic Society
- Dr Peter Carpenter, Royal College of Psychiatrists
- Ian Carre, Betty Productions
- James Cusack, Autistica
- Angela Cutler, Parent
- Ian Cutler, Parent
- Ian Davidson, Royal College of Psychiatrists
- Helen Ellis, Self-advocate
- Ian Ensum, Avon and Wiltshire Clinical Commissioning Group
- Dr Sally Fitzpatrick, HM Prison Wakefield
- Dr Ian Gargan, Capita
- Glenn Garrod, Association of Directors of Adult Social Services
- Max Green, Self-advocate
- Tamsin Green, Parent
- Jane Harris, National Autistic Society
- Phillip Hanscombe, All Party Parliamentary Group on Autism Advisory Group
- Roxanne Hobbs, The Hobbs Consultancy
- Jane Howson, Autism Alliance
- Robin Howland, Workman LLP
- Clare Hughes, National Autistic Society
- Anna Javed, National Probation Service
- Holly Judge, Self-advocate
- Emma Kearns, National Autistic Society
- Judith Kerem, Care Trade
- Rosie Leatherland, Sibling
- Paul Lelliott, Care Quality Commission
- Dame Christine Lenehan, Council for Disabled Children
- Dr Alexandra Lewis, Consultant Psychiatrist
- Jo Lewis, Parent
- Dr Katie Maras, Centre for Applied Autism Research
- Sara Marchant, Gatwick Airport
- Liz Maudslay, Association of Colleges
- Melissa McAuliffe, Newham Council
- Cos Michael, Self-advocate
- Jo Minchin, Self-advocate
- Ellie Moore, Don't Panic
- John Nelson, National Police Autism Association
- Tim Nicholls, National Autistic Society
- Sarah Pickup, Local Government Association
- Alex Preston, Solicitor
- Tom Purser, National Autistic Society
- Dr Jacqui Shepherd, University of Sussex
- Emily Simonoff, King's College London
- Joseph Simon, National Autistic Society
- James Sinclair, Self-advocate
- Jon Spiers, Autistica
- Kerry Thornley, Salford CCG
- Moira Wilson, Association of Directors of Adult Social Services
- Gill Wilson, Channel 4
- Jenny Talbot, Prison Reform Trust
- Zandrea Stewart, Bristol City Council
- Anna Thomas, National Autistic Society
- Jim Thomas, Skills for Care
- Christos Tsaprounis, Auto Trader
- Dr Silvana Unigwe, Royal College of General Practitioners
- Alison Worsley, Ambitious About Autism
- Trevor Wright, Self-advocate



We thank the Pears Foundation for supporting the inquiry and this report.

**The All Party Parliamentary Group on Autism (APPGA)** is a formal cross-party backbench group of MPs and Peers who share an interest in autism. It was set up in February 2000. Its role is to campaign in Parliament for greater awareness of autism, and to lobby the Government for improved services for people on the autism spectrum and their carers.

## Officers:

Rt Hon Dame Cheryl Gillan MP (Chair)

Jonathan Reynolds MP (Vice-Chair)

Lord Touhig (Vice-Chair)

Lisa Cameron MP

Thangam Debbonaire MP

Baroness Hollins

Huw Merriman MP

Cat Smith MP

Lord Sterling of Plaistow

Christina Rees MP

Baroness Uddin

Lord Warner

Mike Wood MP