

# The national strategy for autistic children, young people and adults: 2021 to 2026

21 July 2021



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### Contents

Foreword from the Secretary of State for Health and Social Care	3
In memory of Rt Hon Dame Cheryl Gillan DBE MP	5
Joint Ministerial foreword	6
Chapter 1 : introduction	8
About autism	8
Why a new autism strategy is needed	8
Impact of the COVID-19 pandemic	9
Approach to this strategy	10
Chapter 2 : our roadmap for the next 5 years	12
How we will make our vision a reality	12
Chapter 3 : improving understanding and acceptance of autism within society	14
Our vision	14
How we will work towards this in 2021/2022	15
Our commitments in the first year	16
Chapter 4 : improving autistic children and young people's access to education supporting positive transitions into adulthood	n, and 17
Our vision	17
How we will work towards this in 2021/2022	18
Our commitments in the first year	20
Chapter 5 : supporting more autistic people into employment	21
Our vision	21
How we will work towards this in 2021/2022	22
Our commitments in the first year	23
Chapter 6 : tackling health and care inequalities for autistic people	25
Our vision	25
How we will work towards this in 2021/2022	26
Our commitments in the first year	28

30
30
31
34
35
35
36
38
39
39
39
40

## Foreword from the Secretary of State for Health and Social Care



As a society, we've come a long way since the landmark 2009 Autism Act. We've never had a greater public awareness of hidden disabilities like autism. That awareness is increasingly reflected in how our country is run, from the NHS to local government services.

Although we've come so far over the last decade, there must be no limit to the ambitions of autistic people; they should have the same opportunities as everyone else in society.

For me, our goal must be nothing less than making sure autistic people from all backgrounds, ethnicities, genders, sexualities and ages – in all parts of the country – get the support they need to live full and happy lives.

I'm painfully aware that the pandemic has been a setback in our efforts to reach this goal. People are having to wait longer for autism assessments and diagnosis, and the restrictions have been a barrier to access for important services like day centres and community mental health services, which help keep people well. In addition, we know that wider pressures on the labour market may make it even harder for autistic people to get into and stay in work.

I want to underline my thanks to everyone who played their part in helping us keep each other safe. I understand just how much this disruption has taken its toll on autistic people's livelihoods and mental health.

We've also learned some valuable lessons from the pandemic, from the benefits of flexible working to new ways of providing community support online, and the need to improve data collection about autism so we have a deeper understanding of people's experiences across health and care services.

As we move out of the pandemic, I encourage us all to take part in levelling up society. In particular, I hope that employers across the country, including the public sector, will help more autistic people get into work and make sure they provide the reasonable adjustments people need to thrive, making use of the support that is being made available.

I'm determined we build on the experience of the pandemic as we work to build back better and level up opportunity in this country. This new strategy will help us do that and much more.

Whether it's delivering world-class education for everyone, reducing diagnosis waiting times, or supporting autistic people with training and employment, this strategy sets out the real steps we're going to take over the next five years. These are steps I know will make a difference and help all autistic people across England lead the full and happy lives they deserve.

S.J.A.

# In memory of Rt Hon Dame Cheryl Gillan DBE MP



This new strategy honours and marks the contribution of Dame Cheryl Gillan, Chair of the All-Party Parliamentary Group on Autism (APPGA), and long-standing champion for autistic people and their families. Dame Cheryl, who died in April 2021, was instrumental in tackling the inequalities autistic adults face, when, in 2009, she brought forward the Private Member's Bill on autism. Since its inception, the Autism Act has made an important difference to many autistic people and their families' lives.

In addition, Dame Cheryl made significant progress in improving parliamentarians' understanding of autism by introducing autism understanding training, which over 100 MPs have undertaken. We have both completed this training and will be encouraging other Ministers and parliamentarians to do so going forward.

We are deeply grateful for Dame Cheryl's tireless work to improve support and services for autistic people and their families across the country, in particular for the inquiries she led as Chair of the APPGA. The findings from the 2017 inquiry into the education system contributed to our decision to extend the autism strategy for the first time to children and young people. Furthermore, the 2019 inquiry into the impact of the Autism Act ten years on from its enactment has been vital in the development of this new strategy. We will all remember and are deeply grateful for Dame Cheryl's perseverance, drive and contributions to improving the lives of autistic people and their families across the country.

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Mdry bord.

### Joint Ministerial foreword

The introduction of the Autism Act 2009 was ground-breaking because it was the first disability-specific piece of legislation in England. Over the decade since its inception, it has resulted in improvements in support for autistic adults across the country, and greater awareness of autism in society. However, we know that more still needs to be done to improve autistic people's lives.

Before the Autism Act, autism was often misunderstood by the public and professionals, and too many autistic people faced significant barriers to living full and rewarding lives in the community. It was clear that action was needed to improve services and support for autistic adults and their families, and to improve society's awareness of autism. The first 2 strategies, published in 2010 and 2014, set out actions to this end and, since then, we have been able to make significant headway in tackling the inequalities people face over the last ten years.

Working together with the National Health Service (NHS) and Local Authorities at both the national and local level, we have been able to increase the availability of autism diagnostic services across the country, with a 2018 survey of Local Authorities on the implementation of the autism strategy showing that all areas now have these services.

This means that more autistic people can access a diagnosis that is often vital in unlocking the right services, support and adjustments they need to live a healthy and full life. In 2019, we included autism as one of the priorities in the NHS Long Term Plan, in recognition of the work that needs to be done to improve autistic people's access to healthcare. Delivering on the NHS Long Term Plan's commitments will enable autistic people to live healthier lives.

Moreover, we have been able to transform society's awareness of autism, as an estimated 99.5% of the public have heard of autism according to the National Autistic Society (<u>The Autism Act, Ten Years On</u>), which is so important in autistic people being able to feel included as part of their community.

While we have made these important improvements, there is still much more to do to ensure that autistic people across the country have equal opportunities to the rest of society, access to the services they need to have good health and wellbeing and to participate fully in their communities.

In 2021, too many autistic people still face long waits for their diagnosis – and do not always receive support that is tailored to their needs at an early enough stage. Far too many autistic people still struggle in childhood, both with getting a diagnosis and with support following a diagnosis, including at school, and find it hard to get a job when they reach adulthood.

Since the last autism strategy was published, new challenges have also emerged for autistic people, as has our understanding of the barriers people face across their lives. We have seen the number of people identified as being autistic in inpatient mental health services increase, and now know more about the scale of the life expectancy gap for autistic people, which is we know is approximately 16 years compared to the general population.

In addition, we know the COVID-19 pandemic has had a significant impact on autistic people and their families' lives. We commissioned research on the impact of the pandemic, and have also heard concerning findings from autism charities' <u>Left Stranded</u> report. These reports have shown that the pandemic exacerbated many of the inequalities autistic people already faced, like loneliness, anxiety and exclusion from public spaces, as well as creating new challenges like problems with shopping for food and understanding social distancing measures. The pandemic also risks making it harder for autistic people to get into work due to wider challenges in the labour market.

We will work in collaboration across government, with autistic people and their families, the NHS, local government, and the voluntary sector, to implement the strategy, starting with the actions in our implementation plan for 2021 to 2022.

Over the next 5 years, we want to create a society that truly understands and includes autistic people in all aspects of life; one in which autistic people of all ages, backgrounds and across the country have equal opportunities to play a full part in their communities and to have better access to the services they need throughout their lives. This is our vision to make life fundamentally better for autistic people, their families and carers by 2026 and we are determined to make it happen.



Helen Whately MP, Minister of State for Social Care





Vicky Ford MP, Parliamentary Under-Secretary of State for Children and Families

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## Chapter 1 : introduction

#### About autism

Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. With an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population – most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (<u>National Autistic Society</u>).

Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. While autism is not a learning disability, around 4 in 10 autistic people have a learning disability (<u>Autistica</u>).

Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. People may need help with a range of things, from forming friendships, coping at school, managing at work, or being able to get out and about in the community. In this strategy, we also talk about neurodiversity, which refers to the different ways the brain can work and interpret information. It is estimated that around 1 in 10 people across the UK are neurodivergent, meaning that the brain functions, learns and processes information differently (Embracing Complexity Coalition, 2019).

#### Why a new autism strategy is needed

This document is the government's refreshed national strategy for improving the lives of autistic people and their families and carers in England. It builds on and replaces the preceding adult autism strategy Think Autism, which was published in April 2014 and related to adults. It extends the scope of the strategy to children and young people for the first time, in recognition of the importance of ensuring that they are diagnosed and receive the right support as early as possible and across their lifetime. The strategy and its underpinning implementation plan are issued pursuant to the Secretary of State for Health and Social Care's powers under section 1 of the Autism Act 2009.

The Autism Act (2009), which only applies to adults, was enacted over ten years ago with the aim of addressing the multiple social disadvantages and health and care inequalities autistic adults faced. Since then, we have published 2 adult autism strategies, which have resulted in greater awareness of autism across society and significant improvements in the priority placed on autism across government.

This new strategy aligns with the existing statutory guidance on implementing the Autism Act for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015). This sets out Local Authorities' and NHS organisations' duties to support autistic adults and remains in force, which means that local systems should continue to deliver on existing requirements, including having active Autism Partnership Boards in local areas. This guidance will be reviewed in subsequent years of the strategy, to ensure it aligns with actions we take in implementation plans for years 2 and beyond. Meanwhile, for children, the Special Educational Needs and Disability (SEND) Code of Practice (2015), continues to place duties on Local Authorities, NHS organisations and schools in respect of autistic children and young people.

In 2019, we committed to a review of the existing autism strategy Think Autism to ensure it is still fit for purpose. We launched a <u>public call for evidence</u> on 14 March 2019, involving autistic people, their families and carers, professionals and voluntary organisations. This call for evidence, published alongside this strategy, received 2,700 responses and has shaped our understanding of the issues autistic people and their families face across their lives. This, as well as the findings from the APPGA inquiry into the Autism Act, has shaped the focus and actions we are taking in this strategy. This strategy aligns with wider government work underway, for example the National Disability Strategy, which will also impact on autistic people and their families. We will ensure issues relevant to autistic people are considered as part of these programmes of work.

#### Impact of the COVID-19 pandemic

This strategy takes into account the impact of the COVID-19 pandemic on autistic people and their families' lives, as we know this has been very challenging for many. In summer 2020, we commissioned the Policy Innovation and Evaluation Research Unit (London School of Economics) to undertake rapid research to improve our understanding of autistic people's experiences during this time, and our ability to respond appropriately. The final report from this rapid research is published alongside this strategy.

The research showed that the COVID-19 pandemic has exacerbated challenges many autistic people already faced, such as loneliness and social isolation, and anxiety. While reasons for this vary, the research found that many autistic people have struggled with understanding restrictions and practicing infection control measures. In addition, the pandemic has created new issues for autistic people, for example in being able to shop at supermarkets due to new social distancing measures. At the same time, the research also showed the benefits of lockdowns for some autistic people, who have been better able to engage in virtual spaces, have felt less societal pressure and have been able to avoid anxiety-inducing activities like using public transport. This has also provided learning about what works for autistic people as we move out of the pandemic.

Findings from this research have enabled us to take action to protect autistic children and young people, adults and their families from being disproportionately affected by the pandemic across the areas that affect their lives. We have put in place specific exemptions for autistic people where restrictions have adversely impacted them, for example enabling people to leave their homes more than once a day and putting in place exemptions on face covering rules. To prevent autistic people from becoming more lonely and isolated, they have been able to access support groups during lockdown. In total since the start of the pandemic, over £34 million of the £750 million VCSE funding package has gone

specifically towards reducing loneliness. Moreover, we have provided £1.6 million to charities supporting autistic people and people with a learning disability to enable them to provide virtual peer support and boost helpline capacity.

In addition, we have taken wider actions that have also supported autistic people during the COVID-19 pandemic across education, health and social care. Throughout the pandemic, children and young people who are vulnerable, including anyone with an Education Health and Care (EHC) plan, have been able to attend school as normal. In February, we also announced an additional £700 million for schools and providers of 16-19 education to support students during the pandemic. We have also provided over £1.3 billion of specific adult social care sector funding through the Infection Control Fund during the pandemic, and provided £500 million of funding to support the Mental Health and Wellbeing Recovery Action Plan in March 2020. This plan includes £31 million specifically for autistic people and people with a learning disability.

This research, as well as autism charities' <u>Left Stranded</u> report, have informed our focus for this new strategy, and particularly the actions we are taking in the first year. For example, the pandemic highlighted gaps in data relating to autistic people and reinforced the need to improve collection and reporting across health and social care, as well as other areas. That is why we are committing to develop a cross-government action plan on improving data in the first year of the strategy.

#### Approach to this strategy

Based on our understanding of the challenges faced by autistic people and, informed by their experiences of the COVID-19 pandemic, we are setting out in chapter 2 our vision for the next 5 years. This depicts the changes we want to make across 6 areas that would have a significant impact on autistic people's lives, and the approach we are taking towards delivering on this in 2021 to 2022. We will ensure that progress towards our vision can be measured and evaluated in each of these areas. The 6 themes are as follows and form the basis of chapters 3 to 8:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

We are clear that in some areas work will only begin after the first year (2021 to 2022), and in many there will need to be additional actions in the subsequent years of the strategy to fully realise our vision. In some areas work is still in early stages or ongoing so we will wait on findings or further progress before we take action. This includes the National Autistic Society's research on developing a tailored Improving Access to Psychological Therapies (IAPT) model and the development of Oliver McGowan Mandatory Training for health and care professionals. Once developed, this can be adapted to other public servants, including the police or housing officers. In other areas like employment, we have work underway to improve support for autistic people but will monitor the full impact of the pandemic to ensure we are continuing to take the right actions.

In chapter 9, we set out the enablers we will need to work on in the first year to drive forward progress on the actions in this strategy. This includes improving autism data collection and reporting across government, which will be important in determining our progress towards our vision for 2026. In addition, we are committing to improve research on the barriers people face and the interventions that work for autistic people. The implementation plan (Annex A) sets out the actions we will take within the first year of the strategy. The actions we commit to will lay the foundations for what we aim to achieve over the course of the next 5 years. We will refresh this plan for subsequent years, in line with future Spending Review rounds.

To succeed in improving autistic people's and their families' lives we will need to work collaboratively to implement these actions across national and local government, the NHS, the education system, the criminal and youth justice systems, and with autistic people and their families. We will refresh our national governance arrangements to ensure government, delivery partners and other organisations responsible for implementing actions set out in the implementation plan are held to account on progress.

# Chapter 2 : our roadmap for the next 5 years

#### How we will make our vision a reality

Below, we set out our vision for what we want autistic people and their families' lives to be like in 2026 across 6 priority areas, and the steps we as national and local government, the NHS and others will take towards this within the first year of our implementation plan (2021 to 2022). We will refresh this implementation plan for subsequent years of the strategy, setting out further actions we will take across government, working in partnership with Local Authorities, the NHS and the voluntary sector, as well as autistic people, to enable us to move closer towards our vision.

We will set measures of success for each of the priority areas in the strategy to make sure we can effectively monitor progress in year one and beyond, being clear about what we expect to achieve by 2026. This is important in knowing and demonstrating that we are making a difference to autistic people and their families' lives. the end of this strategy, we want life to be fundamentally better for autistic people, their families and carers. We want to be able to demonstrate that we have transformed autistic people and their families' lives by:

**Improving understanding and acceptance of autism within society:** we will significantly improve the public's understanding and acceptance of autism, and show that autistic people feel more included and accepted in their communities. We also want the public to understand how autism can affect people differently, including the difference in how autistic women and girls present, and to help change people's behaviour towards autistic people and their families. We want many more businesses, public sector services and different parts of the transport system to become more autism-inclusive, so that autistic people can access these spaces and services, just like everyone else.

Improving autistic children and young people's access to education and supporting positive transitions into adulthood: we want the Special Educational Needs and Disability (SEND) system to enable autistic children and young people to access the right support, within and outside of school. We want schools to provide better support to autistic children and young people, so they are able to reach their potential, and to show that fewer autistic children are permanently excluded or suspended from school due to their behaviour. We will make improvements to the support autistic people get in their transitions into adulthood, so that more autistic people can live well in their own communities, find work or higher education or other opportunities. This is important in preventing more young people from avoidably reaching crisis point or being admitted into inpatient mental health services.

**Supporting more autistic people into employment:** we will make progress on closing the employment gap for autistic people, ensuring that more people who are able and want to work can do so and that those who have found a job are less likely to fall out of work. We want more employers to be confident in hiring and supporting autistic people, and to improve autistic people's experiences of being in work.

Tackling health and care inequalities for autistic people: we want to reduce the health and care inequalities that autistic people face throughout their lives, and to show that autistic people are living healthier and longer lives. In addition, we want to have made significant progress on improving early identification, reducing diagnosis waiting times and improving diagnostic pathways for children and adults, so autistic people can access a timely diagnosis and the support they may need across their lives.

Building the right support in the community and supporting people in inpatient care: we will achieve the targets set out in the NHS Long Term Plan to reduce the number of autistic people and people with a learning disability being admitted into inpatient mental health services. We will do so by improving the treatment of autistic people in mental health legislation to prevent people from being avoidably admitted to inpatient care and improving the provision of community mental health and crisis support. We will also improve the suitability and availability of housing support and social care. In addition, for people who do need to be in inpatient mental health settings, the quality of care will be better and more tailored to their individual needs and people will be discharged back into their communities as soon as they are well enough to leave.

**Improving support within the criminal and youth justice systems:** we will build a clearer understanding of how autistic people come into contact with the criminal and youth justice systems, and the type of support they may need across court, prison and under probation supervision. We will improve the police and wider criminal and youth justice system staff's understanding of autism so that autistic people are more able to receive the right support, adjusted to their needs, as well as ensuring that different parts of the justice system – from prisons to courts – become more autism-inclusive.

# Chapter 3 : improving understanding and acceptance of autism within society

#### Our vision

By 2026, we want to demonstrate that we have significantly improved public understanding and acceptance of autism, and that autistic people feel more included in their communities and less lonely and/or isolated. We want the public to have a better understanding of autism and to have changed their behaviour towards autistic people and their families.

By the end of the strategy, we want many more organisations, businesses and public sector services to have become autism-inclusive, so that autistic people can engage in their communities, just like everyone else. This will mean taking part in initiatives like Autism Hour, the Autism Friendly Award or taking other steps to become more autism-aware. In 5 years' time, we want to show that autistic people feel more able to take part in their communities than they do today, including feeling more comfortable using public transport.

Since the inception of the Autism Act (2009), awareness of autism has increased substantially, with the National Autistic Society (NAS) estimating that 99.5% of the public are now aware of autism. There are many reasons for this, including increasing representation of autism in public life and the media, as well as the Autism Act itself, as this raised the profile of autism both locally and at a national level. While this is an important change, evidence from the APPGA's <u>The Autism Act, 10 Years On</u> report found that there is still a significant lack of understanding about autism amongst the public, including what it means to be autistic and the diversity of the autistic community. The APPG report highlighted that just 24% of autistic adults and 26% of family members think public understanding has improved since the introduction of the Act.

Over the last few years, we have seen many public sector services and organisations taking steps to become autism-inclusive, with many becoming autism-accredited or taking other steps to improve how they support autistic people. However, we know that many autistic people still feel excluded from public spaces and civil society because these can be overwhelming, busy or noisy and because staff or the public may react negatively to autistic people's behaviour or support needs. Even before the COVID-19 pandemic autistic adults reported higher levels of loneliness than the general public. Evidence from the LSE research we commissioned into the impact of the pandemic has shown that autistic people may be at risk of further exclusion, due to the challenges many have faced with social distancing restrictions and changes to support networks. This has affected their confidence

with getting out into their communities. The <u>NAS Left Stranded</u> report found that compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July 2020.

Transport is a key enabler to autistic people and their families being included in their communities and being able to find employment, but anecdotal evidence tells us that many find this inaccessible because of how anxiety-inducing noisy and busy environments can be. Many autistic people also struggle with unanticipated changes to their journeys, including cancellations and delays. We need to do more to make transport accessible to autistic people as this is important in improving inclusion. Doing so is even more important in light of the COVID-19 pandemic, as many autistic people will feel even more anxious about getting back on public transport – in particular due to changes to the system put in place to prevent the spread of COVID-19.

#### How we will work towards this in 2021/2022

#### Improving public understanding of autism and inclusion across the public sector

We will develop and test an autism public understanding and acceptance initiative, working with autistic people, their families and the voluntary sector. We want this initiative to help the public adapt their behaviour towards autistic people and recognise the diversity of the autistic community; that every autistic person is different. This includes improving understanding of the strengths and positives of being autistic, as well as the challenges people might face in their daily lives and how distressed behaviour can manifest itself. We will also ensure this covers the diversity of the autistic community, including the presentation of autism in women and girls, the LGBT community and autistic people from ethnic minority groups.

As government, we will lead the way in becoming more inclusive to autistic people and will improve Ministers' and policy makers' understanding of autism. We will do so by encouraging Ministers across Departments to undertake the APPGA's <u>Understanding</u> <u>Autism sessions</u>, and increasing recognition and representation of neurodiversity across government Departments. To raise the profile of neurodiversity including autism, across the Civil Service we will encourage the establishment of a neurodiversity priority for Disability and Inclusion Champions within government Departments. These champions, who are senior civil servants, will increase awareness of neurodiversity and engage with neurodivergent staff through staff networks to ensure their needs are being considered and heard.

We will also review cross-Civil Service learning and development to ensure that neurodiversity is an integral part of courses, to enable managers to recruit and support neurodivergent employees. Furthermore, the Ministry of Justice (MoJ) continues to work towards the Autism Friendly Award at the MoJ headquarters, to improve accessibility and support for autistic visitors and staff. The MoJ will share learning with other government departments.

#### Making transport and communities more autism-inclusive

We are taking a number of steps to improve the accessibility of transport for autistic people as we move out of the COVID-19 pandemic. In July 2018, we published the <u>Inclusive</u>

<u>Transport Strategy</u>, as part of our ambition to ensure equal access for disabled people, including autistic people, using the transport system by 2030. As part of this, in December 2020, we launched our <u>disability equality training</u> for transport operators, which is vital in enabling them to understand the types of adjustments people might need.

In addition, we resumed our <u>'it's everyone's journey'</u> campaign on the 25 May 2021, which is aimed at helping the public to be more mindful of passengers, including those who are autistic, and the challenges they may face when using transport. As we move out of restrictions, we will support disabled people returning to the transport system by ensuring that rules around face covering exemptions are well understood, that the decision to carry an exemptions card is entirely a matter for individuals, and that people should be supported not to feel uncomfortable or intimidated where they do not wear a face covering, or are unable to socially distance.

We want to encourage businesses and organisations across the country to take steps to become more autism friendly as this is important in tackling exclusion, loneliness and social isolation. In this first year and, as we move out of COVID-19 restrictions, we want to enable more autistic people to take part in sports, culture and the arts. For example, Sport England's new strategy, launched in January 2021, is working to enable more people, including autistic people, to be physically active. They are working to tackle the inequalities and barriers that exist within sport and physical activity, and to unlock the benefits of being active for everyone, regardless of background or ability. As part of this effort, Sport England will be working with key partners to engage more autistic people at all levels and in all forms of sport and physical activity, including across volunteering and coaching. In addition, we are ensuring that organisations in arts, heritage and culture increase participation and take steps to make their environments more accessible, including for autistic people.

#### Our commitments in the first year

In the first year, our key commitments will be to:

- develop and test an autism public understanding and acceptance initiative, working with autistic people and their families, and the voluntary sector
- continue to promote our disability equality training package for transport operators
- resume the 'it's everyone's journey' campaign to create a more inclusive and supportive public transport environment for disabled people

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

# Chapter 4 : improving autistic children and young people's access to education, and supporting positive transitions into adulthood

Our vision

By 2026, we want the SEND system to enable autistic children and young people to access the right support, both within and outside of education settings. By the end of this strategy, we want transitions into adulthood to improve, so that more autistic young people are able to live well in their communities, find work or higher education opportunities. We want these improved transitions to result in fewer mental health crises and admissions into inpatient care.

We want education settings to provide better and more inclusive support to autistic children and young people so that autistic people are better able to achieve their potential. We want more teachers and educational staff to understand the specific needs of their autistic pupils, ensuring that more school placements can be sustained. We also want to demonstrate that more autistic children have had their needs identified early on and that they are having positive experiences in education settings.

A growing number of children and young people are being diagnosed as autistic, with <u>Special Educational Needs data</u> suggesting that 1.8% of all pupils in England now have an autism diagnosis. In spite of this, we know that many autistic children and young people are still having poor experiences within school, are not reaching their potential and are struggling in the transition to adult life. The <u>APPGA's The Autism Act</u>, <u>10 Years On</u> report showed that autistic children and young people often find it difficult to get the help they need at school due to poor understanding of autism amongst education staff. It also highlighted that less than 5 in 10 were confident about supporting autistic children and young people, and this can result in missed opportunities to help children reach their potential or prevent children's needs or distressed behaviour from escalating.

Many autistic children find school environments overwhelming and evidence from the APPGA shows they often feel misunderstood or judged by their peers because of their behaviour, which can impact their ability to engage and succeed in education. In addition, the research highlighted that autistic children and young people often struggle to get

support they need through the Special Educational Needs and Disability (SEND) system more generally, including being able to access support early enough from health and social care, as well as education. We also know that many autistic young people find transitions into adulthood difficult because this is a period of heightened uncertainty and can result in changing access to services and support. Evidence from the APPGA's <u>Autism and Education in England in 2017</u> report points to staff often lacking the skills needed to put in place the right plans and support for autistic young people, which can result in them missing out on opportunities. In addition, we know that many autistic children may benefit from support to get into higher education or find employment opportunities as they become adults but struggle to access this.

#### How we will work towards this in 2021/2022

### Improving educational professionals' understanding of autism and inclusive cultures within schools

We are taking a number of steps to improve understanding of autism amongst educational professionals, including providing £600,000 of funding for staff autism training and professional development in schools and colleges. We will work with our training partners to develop materials and resources and will consider the issue of identification and support for autistic girls within this. In addition, we will embed autism as a priority for educational leadership as this is important in developing autism-inclusive cultures and we will share good autism practice within education settings, focusing on mainstream schools. This will encourage the provision of early support for autistic children and young people, setting out the benefits of this in preventing escalation of needs, sustaining school placements and ensuring more autistic children and young people can achieve their potential.

We want schools to become more inclusive to those with protected characteristics, including autistic children and young people, which is why we will launch a new antibullying programme. This will be important in making schools more welcoming and understanding, improving autistic children's experiences of education as well as their ability to succeed. We expect this new programme to begin in September 2021. In recognition of the role that mental health can play in determining children and young people's experiences in schools, we are also putting in place new Mental Health Support Teams and training for Designated Senior Mental Health Leads within schools, which will also benefit autistic pupils who are more likely to experience poor mental health. We are aiming to start rolling this training out in the next academic year 2021 to 2022.

More broadly, we have worked with experts in SEND and organisations to develop a qualification for early years staff who want to specialise in SEND. In light of the COVID-19 pandemic we have broadened our funding for the voluntary sector to support parent and child mental health and wellbeing, to help early years providers identify SEN and catch up children who may be falling behind, including autistic children.

#### Improving how the SEND system supports autistic children and young people

We want to improve how the SEND system works for children with SEN, including autistic children and young people, and their families. This will include putting forward proposals to improve early identification of children and young people's needs, and making sure that the health, social care and education systems work together to support children holistically

before their needs escalate. We will be putting forward proposals to improve the system in the SEND review, which we will publish as soon as possible.

It is important that autistic children, as well as other children with SEN, get the right school placement, and some will need special school provision to reach their potential. To this end, we have committed to opening 37 new special free schools across the country, of which 24 have provision specifically for autistic children and young people. We will move forward with plans to open these schools, which are expected to start operating from September 2022. This will enable more children to get the right school placement closer to home.

We want the right services to be available for children and young people with SEN and their families in the community, including those who are autistic. To improve the availability of these services we will promote guidance on planning and commissioning provision for autistic children and young people as outlined in chapter 6. We will also improve the engagement of families and children and young people in planning SEND services and policies at the local level, as we know this makes a difference in meeting people's needs. To this end, we are providing a further £8.6 million to facilitate engagement, including supporting up to 152 Parent Carer Forums, to strengthen the engagement of parents and young people in the SEND system.

#### Supporting positive transitions into adulthood

To improve transitions into adulthood, we will continue our work to ensure education staff have the skills required to support autistic young people during this time. That is why we are including transitions as a topic within our programme of school and college workforce training and development on SEND. As part of this work, we are ensuring that preparation for adulthood is discussed much earlier in young people's school careers to ensure that they are given appropriate information, advice and guidance.

Some autistic young people need support to get into employment, and we want to ensure more people can get this. That is why we are strengthening and promoting pathways to employment, such as Supported Internships, traineeships and apprenticeships. To make this happen, we are working to support all local areas to develop Supported Employment Forums bringing together employers, Jobcentres, education providers, Local Authorities, young people and their parents to discuss employment opportunities for young people with SEND in their local areas. These forums will focus local skills provision on local employment needs, publicise opportunities for young people with SEND, including to employers, and create work placement opportunities for autistic young people.

We also want to build on our success in increasing the representation of disabled people, including autistic people, in apprenticeships – ensuring that disabled people not only access apprenticeships, but go on to succeed in their apprenticeship. We will do this by engaging with employers, providers, apprentices and the disability sector to determine what works and how best to disseminate this.

### Continuing to support autistic children and young people during the COVID-19 pandemic

We will take action to support children with SEND, including autistic children and young people in schools, as we move out of COVID-19 restrictions over the academic year 2021

to 2022. So far, we have published a range of guidance to support remote education, including specific support for children and young people with SEND. We recognise that some autistic children and young people have benefitted from access to remote learning which can be personalised and accessed flexibly and we will continue to personalise support for individuals as we move into recovery. We have also provided a hub of guidance and resources for families, teachers and other professionals aimed at supporting autistic children and young people during COVID-19.

#### Our commitments in the first year

In the first year, our key commitments will be to:

- improve understanding of autism amongst educational professionals by continuing to provide funding for autism training and professional development in schools and colleges in 2021 to 2022
- publish and consult on the SEND review as soon as possible
- carry out a new anti-bullying programme in schools, to improve the wellbeing of children and young people in schools, including those who are autistic
- provide a further £8.6 million funding in 2021 to strengthen the participation of parents and young people – including those who are autistic in the design of SEND policies and services and ensure that they are able to access high quality information, advice and support
- take action to strengthen and promote pathways to employment, such as Supported Internships, Traineeships and apprenticeships, and work to support all local areas to develop Supported Employment Forums

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

# Chapter 5 : supporting more autistic people into employment

#### Our vision

By 2026, we want data to show that we have made progress on closing the employment gap for autistic people, drawing on the Labour Force Survey. We want more autistic people who can and want to work to do so, and to ensure that those who have found a job are less likely to fall out of work. We also want to show that employers have become more confident in hiring and supporting autistic people, and that autistic people's experience of being in work has improved.

By the end of the strategy, we will have improved the support autistic people can access to find and stay in work. This includes making sure that existing services and work programmes are more autism-inclusive and better able to help autistic people find the right employment opportunity for them. In addition, we will have improved welfare support for autistic people who are unable to work, so they can get the support they need to live well in their communities.

Evidence shows that there is currently a significant employment gap for autistic people. Data published by the Office of National Statistics for the first time in February 2021 shows that as of December 2020, 22% of autistic people aged 16 to 64 are in employment, in contrast to 52% of disabled people, and 81% of non-disabled people. The <u>The Autism Act</u>, <u>Ten Years On</u> report found that there are many factors contributing to the scale of this gap, including struggling to get a job because of recruitment processes not being autism-friendly or difficulty accessing the support people might need to get into work or while in work.

Employer awareness plays a crucial role in addressing many of these issues, both in enabling them to make the right adjustments to recruitment practices or identifying the adjustments their employees might need. A YouGov poll by the National Autistic Society in 2019 has shown improvements in employer awareness of autism, as well as confidence in recruiting autistic people (<u>The Autism Act, 10 Years On</u>, 2019). However, there is still more to do as 31% of employers surveyed said autistic employees would require too much support, and many reported needing more advice on how to support people. The COVID-19 pandemic may also cause further difficulty for autistic people trying to find work, given the considerable pressures on the labour market as a whole in the short-term. Some autistic people will have lost their jobs, while others are finding it even more difficult to get into work due to the increased competition for roles. To prevent the gap from widening

further due to the pandemic, we will consider autistic people's specific needs as we take wider actions to protect jobs and put in place support to get people into work.

Some autistic people will require help to get into work, for example from Jobcentres. However, the <u>The Autism Act, Ten Years On</u> report suggests many struggle to get the right support because they feel Jobcentre staff do not understand their needs or the adaptations they need to make to engage with autistic people. Some also feel the environment can be anxiety-inducing or distressing. Others are not able to work and need support from the welfare system in order to live healthy and independent lives, but struggle to access this because they feel health assessors may not understand autistic people's needs, or because they find the assessments process difficult to engage with.

#### How we will work towards this in 2021/2022

In the first year of the strategy, we will drive improved employer awareness of autism, so they better understand the benefits of employing autistic people and are able to make the adjustments needed to recruit and properly support them. We will also continue to promote better access to employment support programmes for autistic people and move forward with our plans to improve the benefits system for disabled people to ensure this better supports autistic people who are unable to work.

As we move out of COVID-19 restrictions, we will also continue our efforts to make Jobcentres more autism-inclusive, to ensure autistic people receive the help they need to move into employment or employment programmes. More broadly, supporting disabled people, including autistic people, will be a focus of our approach to labour market recovery as we come out of the COVID-19 pandemic. This is vital in protecting autistic people from being disproportionately affected and preventing the employment gap from widening further in a challenging context.

#### Improving employment support and the welfare system

To improve employer confidence, we will continue to engage with employers through the Disability Confident Scheme. This provides advice and support to employers, and to promote the skills, talents and abilities of autistic people, as well as other disabled people. In recognition of the specific need to improve employer understanding of autism, we are currently holding webinars focused specifically on supporting autistic people in the workplace. We will also shortly publish the response to the <u>Health is Everyone's Business</u> consultation, which looked at ways to support disabled people and people with long term health conditions at work. This response will discuss employer needs, including information and advice on health and disability that is easier to find and act upon, with design work this year to develop an improved support offer for employers.

In addition, we want to ensure that autistic people can get the adaptations or extra support they need while in work, or to get into work. As government, we will lead the way in becoming a more autism-inclusive employer by expanding our Autism Exchange Internship Programme, which is aimed at providing more autistic people with experience of working in the Civil Service. We will also begin to collect data on the number of autistic people working in our Departments to understand further improvements we may need to make to recruit and support autistic people. We will continue to promote the Access to Work scheme, which provides a range of practical and financial support to disabled people, including autistic people. During the COVID-19 pandemic, this has been extended to ensuring those who are working from home can access equipment and support they need and will continue in the first year of this strategy. To enable those who need more intensive support to get into work, we will continue to ensure that the Intensive Personalised Employment Support Programme (IPES) is open to autistic people who qualify. IPES provides personalised packages of employment support for people who are at least a year away from moving into work. People on the scheme have a dedicated key worker to help them overcome barriers that may be preventing them from entering work, and participants receive up to 15 months of flexible pre-employment support.

As COVID-19 restrictions ease, we will be able to continue making our Jobcentre network more welcoming and supportive to autistic customers. We will continue to upskill staff and increase the number of Disability Employment Advisors to support our Work Coaches. We are also looking at ways of adapting physical spaces and ways of working to better support autistic people. We will be taking this forward through our Health Model Offices, which are Jobcentres that provide more intensive support to disabled people and test innovative approaches to disability employment support. In addition, we will continue to promote the Autism Centre for Research on Employment's (ACRE) free Autism Employment Profiling Service, which went live in October 2020 and enables Jobcentres to signpost and provide appropriate support to autistic people without a learning disability.

We also want to ensure that autistic people who are unable to work can access the benefits and support they might need. The Department for Work and Pensions' (DWP) forthcoming Health and Disability Support Green Paper will consider how the welfare system can better meet the needs of disabled people, including autistic people, and how the DWP can improve the service it provides. Once published, this Green Paper will be subject to a 12 week consultation.

## Including autistic people in plans for restoration and recovery from the COVID-19 pandemic

In September 2020, we published our Plan for Jobs to protect, support and create jobs during the COVID-19 pandemic. In this plan, we outlined a number of actions that will also benefit autistic people, including increasing the number of Work Coaches, who provide help to people who are newly unemployed and making sure that Jobcentres continue to be open to help customers who really need face-to-face support. We will continue to review how our provision meets the needs of autistic people as we move out of the COVID-19 pandemic, and tailor our response based on this. In addition, we will continue to ensure that job programmes are accessible to autistic candidates.

#### Our commitments in the first year

In the first year, our key commitments will be to:

• continue our work to ensure our Jobcentre network is welcoming and supportive to autistic customers, developing and testing new approaches through our Health Model Offices.

- continue to ensure that through the Disability Confident Scheme, we promote the skills and abilities of autistic people, and signpost employers to resources on supporting autistic people
- continue to promote employment support programmes, including Access to Work and IPES to autistic people who are at least a year away from work
- continue to recognise the specific needs of autistic people during the COVID-19 pandemic, and take appropriate action to mitigate a disproportionate impact on autistic people

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

# Chapter 6 : tackling health and care inequalities for autistic people

#### Our vision

By 2026, we will have made headway on reducing the health and care inequalities autistic people face, and show that autistic people are living healthier lives. This includes evidencing that we are making progress on improving autistic people's health outcomes and reducing the gap in life expectancy.

By the end of the strategy, we will have made demonstrable progress on reducing diagnosis waiting times and improving diagnostic pathways for children, young people and adults across the country. Autistic people will be able to access a high quality and timely diagnosis, as well as the support they need following diagnosis. We will have also made progress on improving early identification of autism, so more children and young people can get the support they need at an early age.

Receiving a timely autism diagnosis is vital in getting the right support and helping autistic people and those supporting them to better understand their needs. While many more adults are receiving a diagnosis than when the first autism strategy was published over ten years ago (Autism Self-Assessment Exercise), too many people are still waiting longer than the National Institute for Health and Care Excellence (NICE) recommended 13 weeks between referral and first assessment. Autism Waiting Times statistics, which are still experimental, indicate that many wait longer than the recommended 13 weeks.

There are several factors contributing to these long waits, including increasing demand on services due to growing public awareness of autism, which has resulted in increased referrals and more people on waiting lists. This has been further impacted by the COVID-19 pandemic, which has resulted in some local systems pausing or delaying assessments. Furthermore, we know there are often blockages within diagnostic pathways, both due to the diagnostic models used and pressures on the workforce, which can result in longer waits. It is widely recognised that children and young people should be identified as autistic as early on in life as possible, as this is important in ensuring children have the right support in school and as they transition into adulthood. However, evidence from the National Autistic Society shows that many, in particular girls, are not diagnosed until adolescence or adulthood because the signs are not recognised.

Autistica's <u>Happier</u>, <u>Healthier</u>, <u>Longer Lives</u> briefings have identified that autistic people have poorer physical health outcomes and a lower life expectancy than the general population. The available evidence indicates that autistic people die on average 16 years earlier than the general population (Premature Mortality in Autism Spectrum Disorder, The British Journal of Psychiatry, 2016). There are many possible reasons for this gap, including poor professional understanding of autism amongst health and care staff, which can result in autistic people having signs of illness or their needs overlooked. Without the right understanding, autistic people can miss out on adjustments needed for them to engage in medical appointments, which often leads to distressing experiences, avoiding seeking medical attention or losing out on support.

#### How we will work towards this in 2021/2022

We will work towards our vision by tackling long diagnosis waiting times for children and young people, as well as adults. In 2021 to 2022, funding will help regions to begin innovating and improving the quality of diagnostic pathways and post-diagnostic support. This will enable us to find ways of addressing backlogs from the pandemic and proactively identify children and young people who are on waiting lists and are at risk of falling into crisis. To enable autistic children and young people to get support they need earlier on in life and prevent needs from escalating, we will fund the significant expansion of a pilot developed in Bradford. This involves healthcare and education staff working together to assess children who may be autistic in schools.

To tackle the health and care inequalities autistic people face, we will take actions in the first year to improve health and care staff understanding of autism. Subject to evaluation, we will move forward with our commitment to develop Oliver McGowan Mandatory Training for all health and care staff and will improve commissioners' and social workers' capability so they develop the right services and provide the support autistic people need. To improve autistic people's health outcomes, we will also move forward with our NHS Long Term Plan commitments and develop a better understanding of autistic people's experiences of healthcare. We will improve professionals' ability to identify autistic people across the health service so they can make necessary adjustments and develop programmes intended to improve autistic people's physical health, such as trialling autism health checks.

#### Improving early identification and reducing autism diagnosis waiting times

We are investing £13 million to begin reducing diagnosis waiting times for children and young people, as well as adults, in line with the <u>NHS Long Term Plan</u> and the <u>Mental Health and Wellbeing Recovery Action Plan</u>. This funding will enable local systems to test different diagnostic pathways and post-diagnostic pathways, as well as explore ways to reduce diagnosis waiting times and address backlogs of people waiting for assessments made worse by the pandemic. The NHS England and Improvement (NHSE/I)-funded Realist Evaluation of Autism Service Delivery, will also continue to identify autism diagnostic pathways that work best for children so we can share learning across the country as part of our evaluation.

We want to prevent children and young people from reaching crisis point while they are waiting for an autism diagnosis and stop them from being avoidably admitted into inpatient mental health settings. To help achieve this, we are investing £3.5 million of the £13 million to enable local systems to begin proactively identifying children and young people on waiting lists (as well as those on waiting lists for mental health support) who might be at risk of crisis so they can get the support they need.

Early identification can play an important role in enabling children and young people to get timely support, which is crucial in preventing escalation of needs. That is why we are going to significantly expand a school-based identification programme based on a pilot in Bradford from 10 to over 100 schools over the next 3 years. This involves health and education staff working together in schools to assess children suspected to be autistic. Early findings from the pilot are positive, with children being identified and getting support earlier. As part of this work, we are monitoring indicators of prevalence of autism in girls as current assessment and diagnostic approaches identify a higher proportion of boys than girls as autistic. We want to test whether novel approaches can improve identification and will include this within our evaluation of the programme.

To monitor our progress on reducing waiting times, we will continue to collect and improve data on autism diagnosis waiting times and identify areas that are not meeting the NICE-recommended 13 weeks between referral and assessment (<u>Autism waiting times statistics</u>, NHS Digital). In addition, we are developing an action plan with NHSE/I and NHS Digital to enable us to report on diagnostic waiting times for children and young people. Current data on diagnostic waiting times is based on reporting of diagnoses by mental health organisations, while community services where children are usually diagnosed are not reported.

#### Improving health and care professionals' understanding of autism

Improving health and care staff's understanding of autism is crucial in enabling us to make progress on reducing health inequalities for autistic people. In 2021 to 2022, we will continue to trial and develop the <u>Oliver McGowan Mandatory Training</u> in learning disability and autism for all health and adult social care staff across England. This draws on the <u>Core Capabilities Framework for Supporting Autistic People</u>, which sets out the essential capabilities necessary for staff involved in supporting autistic people. The training will provide staff with knowledge they need to provide reasonable adjustments for autistic people, which will play an important role in tackling health and care inequalities and improving autistic people's wellbeing.

Social workers play an important role in identifying the support autistic people need throughout their lives. That is why, in addition to developing Oliver McGowan Mandatory Training, we will publish a Capability Statement for social work with autistic children and their families in line with the existing <u>Capability Statement for Social Work with Autistic</u> <u>Adults</u> to ensure they have the knowledge required to support people throughout their lives. We will also introduce new National Assessment and Accreditation System (NAAS) simulated practice and knowledge assessment materials for social workers working with autistic children.

Commissioners need the right skills and tools to develop services that work for autistic people. To improve their capabilities, the Local Government Association (LGA), Skills for Care and the Association of Directors of Adult Social Services (ADASS) will roll out their qualification for commissioners who work with autistic people and people with a learning disability to a further 120 NHS and Local Authority commissioners. In addition, we commissioned Skills for Care and the National Development Team for Inclusion (NDTi) to develop guidance to help commissioners identify local demand and develop the right services for autistic people. This guide is published alongside the strategy.

To deliver on the commitments set out in the NHS Long Term Plan and the actions in this strategy, we need autism to be prioritised by leadership in local health systems. To this end, we are providing £1.25 million to recruit Champions in autism and learning disability to embed high quality and accessible autism and learning disability services in every Integrated Care System. We also expect that all Integrated Care Boards, which will be established by the proposed Health and Care Bill, will focus on autism and learning disabilities at the highest level, for example by having a named executive lead for autism and learning disability.

#### Reducing the health and care inequalities autistic people face

We want to develop a better understanding of the inequalities autistic people face and the causes for the gap in life expectancy so we can take the right actions to improve people's health outcomes. To do so, NHSE/I's new Learning from Lives and Deaths – People with a Learning Disability and Autistic People programme (LeDeR) will, for the first time, include autistic people. This means that all autistic adults whose deaths are notified to the programme will be able to have a review.

We know autistic people can experience poor health outcomes because signs of illness can be overlooked, or because people may delay seeking medical attention until their needs have escalated. NHSE/I will be trialling a primary care health check for autistic adults in the North East, developed by a <u>research consortium by Newcastle University</u> and funded by Autistica. The aim of this will be to identify autistic people's needs earlier and improve their physical and mental health. To this end, NHSE/I will also resume its pilot of hearing, sight and dental checks for children in special residential schools.

We know that autistic people often need adjustments to their healthcare for this to meet their needs, but that currently professionals cannot always identify that people are autistic or the adjustments they may require. That is why NHSE/I are developing 'digital flags' in patient records so healthcare professionals across the NHS are aware that someone is autistic and can tailor the support they provide accordingly. NHSE/I will work with 12 early adopter sites across regions to test this reasonable adjustment flag this year.

#### Our commitments in the first year

In the first year, our key commitments will be to:

- invest £10.5 million to test and implement the most effective ways to reduce diagnosis waiting times for children and young people, the impact of the COVID-19 pandemic on waiting lists, and proactively identify those who are waiting for an assessment and are at risk of crisis
- invest £2.5 million of funding to improve the quality of adult diagnostic and postdiagnostic pathways, and help to address the impact of the COVID-19 pandemic on waiting lists
- fund an expansion of an early identification pilot programme, which involves health and education professionals working together in schools to assess children who may be autistic or have other SEN
- move forward with existing Long Term Plan commitments on reducing health inequalities, including trialling an autism health check, piloting hearing, sight and

dental checks for children in residential schools and laying the foundation for improved recording of reasonable adjustments in patient records

• continue to trial and develop the Oliver McGowan Mandatory Training on learning disability and autism for all health and adult social care staff

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

# Chapter 7 : building the right support in the community and supporting people in inpatient care

#### Our vision

We will have achieved the targets we set out in the NHS Long Term Plan for reductions in the number of autistic people and people with a learning disability who are mental health inpatients by 2024. We are also seeking to modernise the Mental Health Act and will bring forward changes which would mean that autistic people are only admitted to inpatient mental health settings if absolutely necessary. These changes would mean that autism alone is no longer a lawful basis for ongoing detention in inpatient care and would enable people in inpatient care to be discharged as soon as they are well enough to leave.

By the end of the strategy, we will have also delivered significant improvements to the provision and quality of community support, including social care, mental health and housing support. This will prevent more autistic people from reaching crisis point. For autistic people who really need care in inpatient settings, we want to show this is of high quality, therapeutic and tailored to their needs, and as close to home as possible.

As we set out in the <u>Building the Right Support national plan</u> in March 2015, all autistic people should have the opportunity to participate in their communities amongst friends and family, and live in their own home or with people they choose to live with. We are clear that people should not be in inpatient mental health settings unless absolutely necessary for clinical reasons, and set out our target of a 50% reduction in the number of autistic people and people with a learning disability in these settings by 2023/2024 (compared with March 2015 levels) in the NHS Long Term Plan. Since 2015, we have made progress towards this target, as we have achieved a net decrease in inpatient numbers of 28% as of June 2021 (Assuring Transformation data).

When compared to the decrease in overall inpatient numbers, the data shows that the decrease for people with an autism diagnosis has not been at the same rate. As of the end of June 2021, there are still 1,200 people with an autism diagnosis in these settings (<u>Assuring Transformation</u>, July 2021). There are several reasons for this, including better identification and diagnosis of autism when people are admitted into inpatient care. While we are making progress in discharging people, too many autistic people (particularly adolescents and young adults) are still being admitted into these settings. This is because they often struggle to access community support, including social care, mental health and housing support before their needs escalate. This is not always available at the right time or tailored to their needs. The law also currently allows clinicians to admit autistic people to

inpatient care without them having a clear mental health need, which can result in inappropriate admissions.

For autistic people in inpatient care, we know more needs to be done to improve the quality of support. Many reports have highlighted concerns about poor care and risks of abuse in inpatient care, which we are clear is totally unacceptable. These reports have also set out that for autistic people, inpatient environments can contribute to additional distress and worsening mental health. Inpatient care staff often do not understand autistic people's needs and misinterpret their behaviour, which can lead to use of restraint, seclusion or segregation. The environments themselves can also cause sensory distress as they can be chaotic, noisy and unfamiliar to people.

#### How we will work towards this in 2021/2022

We will drive reductions in the number of autistic people and people with a learning disability in inpatient settings through our Delivery Board for Building the Right Support, which is chaired by the Minister of State for Social Care. The Board brings together representatives from government Departments, NHSE/I, local government and other organisations responsible for delivering on Building the Right Support. The Board, alongside an Advisory Group of people with lived experience, is addressing challenges in making further progress on reducing the number of people in inpatient care including; improving community support and crisis prevention, access to housing and preventing admissions during the transition to adulthood.

We want to prevent autistic people from being avoidably admitted to inpatient care, which is why we are seeking to make legislative changes through the <u>Mental Health Act White</u> <u>Paper</u>. Specifically, we are proposing to change the detention criteria so autistic people can only be admitted if there is a probable mental health need.

As part of the NHS Long Term Plan, we are investing over £40 million in 2021 to 2022 to prevent avoidable admissions and improve community support. This includes £25 million to improve the capacity and capability of 7-day specialist multidisciplinary and crisis support for autistic people and people with a learning disability in every area of the country. In addition, we are providing £15 million of funding to put in place keyworkers for children and young people with complex needs in inpatient mental health settings, as well as those at risk of being admitted to these settings. We will also improve autistic people's access to housing and social care that meets their needs, by increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose.

To speed up discharges, we also established the £62 million <u>Community Discharge Grant</u> to tackle the financial barriers and disincentives to discharging people from inpatient care. This grant provides extra funding to Local Authorities to accelerate discharges and will provide this funding to nominated lead Local Authorities in England for the second of 3 years (£21 million). In addition, we are investing funding as part of the wider £31 million from the <u>COVID-19 Mental Health and Wellbeing Recovery Action Plan</u> to address the additional pressure caused by the pandemic on community and mental health services supporting autistic people and people with a learning disability. It will help to prevent avoidable admissions by increasing respite support and providing help for autistic children and young people in schools to prevent suspensions or permanent exclusions. This

funding will also enable us to drive improvements to inpatient care provision for autistic people through autism training for staff and funding to adapt environments. More broadly, we will move forward with a number of actions to improve the quality of inpatient care, including reducing the use of restraint, seclusion and segregation.

#### Improving crisis prevention and avoidable admissions into inpatient settings

As part of the <u>COVID-19 Mental Health and Wellbeing Recovery Action Plan</u> funding, we are investing in a number of actions to prevent crisis and avoidable admissions of children and young people. To alleviate the pressures many families and autistic children and young people with and without a learning disability have experienced, we are providing £3 million for respite and short breaks after COVID-19. In addition, we will invest £4 million in 2021 to 2022 to roll out the Transforming Care for Children and Young People accelerator programme. The latter involves NHS local systems, Local Authorities, parent carer forums and the voluntary sector working together to put in place appropriate support to reduce the number of children being permanently excluded from school.

The <u>Mental Health Act White Paper</u> consultation made a number of proposals to improve the availability of community support and prevent avoidable admissions. This includes new legal duties on NHS local systems and Local Authorities to ensure an adequate supply of community services. To enable local areas to better plan for services and prevent avoidable admissions, it also proposed a duty on local areas to monitor the risk of crisis for autistic people and people with a learning disability. Furthermore, to ensure autistic people are only admitted if there is a therapeutic need, we proposed that an autism diagnosis should not itself be grounds for detention under the Act, and that mental illness should be the reason for any inpatient admission. We will issue our response to this in summer 2021.

To ensure autistic people, as well as disabled and older people, have better access to supported housing, we have committed that 10% of the homes built via the £11.5 billion new <u>Affordable Homes Programme</u> will be supported housing by 2026. Many autistic people can live well in their own homes if these are adapted to their needs, for example by having their walls sound-proofed to prevent sensory distress. The Disabled Facilities Grant (DFG) is provided by councils to meet the costs of such adaptations. However, we anecdotally know that Local Authorities are not always aware of how adaptations can support autistic people, and that many autistic people do not know of the grant's existence. That is why we will work with the National Body for Home Improvement Agencies to offer support to Local Authority DFG teams and will reach out to autism charities to raise autistic people's awareness of how the DFG can support autistic people.

We are committed to sustainable improvement of the adult social care system and will bring forward proposals in 2021. The objectives for reform are to enable an affordable, high quality adult social care system that meets people's needs, while supporting health and care to join up services around them. We want to ensure that everyone, including autistic people, receive the care they need to enable them to live full and independent lives.

On 15 January 2021, we also launched the Independent Review of Children's care. The Independent Review of Children's Social Care is a manifesto commitment and a part of the Government's commitment to levelling up across the country. The review will take a fundamental look at what is needed to make a real difference to children who need social care.

In addition, to prevent more autistic people from being avoidably admitted to inpatient care, we need a better understanding of the types of community support that meet autistic people's needs before and during crisis. That is why, as part of the Building the Right Support Delivery Board, our Advisory Group of people with lived experience, the LGA and ADASS are leading work to review best practice models of community-based support for autistic people, people with a learning disability or both. The LGA and an NDTi-led partnership will also continue to roll out their Small Supports programme to an additional 8 Transforming Care Partnerships across the country. This programme involves working with and encouraging the establishment of small providers that promote people's individual choice and control in the community.

## Improving the quality of inpatient care for autistic people and facilitating timely discharges from inpatient care

Ensuring that people can make their voices heard and that they and their families can speak up where there are concerns about care is crucial in improving people's experiences. Advocates can play a crucial role in making sure people's views are listened to, and that issues are addressed. This is why we are committing £4.5 million to undertake a joint DHSC and NHSE/I review of advocacy to ensure it is fit for purpose and will make recommendations based on this by 2022. Families and carers should be able to speak up about their loved ones' experiences, and we agree with the Joint Committee on Human Rights' report on the Detention of Young People with Learning Disabilities and/or Autism that injunctions, which are court orders to prevent people from speaking up about their care, should not be used to this end. To prevent this from happening, we will commission guidance on the use of injunctions by May 2022 and require health and care bodies to inform the Secretary of state if they apply for an injunction.

We are also taking actions specifically aimed at improving the quality of inpatient care for autistic people who often find these settings distressing. Improving staff understanding of autism can play an important role in enabling staff to provide autistic people with adjusted support and/or responding to distress. To improve how these services support autistic people, we are investing £1.5 million of funding to develop training for staff working in adult inpatient mental health settings, in line with tier 3 of the <u>Core Capabilities Framework for supporting autistic people</u>. We know inpatient environments themselves can be overwhelming to autistic people, which is why we are also providing £4 million to enable inpatient settings to become more autism-friendly.

In addition to improving the quality of inpatient care, we are working to facilitate timely discharges for autistic people. Care and Treatment Reviews (CTRs) and Care, Education and Treatment Reviews (CETRs) can play an important role in supporting people towards discharge, but are not always taking place or being properly acted upon. That is why, in the <u>Mental Health Act White Paper</u>, we proposed to put these on a statutory footing and to require that clinical teams justify why they have not acted on these reviews.

#### Addressing the use of restrictive practice

In 2018, the Secretary of State for Health and Social Care commissioned the Care Quality Commission (CQC) to undertake a review into the use of restrictive practices. In response to recommendations made in the CQC's <u>Interim report: review of restraint, seclusion and</u> <u>segregation</u>, we committed to review cases of all autistic people and people with a learning disability in inpatient care, and undertake independent case reviews for people in long-

term segregation to ensure people are getting the right care and being supported towards discharge in the community. An Oversight Panel chaired by Baroness Sheila Hollins was established to examine findings from these reviews and develop recommendations to government, NHSE/I and care organisations about improving support for those in long-term segregation, which is being published on the same day as this strategy. The CQC's final report, <u>Out of Sight – who cares?</u>, published on 22 October 2020, made recommendations to improve the quality of inpatient care and reduce the use of restrictive practices. Our response to this report is also published today.

We are clear that restrictive practices should only ever be used as a last resort, when all attempts to de-escalate a situation have been tried. In November 2018, we passed the Mental Health Units (Use of Force) Act, also known as Seni's Law, to increase oversight and management over the use of force in mental health settings. We published the draft statutory guidance on the implementation of the Act for consultation in Spring 2021 and will set out a full timetable for commencing the Act at the earliest opportunity.

As part of our effort to reduce the use of restrictive practices and facilitate discharge for autistic people and people with a learning disability with long stays in inpatient mental health settings, we are working with NHSE/I to develop a Senior Intervenor pilot. This will involve Senior Intervenors working with people in inpatient settings, supporting and overseeing actions from Independent Care (and Education) Treatment Reviews and helping those in long-term segregation towards discharge. We have agreed to support the implementation of this pilot as part of a wider package of £1.35 million to implement dynamic life planning and support for people experiencing long-term segregation and seclusion.

#### Our commitments in the first year

In the first year, our key commitments will be to:

- provide £25 million of funding to improve the capacity and capability of 7-day specialist multidisciplinary learning disability services and crisis support for each local area, and £15 million of funding to put in place keyworkers for children and young people with complex needs, including those who are autistic
- provide £18.35 million to prevent crises and avoidable admissions into inpatient care, improve the quality of care for autistic people in inpatient mental health services and facilitate discharges back into the community
- review the results of our proposals to improve the treatment of autistic people under the Mental Health Act and issue our response in summer 2021
- provide £21 million funding to Local Authorities through the Community Discharge Grant, to accelerate discharges

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

# Chapter 8 : improving support within the criminal and youth justice systems

#### Our vision

By 2026, we want to have made improvements in autistic people's experiences of coming into contact with the criminal and youth justice systems, by ensuring that all staff understand autism and how to support autistic people. We want all parts of the criminal and youth justice systems, from the police to prisons, to have made demonstrable progress in ensuring that autistic people have equal access to care and support where needed. In addition, we want autistic people who have been convicted of a crime to be able to get the additional support they may require to engage fully in their sentence and rehabilitation.

Available evidence indicates that autistic people may be over-represented as people who come into contact with the criminal and youth justice systems, as victims, witnesses or defendants. However, we know from the <u>APPGA inquiry</u> that they often have poor experiences when they come into contact with these systems. There are many reasons for this, including poor understanding of autism amongst professionals as well as challenges with getting adjustments they need to engage in processes. This lack of understanding can cause staff to misinterpret autistic people's behaviour, resulting in missed opportunities to divert them from the criminal and youth justice systems. Research from the <u>Equality and Human Rights Commission</u> also found that disabled people, including autistic people, often struggle to participate and engage in areas like sentencing. This is because adjustments are not made to these processes, or because their needs are not identified early enough.

Evidence from the <u>APPGA inquiry</u> highlighted that autistic people often find prison environments overwhelming because they can be noisy, brightly lit and cause sensory distress. The inquiry found that prison staff do not always understand people's needs or miss those who may be undiagnosed. In addition, autistic people who are in contact with the criminal justice system often struggle to access support or the health and social care services they may need. This includes difficulties accessing the care and support they may require on leaving custody, which can make transitions back into the community more challenging.

#### How we will work towards this in 2021/2022

In the first year of the strategy, we will develop a better view of existing provision for neurodivergent adults, including autistic adults, through our call for evidence on neurodiversity in the criminal justice system. This is being led by HM Inspectorates of Prisons and Probation, with support from HM Inspectorate of Constabulary and Fire & Rescue Services and will provide us with a better understanding of the improvements we need to make.

We will take a number of steps this year to improve staff awareness and understanding of autism across the criminal and youth justice systems, including prison and probation staff, and youth custodial specialists. We will undertake work to improve autistic people's access to adjustments and support and help make environments like prisons and probation services more autism friendly. We will also drive better access to health and social care services for those in contact with the criminal and youth justice systems, including the support they may need as they leave custody.

#### Improving understanding of autism across the criminal and youth justice systems

We know that frontline criminal and youth justice staff's understanding of autism and wider neurodiversity issues needs to improve. Based on findings from the Neurodiversity call for evidence, we will develop a training toolkit for frontline staff on neurodiversity and the additional support people might need. We will also take steps to specifically upskill staff across the criminal and youth justice systems on autism, including prison staff, to help ensure autistic people receive the additional or adjusted support they may need. To this end, we will introduce an autism-specific session as part of the new prison staff 'Custody and Detention' apprenticeship, which will be undertaken by all new prison officers, in England and Wales. We will also consider autistic prisoners' needs in the development of improved safety training for prison staff, which will cover issues such as support for prisoners identified at risk of self-harm or violence. This will ensure staff have the skills and knowledge they need to support good safety outcomes.

In addition, Her Majesty's Prison and Probation Service (HMPPS) is developing a revised Policy Framework and guidance for 'Advancing Diversity and Inclusion for offenders and children in custody', which will include addressing the needs of autistic children and adults. This framework and guidance will be published by the end of 2021. Probation services and staff also need to understand autistic people's needs, which is why we will also continue to promote the National Probation Service's resources in addition to the Youth Custody Service's Effective Practice Briefing on '*Supporting Children with Autism Spectrum Conditions*'.

To improve support for neurodivergent people in prison we are also introducing and testing a new Neurodiversity Support Manager role in a number of prisons, who will be responsible for developing a neurodiversity strategy for the prison, liaising with education and skills teams and ensuring that departments across the prison are aware of prisoners' individual needs. Prison Governors are also expected to commission education providers to screen a percentage of sentenced prisoners for learning disabilities or learning difficulties, and autism, on reception in prison. As well as improving prison staff's skills and capability in supporting autistic prisoners, we need to have a better knowledge of how many prisoners are autistic, as this will enable prisons to put in place the right support for people. To this end, we will explore ways of implementing a new data categorisation list on disability, which will include autism, as part of HMPPS digital prison management system.

We also want to ensure police officers understand autistic people's specific needs – for example around communication and sensory needs – and the reasonable adjustments they might need to make to standard police practices, as this is crucial in ensuring autistic people are treated fairly and are appropriately diverted away from the criminal and youth justice systems where possible and appropriate. That is why we will ensure the College of Policing's Mental Health Authorised Practice is kept updated to reflect current advice and guidelines on supporting autistic people.

### Improving access to services for autistic people in touch with the criminal and youth justice systems

To improve autistic people's experience of interacting with the criminal and youth justice systems, regardless of the reason, we need to ensure they are able to access adjustments and the support they need, and tools available to enable them to engage in processes. For those in prison, we want to make improvements to these environments so they are more autism-inclusive. To do so, we will encourage more prisons and probation areas to undertake the National Autistic Society's Autism Accreditation scheme, which involves organisations reviewing all aspects of their services and ensuring they are providing good quality support to autistic people. To date, 3 prisons across the youth and adult estate and the first ever probation area have been awarded this accreditation, and others are currently working towards this.

We want autistic people to be able to access support throughout the criminal and youth justice systems, including in court, as this is vital in enabling autistic people to have equal access to justice. We are taking a number of actions to this end, including reviewing intermediary provision, as we know they can play an important role in helping autistic people with communication, including in giving evidence to the courts and participating in proceedings. This review will make recommendations about the future of intermediaries, including considering the use of intermediaries for defendants. In addition, Her Majesty's Courts and Tribunals Service (HMCTS) will also continue its national programme to increase training and awareness for staff on reasonable adjustments, and hold events focused on accessibility and inclusion – which covers autism. HMCTS has also reviewed its tools and processes supporting the delivery of services for disabled court and tribunal users, which includes reviewing the approach to supporting autistic people.

We want to explore how we can find alternatives to prosecution and custody for autistic adults and those with other vulnerabilities. That is why we are funding research over 3 years (starting in 2021) about the use of Out of Court Disposals. The findings from this research will enable us to review policy and practice for joint work between the police, NHS and other services, as well as produce practical advice for frontline teams and service providers. Community Sentence Treatment Requirements (CSTRs), which are partnership programmes between NHSE/I, the MoJ, DHSC, Public Health England and HMPPS, and can be used as an alternative short custodial sentence in prison. To help ensure that treatment programmes available in CSTR sites are accessible to neurodivergent people, including any adaptations required for autistic people, the programme will employ a national neurodiversity advisor.

We are clear that autistic people who come into contact with the criminal justice system should have equal access to healthcare and social care. Health and justice partners will continue to work together to improve access to assessments and referrals for support for autistic people in contact with the criminal and youth justice systems, and ensure all NHSE/I-commissioned services are able to identify, assess and meet the needs of autistic people. Healthcare services within the adult prison estate have an important role to play in meeting the healthcare needs of autistic prisoners, and helping to identify people who may be autistic, which is why NHSE/I will publish guidance on this in June 2021. Services will also be supported to develop their own prison autism pathway and, as per the <u>2020 prison health primary care service specification</u>, prison healthcare services should also consider nominating an autism and learning disability Champion.

NHSE/I are rolling out a new service called RECONNECT over the next 3 years, to provide care after custody for people leaving prison who have ongoing health vulnerabilities, including autistic people. The service starts working with people, including those who are autistic, before they leave prison and helps them to make the move to community-based health and care services that will provide the support that they need.

Some autistic people receive care in secure mental health inpatient settings for offending behaviour. In line with the <u>Building the Right Support national plan's</u> aims, different models of support for a safe, effective and timely transition back into the community have been implemented across the country. Some examples are NHSE/I Forensic Outreach and Liaison Service (FOLS), which provides specialist, forensic mental health care for autistic people who have been admitted to secure inpatient care. FOLS ensure that autistic people who require continued specialist support to address risk, psychological or social care needs, are offered support so they can be discharged from secure care into the community.

#### Our commitments in the first year

In the first year, our key commitments will be to:

- review the call for evidence on neurodiversity in the criminal justice system, and begin the development of a toolkit to educate frontline staff about neurodiversity, and the additional support people might need
- introduce the new Custody and Detention apprenticeship, which includes a dedicated autism session, to be undertaken by all new prison officers and youth custodial specialists in England and Wales
- conduct research as part of a 3-year programme which will provide insight about how police use Out of Court Disposal to support adults with vulnerabilities
- continue to work together to improve access to assessments and referrals for support for autistic people in contact with the criminal and youth justice systems, and to ensure all NHSE/I-commissioned services are able to identify, assess and meet the needs of autistic people using these services

The full list of actions we are taking in 2021 to 2022 is set out in our implementation plan (Annex A).

### Chapter 9 : enablers for this strategy

In year one of this strategy, we will focus on putting in place the enablers required to deliver on the strategy and demonstrate that we are making progress on actions, which are as follows; (1) improving autism research, innovation and examples of best practice, (2) improving data collection and reporting to monitor implementation of the strategy and drive system improvement and (3) strengthening governance, leadership and accountability.

#### Improving research, innovation and examples of best practice

While autism research has developed over the last 6 years, there are still notable evidence gaps related to autism policy and practice, and the provision of services for autistic people. The research charity Autistica has reported on <u>research investment and research priorities</u> in the UK. It has found that the balance of research investment has been on the basic science underlying physiological mechanisms of autism, and that there has been a relative lack of research on producing evidence on the best ways to meet autistic people's needs, for example in understanding adult social care services that work for autistic people.

Services informed by high-quality evidence have the potential to allow us to make faster progress in tackling the inequalities autistic people face, for example the gap in life expectancy, preventing avoidable inpatient admissions, and improving employment opportunities. This balance may be starting to shift, as we are seeing a growth in the number of autism studies funded by the National Institute for Health Research (NIHR), a main funder of service and intervention-related research. However, we want to go further in improving autism research across the areas that affect autistic people's lives. That is why, in the first year of the strategy we will draw together a research action plan to identify research priorities for the next 5 years, working together with the research sector, NHSE/I, autistic people and their families as well as the voluntary sector.

#### Improved data collection and reporting to drive system improvement

Over the next 5 years, we want to improve the collection and quality of data on autism used across public services to better support the needs of autistic people and their families. Autistic people interact with a range of mainstream and specialist services across systems, such as health and social care, education and employment, and there are still gaps in data across these areas. There have been significant improvements in autism reporting in recent years, including the introduction of <u>autism diagnosis waiting times data</u> collection, improved recording of autism in information about inpatient admissions (<u>Assuring Transformation</u>) and collection of data about the number of autistic people in employment.

Gaps in autism-related data have been highlighted during the COVID-19 pandemic, which is why we commissioned the London School of Economics to undertake rapid research to understand the impact of the pandemic on autistic people. While useful information about autism can be sourced from the bi-annual Self-Assessment Framework (SAF), the data collected is not mandatory or always comparable, which limits its utility in monitoring the implementation of the statutory guidance underpinning the autism strategy.

Over the course of the strategy, our vision is for reliance on self-assessments to decrease as we move towards a cross-government approach to autism data collection and reporting. In year one of the strategy, we will work across government on the development of an action plan for data collection and reporting, involving autistic people and their families, delivery partners and charities. This will build on previous work done for implementation of the preceding <u>Think Autism</u> strategy, existing work being taken forward by delivery partners to improve data and will consider requirements across systems. We will ensure the data collection and reporting mechanisms we develop align with the statutory guidance, as well as the aims of this new strategy, to measure against progress effectively.

#### Strengthened governance, leadership and accountability

To ensure the actions set out in our implementation plans are delivered and make a real difference to people's lives, we will refresh our governance structure for this strategy and develop specific measures of success for each of the actions we are committing to as part of this. The Department for Health and Social Care, in partnership with the Department for Education, will establish a refreshed national Executive Group to monitor the delivery of the actions set out in the implementation plan, and hold action owners to account on progress. The new group will build on the existing Autism Strategy Executive Group, but will cover all ages, and will continue to include self-advocates, families and carers. We will work with self-advocates, as well as existing members to develop this new group.

The new Executive Group will report directly into the Minister for Children and Families and the Minister of State for Care. There will be bi-annual accountability meetings, chaired by both Ministers to review progress on actions set out in this and subsequent implementation plans, and we will set up Task and Finish groups to oversee and drive progress on the actions set out in these plans. These groups will feed into the Executive Group. We will ensure autistic people, including children and young people, from diverse backgrounds and with a range of needs, are involved in these. The refreshed governance structure for this new strategy will align with other work being taken forward by government, for example the new Building the Right Support governance structure.

At the local level, our expectation is that Local Authorities and the NHS must work in collaboration with each other and relevant local partners to take forward the key priorities in this strategy. This should be done in accordance with their legal duties to identify and support autistic adults, children and young people as stipulated in the following legislation and underpinning statutory guidance; the <u>Autism Act 2009</u>, the <u>Care Act 2014</u>, the <u>Children and Families Act 2014</u>, the <u>Children Act 1989</u> and the <u>Equality Act 2010</u>.



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