

# Building the Right Support for People with a Learning Disability and Autistic People Action Plan



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**Action Plan** 

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# Foreword from the Minister of State for Care and Mental Health

In my first week as Minister of State for Care and Mental Health, I responded to a debate on Cawston Park hospital. I heard about the tragic deaths of Ben, Joanna, and John who died in a place that should have been there to care for them and support them at their time of need.

Since then, I have had the opportunity to meet with the families of some of the people who were at Cawston Park and to hear first-hand their awful experiences. Sadly, as many of you reading this know, this is not the only time an instance of poor care has happened to people with a learning disability and autistic people in mental health hospitals. Like me, I am sure you will never forget the appalling instances of poor care and abuse uncovered at Winterbourne View and then later at Whorlton Hall. Though these extreme cases do not thankfully - reflect the experiences of many people in mental health hospitals, they are completely unacceptable, and I am determined that we must do everything we can to stop this from happening again. It is true that the words 'never again' have been spoken many times before, and I understand the concerns of those of you who fear that this will be just another report that says all the right things but makes little difference.

I recognise the wealth of knowledge and experience that many of you reading this will already have in this area, whether that is through your own life, through the work that you do, or because this is an issue that affects someone you love. I appreciate that many of you will have been pushing for the changes that are so desperately needed for far longer than I have been in post, and I can only imagine how concerned some of you must feel.

While it is important to acknowledge that the issues we grapple with are complex and progress may not be as fast as we would all like, I am optimistic that we now have a real opportunity to bring about changes across systems.

So, what is different this time? Well, for a start, we now have a Delivery Board – which I Chair – focused solely on driving progress on Building the Right Support. The organisations which have the levers to make change happen, across the areas that are important to people's experience in the community and high quality inpatient mental health care, are represented on this Board. These partners are committed to working together to implement the actions that are laid out in this action plan. As you will see in the Partnership Statement that follows, this is a joint endeavour. No one organisation or system can make this happen on their own; but I believe that together, we can - and will - achieve our aims. Through the Board, I will have oversight of progress but also any challenges and blockers that need to be overcome.

Another important difference is that our understanding of the challenges we face is much greater now than it was in 2015, when Building the Right Support was first introduced. For example, there is a much greater awareness of autism and of the picture for children and young people. This action plan builds on the insights gained from years of professional and personal experience and a wealth of research, reports, and recommendations, and I have no doubt that this amassed knowledge will be invaluable as we continue to work together to drive further progress.

As well as the changes we can and must make in the short to medium term, I know that there are calls for more fundamental changes to the system. That is why we are also delivering policy improvements across government and wider changes related to health and social care as a whole. These align with the ambitions of this action plan and build the foundations for tangible, lasting change across systems. From the reforms to the Mental Health Act 1983 and Adult Social Care Reforms white paper, the move to Integrated Care Systems, and the Special Educational Needs and Disabilities (SEND) and alternative provision Green Paper, each change brings us a step closer to the goal that we are all aiming for. We are already meeting some of these goals. For example, we have met our commitment to see one million more disabled people in employment by 2027 and continue to work with people to ensure they have the right support to get and keep a job.

Our ultimate goal is that across England, people with a learning disability and autistic people are equal citizens able to fulfil their potential. They are supported to live full lives in their community, in their home, with access to the care that is right for them, when and where they need it. Just like everyone else.

This action plan sets out the actions we will take to achieve this. Each action has a timescale, one or more designated owners, and a clear, measurable outcome. I won't pretend that it will be easy: if bringing about change in this incredibly complex area were easy, it would almost certainly have happened by now. However, I can promise that we will use all the levers in our power to see this through.

**Signed: Minister of State for Care and Mental Health** 

# Partnership Statement from the Building the Right Support Delivery Board

The Building the Right Support Delivery Board brings together representatives from different government departments, local government, the wider health and care sector, the children's sector, and experts by experience from the Building the Right Support advisory group to accelerate progress and provide oversight for delivery of this action plan. It is chaired by the Minister of State for Care and Mental Health.

As Board members, our shared objective is to ensure people with a learning disability and autistic people of all ages are equal citizens in their communities, in their own home, with the right health and social care support to meet their needs, and, for children and young people, access to education. We want everyone to have access to what they need in order to fulfil their potential.

The key areas of focus set out in this action plan are:

- ensuring that people with a learning disability and autistic people of all ages experience high quality, timely support that respects individual needs and wishes and upholds human rights
- understanding that every citizen has the right to live an ordinary, self-directed life in their community
- keeping each person at the centre of our ambitions and ensuring that we consider a person's whole life journey
- collaborating across systems to to put in place the support that prevents crisis and avoids admission
- ensuring that, when someone would benefit from admission to a mental health hospital, they receive therapeutic, high quality care, and remain in hospital for the shortest time possible
- making sure that the people with a learning disability and autistic people who are in mental health hospitals right now are safe and that they are receiving the care and treatment that is right for them
- working together to ensure that any barriers to an individual leaving a mental health hospital when they are ready to do so are removed

To do this, we are committed to using all the levers in our power to drive progress and make this action plan a reality. This includes:

- working together and recognising the importance of a whole system approach no one organisation can achieve this on their own
- ensuring people with personal experience are meaningfully involved, listened to and an integral part of our workstreams
- monitoring progress on commitments and providing constructive challenge to ensure the principles and values of this plan are upheld in its delivery
- taking action to resolve any blockers to progress and identify solutions

If we own an action in this action plan, this also means

- delivering on time, to the milestones and timelines we have committed to
- sharing our progress to maintain momentum including being transparent about any blockers to progress that we have identified
- working with people, their families, and our partners across systems to ensure effective implementation

We know that there are historic barriers to progress, and heightened challenges following the Coronavirus (COVID-19) pandemic, but we are determined to work together, both within our current systems and within reformed systems, to bring about the changes set out in this action plan and to achieve the objectives outlined in this statement.

This statement has been endorsed by the members of the Building the Right Support Delivery Board. Organisations and groups represented on the Board with responsibility for the delivery of specific commitments in this action plan are:

- Department for Health and Social Care (DHSC)
- Department for Education (DfE)
- Department for Levelling Up, Housing and Communities (DLUHC)
- Department for Work and Pensions (DWP)
- Ministry of Justice (MoJ)
- Association of Directors of Adult Social Services (ADASS)
- Children and Young People's Steering Group
- Health Education England (HEE)
- Local Government Association (LGA)
- NHS England (NHSE)
- Skills for Care (SfC)

We thank the following members of the Board for their ongoing role in providing expertise, advice and challenge which has shaped the development of this action plan, and for their assistance in supporting its implementation:

- Association of Director of Children's Social Services
- Association for Real Change, Care England, Learning Disability England, and the Voluntary Organisations Disability Group, as representatives of the provider sector
- Building the Right Support Advisory Group who are leading work to identify 'what good looks like' and the conditions that enable good practice to happen.
- Care Quality Commission (CQC) and Ofsted, in their roles as regulators
- Chair of the Independent Care (Education) Treatment Reviews Oversight Panel
- Children's Commissioner's Office
- Health and Wellbeing Alliance, as representatives of the voluntary sector

## About this plan

#### What we want to achieve

As set out in the 'Partnership Statement', adults, children, and young people with a learning disability and autistic adults, children, and young people should be equal citizens in their communities. People with a learning disability and autistic people should live in their own home and have the right support in place to live an ordinary life. This includes access to education, employment, and other opportunities which help people to fulfil their aspirations. Building the Right Support seeks to make this a reality through strengthening community support and thereby reducing the overall reliance on specialist inpatient care in mental health hospitals.

This action plan brings together, in one place, the commitments that have been made by different organisations to realise this aim.

We want this action plan to complement and support achievement of the NHS Long Term Plan target that by March 2024 mental health inpatient provision for people with a learning disability and autistic people will reduce to less than half of 2015 levels (on a like for like basis and taking into account population growth). This means that for every 1 million adults, no more than 30 people with a learning disability and autistic people will be cared for in an inpatient unit. For children and young people, no more than 12 to 15 autistic children and young people and children and young people with a learning disability per 1 million children, will be cared for in an inpatient unit. We recognise that we are not yet at this point. As Chart G in the infographic later in this action plan shows, we have made progress in reducing the number of people with a learning disability in inpatient care but it is clear that we still have work to do to bring about a similar reduction in the number of autistic people in inpatient care.

Our objectives recognise that there may be certain times when admission to a mental health hospital would be appropriate and offer a therapeutic benefit. We plan to retain some inpatient capacity to meet the needs of people with co-occurring, treatable, mental health conditions.

When it is necessary, we want the right care to be available to support people before, during and after their time in hospital. Inpatient care and treatment should be high quality, the least restrictive and for the shortest time possible. The hospital should also be close to home to ensure a connection can be maintained and strengthened with family, friends, their local community, and circles of support. From the point at which admission is decided, discharge planning should be put in place, and plans formulated to ensure the right community support will be available to reduce the likelihood of readmission.

We also plan to retain some capacity for forensic inpatient care so that people with a learning disability or autistic people who come into contact with the criminal justice system have a safe and appropriate alternative to prison. As shown in Chart A in the infographic later in this action plan, just over a third of people with a learning disability or autistic people who are inpatients presently are detained under Part III of the Mental Health Act and around a guarter are detained with MoJ restrictions. While this action plan proposes to reduce these numbers, we do expect to continue to require some capacity for restricted patients in the future.

Our proposed reforms to the Mental Health Act will support this by ensuring people with a learning disability and autistic people can only be detained where there is a clear mental health need.

This action plan acknowledges the range of legislation that governs how care and support is provided to people with a learning disability and autistic people. Relevant legislation includes: Human Rights Act 1998, Mental Health Act 1983, Mental Capacity Act 2005, Autism Act 2009. Equality Act 2010. Children and Families Act 2014, and Care Act 2014. Actions have been developed with these in mind, and in conjunction with all the relevant government departments. Where appropriate, we have indicated where reform or changes to legislation are relevant to this action plan and support its overall objectives.

We engaged with a range of individuals and organisations in the development of this action plan. This included people with a learning disability and autistic people, their families, and partners in the voluntary and provider sector. We are grateful to them for sharing their valuable insights and feedback, which influenced the development of this action plan and helped strengthen the vision and ambition for what we want to achieve.

#### What we have learned and what we are doing differently

This action plan builds on a broad range of existing evidence and best practice. This includes the lessons we have learned from the Transforming Care programme, the evaluation of Building the Right Support (published November 2021), and the many reports that have recommended ways to improve the lives of people with a learning disability and autistic people in society.

It seeks both to disseminate the very best practice and to learn from and prevent the appalling cases of abuse and poor care that have continued to come to light since Winterbourne View, including Whorlton Hall and Cawston Park. 'Chapter 1: Keeping people safe and ensuring high quality health and social care' outlines practical actions to make sure that people are kept safe from harm.

We have improved how we use data. The Assuring Transformation (AT) dataset, first introduced in 2015, allows us to monitor the number of people with a learning disability and autistic people in mental health hospitals, providing vital information on who they are, how long they have been in inpatient care, how they came to be there and the quality of care they are receiving. The Assuring Transformation data set has undergone recent review and development with a new version launched in April 2021. The new version of AT includes new data and an increased level of detail to build our understanding. For example, as well as allowing us to see how many people are leaving hospital each month, new data now includes date of most recent oversight visit so that we can monitor whether patients are receiving visits with the frequency required, whether patients are on a dynamic support

register prior to admission, whether young people have a key worker, and reason for admission to hospital.

Using this Assuring Transformation data, we know there is variation in progress across England which affects the overall national picture. We know that 6 out of 42 Integrated Care Systems (ICSs) have already met the 2023 to 2024 Long Term Plan target. An additional 10 out of 42 ICSs have achieved the 37 per million target, as at the end of February 2022. Whilst there is regional variability, this tells us change is possible and that there are examples of good practice. However, this must be the case consistently.

The data also tells us more about children and young people, who were under-reported in the early stages of the Building the Right Support programme. For instance, as shown in Chart I in the infographic later in this action plan, we know that as at January 2022 16% of inpatients under the age of 18 had a learning disability (compared to 90% of inpatients aged 65 and over). Putting the right support in place as soon as possible for a child or young person can help avoid inappropriate admissions and disrupt pathways that might otherwise lead to inpatient care. As at February 2022, the number of children in inpatient settings had reduced by 23% since March 2017. (Figures before 2017 under-reported numbers of children.) To continue to support the reduction of children in inpatient settings, in this plan we have created a chapter specifically focused on actions for children and young people.

We recognised that we needed better support for autistic people. As shown in Chart G in the infographic later in this action plan, we have made significant progress in reducing the number of people with a learning disability in mental health hospitals (the number of inpatients with a learning disability only has decreased by 39% from March 2017 to January 2022) but we haven't achieved the same for autistic people. In fact, the number of inpatients who have a diagnosis of autism (and no learning disability) has increased by nearly 20% from March 2017 to January 2022. As shown in Chart H, this increase has been largely driven by an increasing number of female autistic inpatients, and we know that female autistic children and young people make up the majority of those inpatients who are under 18. Awareness of autism has increased since the Building the Right Support national plan was published, and it may be that more autistic people are now being diagnosed after admission. However, this highlights the need for improved access to timely diagnoses, especially for girls and women for whom autism has tended to be under-diagnosed.

Recognising that a different, holistic approach to supporting autistic people was needed, we published our national autism strategy in July 2021. The strategy has been backed by over £74 million in the first year alone. We invested funding in 2021 to 2022 as part of the wider £31 million from the COVID-19 mental health and wellbeing recovery action plan, to help prevent avoidable admissions and drive improvements to inpatient care provision for autistic people through autism training for staff and funding to adapt environments. We will also build on the actions we have set out in the implementation plan for 2022 to 2024 which we will publish following the end of the first year of the strategy (which runs until July 2022).

We have proposed reforms to the Mental Health Act which will limit the scope to detain autistic people or people with a learning disability for treatment under section 3 of the Act without a clear mental health need. This is because learning disability and autism are not mental health conditions, although some autistic people and people with a learning disability may require treatment for co-occurring mental illness. Our reforms are part of a suite of proposed reforms to the Mental Health Act which will improve the experiences of people with a learning disability and autistic people. For example, we are proposing to

introduce new duties on commissioners to ensure adequate support provision and to hold a dynamic support register, including an 'at risk of admission' component, that would ensure that they (and local authorities) understand and monitor the risk of crisis at an individual level for children, young people and adults with a learning disability or autistic children. young people and adults in their local population.

These wider proposals are outlined in 'Chapter 5: Working with changes to the system', alongside other system reforms that will support us to achieve long-term change.

We have consolidated our understanding of funding flows and how they help or hinder the implementation of Building the Right Support. In September 2021, DHSC commissioned an independent specialist consultancy firm (RedQuadrant) to conduct a rapid review of the financial barriers and disincentives to discharge, and financial incentives to admit people to inpatient care. This rapid review concluded in March 2022 and a report has been published.

We have a clearer understanding of the use of long-term segregation and we are taking action to reduce its use. As a result of the increasing concerns about the use of restraint, seclusion, and segregation for people with a learning disability and autistic people in inpatient settings, in 2018 the Secretary of State for Health and Social Care commissioned CQC to undertake a review of this issue. CQC published an interim report in May 2019 and a final report 'Out of sight – who cares?: Restraint, segregation and seclusion review' in October 2020. The findings were deeply concerning and uncovered evidence of poor care and excessive use of restrictive practices. The reports made a number of recommendations, including that there should be an individual, independent review for everyone in long-term segregation. In total, 77 case reviews were completed in 2019 to 2020. Baroness Hollins, as independent chair, established an Oversight Panel in June 2020 to review the findings from this work. Their recommendations and the Government response were published in July 2021. We continue to undertake independent case reviews, enabling us to understand the issues faced in relation to long term segregation and support action to be taken. More detail on the actions we have taken in response to Baroness Hollins and the Oversight Panel report is set out in 'Chapter 1: Keeping people safe and ensuring high quality health and social care'.

The regulatory environment has changed. Following the identification of abusive practices at Whorlton Hall in 2019, CQC has changed its approach to regulation to increase scrutiny and oversight of providers that support people with a learning disability and autistic people. This includes addressing services which may be at risk of developing a 'closed culture'. In practice, this means that we have seen an increase in the number of units identified as requiring improvement or being placed into special measures or in some cases closed.

We know that we must strike the right balance between cross-health and care system. cross-Government working and clear accountability and ownership for delivery. In recognition of the need for effective partnership working to drive better and faster progress, we established the Building the Right Support Delivery Board. The Board brings together representatives from government departments and organisations across systems. These departments and organisations have been identified as members as they have the levers to make change happen. Board membership includes co-chairs of the personal experience Advisory Group and representatives from across the wider system. Bringing the right expertise together in this way ensures that lessons learned can be shared and collective solutions identified when needed. We also know that while bringing multiple partners together is important, this can dilute or distract from clear ownership of actions. That is why

the Board is chaired by the Minister of State for Care and Mental Health, providing a single point of ministerial oversight. Action owners are clearly set out in this action plan and commitment tables, and the Board will oversee progress in delivering this action plan. 'Chapter 6: National and local accountability to deliver' sets out further detail about the Board and outlines how its members will drive progress on this Action Plan.

#### Where we are now

Since the national plan was published, we have made progress on reducing the number of people in mental health hospitals and have supported more people to live in the community. The inpatient total at the end of May 2022 was 2,010: this is a 30.7% net reduction since March 2015, when there were 2,900 people with a learning disability and autistic people in mental health hospitals. As set out above, we know that there is regional variation within this, with some ICSs having met the Long Term Plan target and others with much to do.

The following charts set out data about people of all ages with a learning disability and autistic people, who are in a mental health hospital. This is the population referred to as 'people' in the charts. Most data presented in the charts is from the NHS Digital Assuring Transformation (AT) dataset, January 2022, and is England-level data. Chart F, Chart H and Chart J contain data provided by NHSE. To note, figures may not sum to 100% due to rounding. Further information about the data and language used in these charts can be found in the section 'Where we are now: glossary of terms used'.

Chart A: Overview of inpatient population

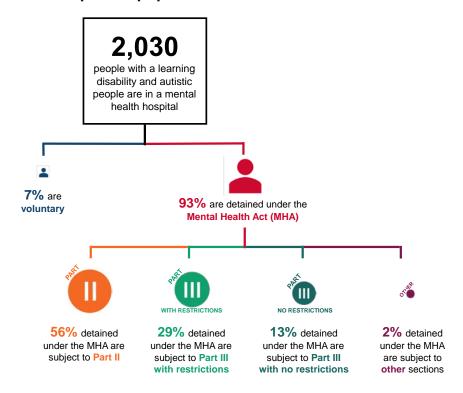


Chart B: Sex of people and reasons people had a delayed transfer of care<sup>1</sup>

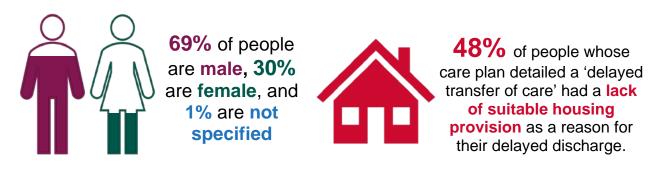
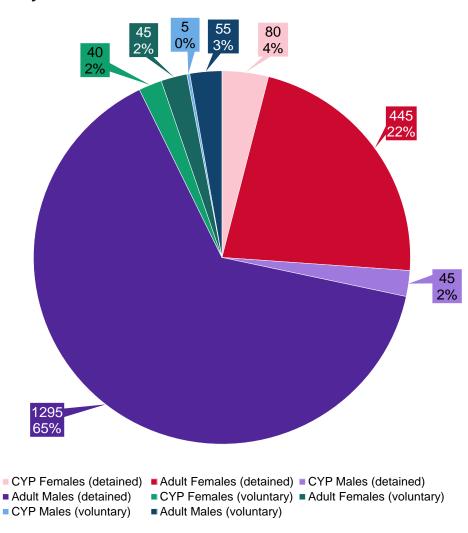


Chart C: People by Mental Health Act status and sex



<sup>&</sup>lt;sup>1</sup> 'Not specified' is the terminology used by NHS Digital in the Assuring Transformation dataset.

Chart D: People by Mental Health Act status and age

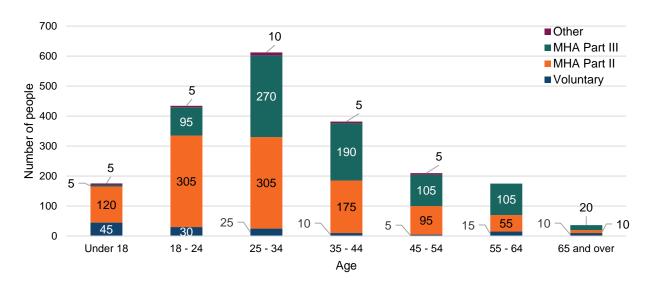


Chart E: Mental Health Act status of people by total length of stay

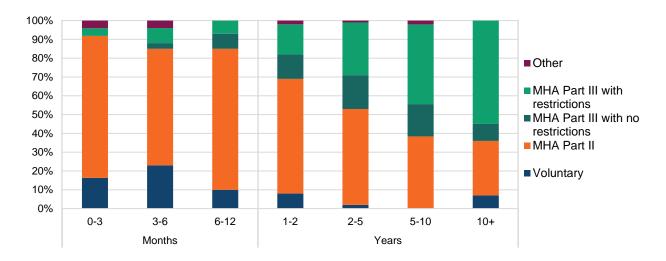


Chart F: Total length of stay by age<sup>2</sup>

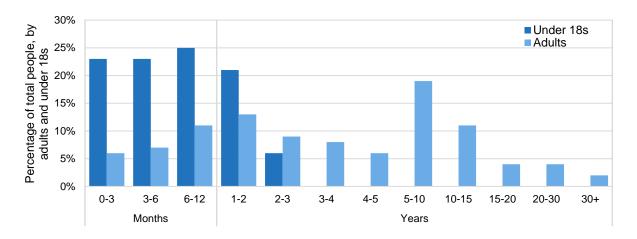
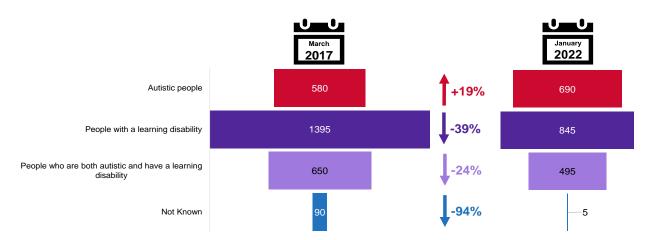
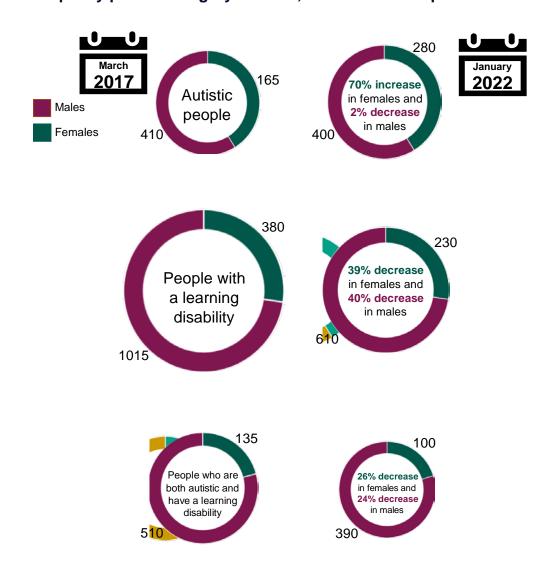


Chart G: People by patient category, March 2017 compared to January 2022



<sup>&</sup>lt;sup>2</sup> This chart contains data provided by NHSE.

Chart H: People by patient category and sex, March 2017 compared to January 2022<sup>3</sup>



<sup>&</sup>lt;sup>3</sup> This chart contains data provided by NHSE.

Chart I: People by patient category and age

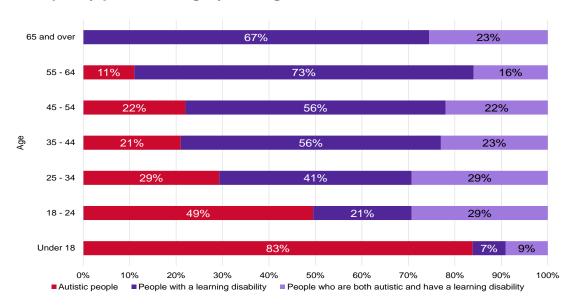
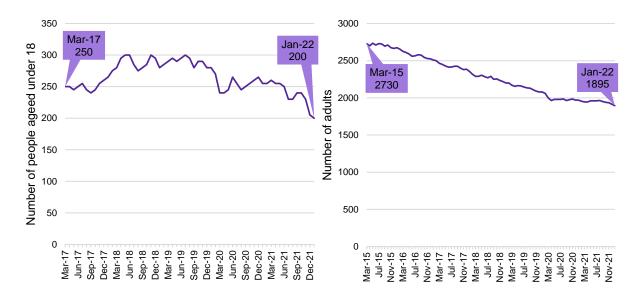


Chart J: The number of people with a learning disability and autistic people in inpatient settings by age over time4



<sup>&</sup>lt;sup>4</sup> This chart contains data provided by NHSE. Data used here is from <u>Assuring Transformation March 2022</u>, following NHSE advice that inpatient counts are retrospectively updated to take account of late reporting or corrections to the data. Under 18 inpatient counts prior to March 2017 were under-reported and are omitted as the trend would be misleading.

#### Making it happen

Collaboration and partnership are key to fulfilling the commitments in this Action Plan. As set out in the Partnership Statement, the Building the Right Support Delivery Board is committed to using the levers in its power to implement the Building the Right Support national plan and deliver this action plan in full.

The Building the Right Support Delivery Board will formally review progress on the commitments in this action plan regularly and ongoing monitoring will take place alongside this. This will make sure that we can identify any risks or issues to successful delivery. The Board will review which commitments have been delivered, which are on track to be delivered to agreed timescales, and where a commitment is not on track, work to understand the reasons why and support one another to get back on track.

Commitment owners will be expected to monitor progress of delivery and provide updates to the Delivery Board as part of formal reviews of this action plan. If appropriate, where barriers to delivery are identified, the Delivery Board will agree a plan with the commitment owner to implement a solution.

Task and finish groups are being established that will also help to drive progress outside of Board meetings. The task and finish groups will focus on delivering specific, tangible activity in areas that will benefit from collaboration between particular Board members. This will include considering actions on funding flows as identified by RedQuadrant's independent report. These groups will report to the Board and Minister for Care and Mental Health.

As part of monitoring this action plan, the Delivery Board may request updates on wider policy developments to improve outcomes for people with a learning disability and autistic people, noting any risks, and issues across systems which may impact the delivery of this action plan.

Further detail on making this plan happen is set out in 'Chapter 6: National and local accountability to deliver'.

#### Who is this action plan for?

We want this action plan to make a positive difference to the lives of people with a learning disability and autistic people of all ages. To achieve this, we want it to be actively used by and inform the health, social care, education, housing, and criminal justice workforce with the levers in their local areas to make positive change happen.

This includes people working in:

- healthcare, social care, education, housing, and criminal justice services
- leaders in local authorities and Integrated Care Boards
- providers of health, social care, and education services
- commissioners of health, social care, and education services
- the voluntary and community sector

We have structured this action plan in chapters to help readers navigate the content, especially those with responsibility for delivering change and implementing this action plan in practice. However, we are mindful of the importance of taking a holistic, whole-life approach. We know that this means we must not view care and support as being divided into distinct 'boxes'. Support must be joined up and adapt to each individual's life. For this reason, the issues explored within individual chapters of this action plan will undoubtedly overlap and to some extent be dependent on one another. Where there are particular connections or links, we have drawn this out as best as possible. Fundamentally, we recognise that every person has a unique set of needs and aspirations and we know that this action plan will not reflect or capture every single circumstance.

#### Our guiding principles

There are a number of overarching principles that are essential to ensuring that people with a learning disability and autistic people of all ages experience high-quality care and support to live ordinary lives in the community. These principles underpin the objectives of Building the Right Support and inform the contents of this action plan.

These principles have been developed in line with the feedback we received through our stakeholder engagement process. Through this process, we heard about the importance of keeping the person at the heart of decisions and building the right leadership, culture, and environment to drive change. We also heard about the challenges faced by people, their families, carers, and advocates when trying to navigate the health and care system. These principles act as a guide and seek to create a common vision across all commitments outlined in this action plan.

#### Keeping people safe

People must be kept safe from harm, abuse, and neglect. There should be an honest and open culture across systems so that people feel safe to challenge services if poor practice is experienced or identified. This includes the need for services that support people to improve transparency and reporting, take appropriate actions to tackle poor practice, and continuously improve quality through learning lessons.

#### Personalised care and support

No one person's aspirations and care and support needs are the same. Care and support should always be personalised. It should be built on the person's strengths – what they can do, not what they can't – and what really matters to them. It should uphold their dignity, human rights, and quality of life at all times. This should be a key consideration in how services are commissioned. By adopting the Universal Personalised Care model more fully, we expect to see more integrated personal budgets being used. This will increase the choice and control people have over their care and support.

#### Working together towards improvement and integration of care and support

In order to achieve long-term improvement to the way people access and experience services, cross-system reform and join-up is crucial. Systems must work together to ensure a person's needs and life journey are considered holistically from the outset so that they receive the care and support they need at the right time and in the right way. Practice should continuously improve through pro-active provision of support upon diagnosis,

learning lessons, disseminating good practice, and adapting to changes in policy and legislation.

#### Holding ourselves and others accountable

People should feel able to trust services to provide them with the care and support they need and to address any concerns that arise. It is important to have the right leadership and culture which is prepared to justify which decisions are made and why. The right leadership provides an environment that is transparent and responsible for actions taken forward, and which encourages continuous improvement of processes and practice, including providing staff with the opportunity to develop their knowledge and skills.

#### Inclusive decision-making

People, their families, loved ones, advocates and carers should be treated with respect at every stage of a person's care and support. The person should be central to all decision making and kept informed as much as possible. Families and people experiencing care and support should have greater choice and control over the services they need and receive.

#### 'What Good Looks Like' project

To realise our ambitions to improve community support, we hope to build on our understanding through a 'What Good Looks Like' project. ADASS and the LGA have been working with the Building the Right Support Advisory Group to identify 'What Good Looks Like' when it comes to community-based support. This work will identify best practice examples, with an emphasis on initiatives that support citizenship and human rights. The project gives us an aspirational view of what positive experiences of support should look and feel like for people with a learning disability and autistic people.

The changes that we want to see as a result of this action plan should be driven by a clear understanding of the type of outcomes desired by people with a learning disability and autistic people. The 'What Good Looks Like' project will help us to consolidate our understanding of the necessary conditions and 'must haves' when it comes to achieving good sustainable outcomes. More information on this project is set out in 'Chapter 3: Living an ordinary life in the community'.

## Executive summary

Building the Right Support focuses on the care and support needed to make sure people with a learning disability and autistic people of all ages can lead ordinary lives on ordinary streets through developing community services and reducing reliance on specialist inpatient care in mental health hospitals.

We know that there have been many recommendations in many reports. Rather than duplicate those reports and replicate every single action individually, we intend that this action plan brings the key elements from these reports, recommendations, and announcements into one place to provide a clear view as to what must be delivered.

We know that some people will be familiar with actions included in this action plan. Our intention is not to suggest that all of these commitments are new, far from it. Instead, we want to bring them together in this way, to demonstrate a cross-system, cross-government focus on delivery and implementation on the things we have said we will - and must - do now and in the future.

This action plan is divided into six chapters. Each chapter focuses on a particular area we know to be crucial in supporting people to live ordinary lives in their communities and clearly sets out the commitments to make positive change happen.

The objectives, timescales, and milestones of commitments in this action plan have been set out in Annex A: Table of Commitments. The lead organisation for each action has been stated, and will be responsible for delivery, working together with relevant partners. Where a commitment appears in the action plan, the corresponding commitment number will appear alongside in brackets.

Unless specified otherwise, references to 'people' in this document mean children, young people, and adults with a learning disability, autistic children, young people, and adults, or both.

An overview of each chapter is set out below.

#### Chapter 1: Keeping people safe and ensuring high quality health and social care

People with a learning disability and autistic people, of all ages, should receive high quality health and social care support. This means making sure that people are treated with dignity and respect, receive personalised care and treatment that is accessible, and have opportunities to live an independent life in their own home as part of their community.

Every person should have a clear plan in place for their care and support which is designed around the person's aspirations and needs. The plan should be focused on achieving outcomes for the person which recognise human rights and trauma-informed approaches. People should have the opportunity and support to understand choices and express their views on matters that affect them and must be involved as much as possible in planning their support, alongside their families, loved ones, and advocates. This is why 'personalised care and support' and 'inclusive decision-making' are guiding principles of this action plan.

Sadly, we know that some people do not receive the quality of care that we would expect. This action plan makes it clear that we will not tolerate people being placed at risk of abuse, harm, or poor-quality care. We welcome the more robust approach CQC is taking to inspecting learning disability and autism services. Safeguarding is also crucial in keeping people safe and respecting and protecting their needs and dignity.

Where inpatient care is needed, there should be regular reviews of care and it should be the least restrictive possible. We are taking steps to increase accountability and reporting on the use of force. We want there to be the right culture within inpatient services, taking a human rights approach, and with a workforce with the right knowledge and skills.

To ensure that people are safe and that they receive high quality health and social care, actions being taken include:

- improving the quality of care in mental health inpatient settings, including striving to ensure that people with a learning disability and autistic people are not admitted to hospital settings rated 'inadequate' by CQC
- making recommendations to improve advocacy support, based on the recent review of advocacy provision undertaken by DHSC and NHSE
- undertaking Independently chaired Care (Education) and Treatment Reviews (IC(E)TRs) for inpatients in long term segregation
- completing the Senior Intervenors pilot to support people in long-term segregation to move to a less restrictive setting or to leave hospital
- providing the health and social care workforce with a training and support offer to ensure they have the right skills, practice, leadership, and culture which empowers them to provide the best possible care

#### Chapter 2: Making it easier to leave hospital

We want to support children, young people and adults who are ready to leave hospital to be discharged safely, in the right way and at the right time. We know that treatment in a mental health hospital can sometimes be the right choice for a person who has a co-occurring mental health condition and would benefit from an intervention that can only be provided through inpatient care. However, we want to ensure that people who are ready to leave hospital are able to do so as soon as possible, with the right support ready in the community so that they can live in their own home.

A plan should be developed with the person from the outset of their admission to support them to leave hospital when they are ready, involving their families and advocates where appropriate. They should also have regular reviews, along with frequent oversight visits from the commissioners involved in their care and support.

We know that there are some people who are ready to leave hospital now but cannot move back into their community. This is often due to difficulties in finding somewhere suitable to live or making sure that the right support is in place. In 'Chapter 3: Living an ordinary life in the community', we outline our plans to build community support in the long term which will ensure that children, young people, and adults can leave mental health hospitals as soon as they are ready.

For some people with a learning disability and autistic people in the criminal justice system, the only alternative to detention in hospital is detention in prison. In such cases, it is likely that detention in hospital may be a more appropriate environment to ensure that restricted patients with learning disability and/or autism needs who have been detained under Part III of the Mental Health Act are able to access the specialist support they need. We know that over a third of the people with a learning disability and autistic people who are currently in mental health hospitals have been admitted for this reason.

According to the Assuring Transformation data published in March 2022, 15,125 autistic inpatients and inpatients with a learning disability have been discharged since between March 2015 and January 2022. However, there have been 2,310 readmissions within a year of previous discharge during this same time period. As well as removing the barriers to discharge, we know that we must do more to make sure people with a learning disability and autistic people of all ages are leaving hospital in a way that is safe and effective, including preventing their re-admission.

To make it easier for people to leave hospital when they are ready, actions being taken include:

- refreshing the policy for Care (Education) and Treatment Reviews (C(E)TRs) to ensure that this includes an increased focus on the physical health of people in hospital, along with an increased emphasis on the importance of the actions that should follow from a C(E)TR
- continuing to help to speed up discharges in England through the Community Discharge Grant, providing local authorities with additional funding to address 'double running' costs
- publishing an action plan on how to improve outcomes for all neurodivergent people who come into contact with the criminal justice system
- proposals to introduce a new duty under the Mental Health Act which will allow some restricted patients to be discharged into conditions in the community which amount to a deprivation of liberty

#### Chapter 3: Living an ordinary life in the community

There should be the right housing, care and support available in the community so people with a learning disability and autistic people can live the lives they choose. Good community provision supports people to live an independent and ordinary life through having a home

and feeling involved in their local community, including through employment and having a reliable network of support.

Although we know that some people benefit from care and treatment that can only be provided in a mental health hospital, it is clear that good quality community support means that people are more likely to avoid being admitted to inpatient care in the first place and is vital to ensuring that people can leave hospital with the right support in place.

To make sure that the right support for people with a learning disability and autistic people is available in local communities, agencies should work together to ensure that support is joined up. The right support needs to be flexible and responsive to people's changes and choices through their lives and should be thoughtfully commissioned. This includes being able to support people in difficult times for them and at times of crisis if they occur. Children and adult social care departments, housing, education, justice agencies and the voluntary and community sector all have a valuable contribution to make.

To make sure that the right housing, care, and support is available in the community, actions being taken include:

- a consultation on 'What Good Looks Like' in community support for people with a learning disability and autistic people which is being taken forward by the Building the Right Support Advisory Group, followed by a review of best practice models and a summary on how to embed best practice within local authorities and wider community services
- investment to boost the supply of supported housing and to improve our understanding of the size, cost, and demand of the supported housing sector
- making sure that commissioners have the right training and information to commission the right services for people with a learning disability and autistic people
- proposals to introduce new duties on commissioners to ensure that there are adequate community-based services in their local area to support people with learning disability and autistic people. This is part of Mental Health Act reform proposals.
- continuing to roll out a programme across England to encourage the establishment of small providers that promote individual choice and control within communities
- providing support around getting and keeping a job

#### Chapter 4: A good start to life

Children and young people with a learning disability and autistic children and young people and their families should be able to access the support they need. This will ensure they have the best possible start to life and can live the lives they choose. We want children to have positive experiences of education, supported by a skilled workforce.

Getting a diagnosis is an important first step, leading to better outcomes in education and physical and mental health, as well as reducing the risk of school exclusions. In addition to receiving an early diagnosis, we also want children and young people to receive appropriate care and support that recognises and plans in advance for their transition to adulthood to prevent escalation of needs, mental health crises and avoidable admissions. We also recognise that additional support may be needed at times, for example respite care.

To help autistic children and children with a learning disability have a good start to life, actions being undertaken include:

- further work to make it guicker and easier to get an autism diagnosis, including bringing multidisciplinary teams together in school settings to diagnose children more rapidly
- improving the experiences of children and young people through the SEND and alternative provision green paper and the government's response to the Independent Review of Children's Social Care
- continuing to support autism awareness training for education staff in early years, schools, and further education settings
- providing further funding for programmes that will directly support schools and colleges to effectively work with pupils with SEND

#### Chapter 5: Working with changes to the system

There is a range of work happening across government to make improvements to systems and to ensure systems can join up around a person's needs and reduce any barriers to having these needs met.

Through our engagement with people with a learning disability, autistic people, and families, we have heard about the challenges people can face to be heard, understood, and valued as they navigate between different services. These challenges can mean that they are often prevented from accessing the services they need or having positive experiences of care and support.

We know that the ambitions and commitments laid out in this action plan are only one part of making change happen. There are other factors that matter to people and would significantly improve their experiences of navigating services and getting the right support. This chapter outlines the changes that are being made across government and across systems outside of this action plan, and we set out how these current and planned changes are intended to achieve long-term improvements for people with a learning disability and autistic people.

Changes taking place across government that will support the aims of this action plan are:

- the proposed reforms to the Mental Health Act which will prevent prolonged detention in mental health hospitals and include a proposed duty for commissioners to hold a local 'at risk' register which allows them to work with local authorities to understand, monitor and respond to the risk of crisis at an individual level for people with a learning disability and autistic people in their population
- the government's 10-year vision to transform adult social care so that people receive the right support in the community at the right time
- the government's ambitions for integrating health and care
- the work the government is doing to improve how funding flows across and between services, for example on pooled budgets

#### Chapter 6: National and local accountability to deliver

No single organisation can do this alone, and so partnership working is key to ensuring that we can deliver the commitments in this action plan. The Building the Right Support Delivery Board will support implementation of this action plan and will hold commitment owners accountable for delivery. Individual organisations with responsibility for commitments will also use their own governance and reporting mechanisms and the levers within their power to drive progress.

We know that wider system reform can help us to achieve our aims; for example, the Health and Care Act 2022 will increase integration between health and social care and work to remove the silos within the NHS, joining up healthcare, social care, and public health services by putting more power and autonomy into the hands of local systems. The adult social care reform white paper will also help us to understand how local authorities can work best with partners to improve the care provided for adults with complex needs.

# Chapter 1: Keeping people safe and ensuring high quality health and social care

#### 'I' statements

When I am supported in a hospital or social care setting:

I am safe and respected, and I feel safe and respected

The care I receive is of the best possible quality; when this care is in a hospital, it helps me get better and is the least restrictive possible

I am supported as close to home as possible, for no longer than necessary, so I can keep my connections to my loved ones and community

I know who is responsible for helping me and I know these people have the right support and resources to do this

The people that support me listen to me, know what matters to me, and I am part of decisions about my care which includes being supported to take positive risks where appropriate

I know what to do or who to contact if I am not being treated fairly or think things are at risk of going wrong

#### Listening to people's voices and meeting their needs

#### Involving the right people in decisions and improving advocacy provision

It is important that people with a learning disability and autistic people, their families, and the people that support them are involved in decisions about their care and improvements to services and practice, and that this improvement is continuous. People should feel safe to share opinions and raise concerns if they feel the right support is not being provided, whether in health or social care settings, and to trust that their concerns will be acted upon.

Advocates can play a crucial role in making sure people's views are listened to, and that issues are addressed. That is why NHSE has committed £4.5 million of the £31 million funding from the Mental Health Recovery Fund for advocacy pilots and a full evaluation of the most effective ways of working (commitment 1a). The evaluation will be completed in 2022 and will be used to inform best practice.

As part of our reforms to the Mental Health Act, we are proposing to extend the right to an Independent Mental Health Advocate (IMHA) to all people who are mental health inpatients, including voluntary patients who are not detained under the Mental Health Act. As part of this, we are improving access to IMHA services to help ensure that patients do not miss out on the valuable support IMHAs provide. We are proposing expansion of IMHAs' roles and responsibilities so that they are better positioned to support the patient to make decisions around their care and treatment. We will continue to explore the best way to improve the quality of IMHA services with stakeholders, and work with stakeholders to ensure that culturally appropriate advocacy better meets the needs of patients from ethnic minority backgrounds.

We recognise that families, loved ones and unpaid carers often make the best advocates. Their involvement can help to ensure that people receive the care and treatment they need in the right way and at the right time. The people who are important to a person should be involved in reviews about their care and support, with the person's permission as appropriate, as they will have valuable insights and knowledge about what matters to the person.

There is wider work underway to ensure people's views are heard, valued, and acted upon. CQC's strategic ambition is to deliver a proactive, inclusive, public 'listening' service which monitors, encourages, enables, and expertly acts on a wider range and volume of people's experiences to drive its decision making. This includes the experiences of people with a learning disability and autistic people.

NHSE has developed Ask, Listen, Do resources. Ask Listen Do supports organisations to learn from and improve the experiences of people with a learning disability and/or autistic people, and their families and carers when giving feedback, raising a concern, or making a complaint. It also makes it easier for people, families, and paid carers to give feedback, raise concerns or complaints. NHSE remain committed to these resources and continue to promote their use.

#### **Upholding the principles of the Mental Capacity Act**

We know that some people with a learning disability or autistic people may 'lack mental capacity' to make specific decisions about their own lives. Their rights are protected by the Mental Capacity Act 2005 (MCA) which sets out how professionals should support and care for people who may lack capacity to make certain decisions and seeks to ensure that they are afforded the dignity and respect that everyone would expect. All health and care providers and commissioners are responsible for ensuring they are compliant with the MCA. This includes ensuring that all professionals working with people who may lack capacity to make certain decisions have a good knowledge of the MCA.

In March 2022, the government launched a public consultation on the proposed changes to the MCA Code of Practice, including guidance on the new Liberty Protection Safeguards (LPS) system. The new LPS system will replace the Deprivation of Liberty Safeguards (DoLS) as the system to authorise the care or treatment arrangements of an individual who lacks capacity to consent to those arrangements. We are committed to ensuring the person is kept at the centre of decision making. This is why the LPS system will introduce an

explicit duty to consult with the person, and those interested in their welfare, to establish their wishes and feelings about proposed arrangements.

We are taking steps to ensure the core principles of the MCA are upheld. The National Mental Capacity Forum (NMCF) is a joint initiative between DHSC and MoJ which seeks to improve understanding and implementation of the MCA. It brings together stakeholders from the different systems that MCA applies to. In 2021, the NMCF held a number of webinars to work through issues affecting the application of the MCA, including challenges associated with a person's transition to adulthood. In addition, training on the new LPS system will include the core principles of the MCA.

#### Providing accessible support

We know that people experience challenges accessing reasonably adjusted support which may prevent them from having their needs met. Under the Equality Act 2010, public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as to everybody else. To make it easier for people with a learning disability and autistic people to use health services, there is work underway in NHSE to make sure that staff in health settings know if they need to make reasonable adjustments for people. Examples of this include providing easy read appointment letters or giving people a priority appointment if they find it difficult waiting in their GP surgery or hospital. NHSE are developing a Reasonable Adjustments Digital Flag which will show on a person's health record that they may need reasonable adjustments. The flag is currently being tested and is planned to be made available across all NHS services.

Some people may have sensory needs, which are important to consider as part of creating the right environment for their care. NHSE commissioned the National Development Team for inclusion (NDTi) to develop 10 principles which can be used to increase awareness and provision of environments which are suited to people's sensory needs.

In 2021 to 2022, as part of COVID-19 Mental Health Recovery Funding, NHSE funded three initiatives. First, NHSE funded some mental health trusts to reduce common sensory aversions for autistic people in inpatient mental health settings. For example, by changing aspects of the physical environments (changing lights, replacing noisy alarms) and by developing systems for seeking and, acting upon, autistic people's feedback about the environments. Second, NHSE commissioned the University of Reading to develop an evidence- and community-informed sensory assessment tool to improve staff ability to assess and accommodate for sensory sensitivities in inpatient settings. Third, NHSE commissioned the NDTi to refresh the greenlight toolkit, a survey designed to identify opportunities for improving inpatient settings.

#### Keeping people safe now

#### Assuring the quality of support in health and care settings

As the regulator for health and social care in England, CQC plays an important role in improving people's experiences of health and social care services and ensuring people's safety and human rights are upheld. We welcome the more robust approach that CQC is taking to inspecting learning disability and autism services to ensure that providers meet expectations for high quality care. They have already taken significant action against

services that are poorly performing, which has included cancellation of several providers' registrations (stopping them from delivering regulated activity), restricted admissions, warning notices and reduced ratings. 'Right Support, Right Care, Right Culture' sets out what CQC expect good care to look like for people with a learning disability and autistic people, which they are ensuring providers comply with through their regulatory activity.

CQC's regulatory approach looks at the culture of a service. How well are people who use a service engaged, involved, and considered in the planning and delivery of their care and the running of the service? How well does a service create a culture that promotes respect and values the humanity of each person? By looking at how well-led a service is, CQC can determine how staff are supported and protected to question practice and raise concerns, creating a culture where both staff and people in the service speak up and make change happen. CQC will look at whether leaders have the skills, knowledge, experience, and integrity they need to lead effectively. This puts a focus on creating a culture that is assessed through quality assurance of interactions and relationships with people, not records.

To improve how they are undertaking inspections, CQC are piloting a range of new tools and have developed training which focuses on the principles of observing people and understanding the care that they are receiving through their eyes. This includes a quality of life tool, communication tools such as Talking Mats, and training for inspectors to understand what good practice looks like. There is also wider work underway in CQC, as set out in their 2021 strategy, to tackle inequalities and improve how local systems are assessed. This includes work to regulate in a more dynamic and flexible way which will allow inspection activity to focus on higher risk services such as closed cultures.

We also welcome the work that CQC is undertaking to check for and tackle closed cultures in services. In July 2021, CQC published guidance on identifying and responding to closed cultures. A closed culture is a poor culture in a health or care service that increases the risk of harm, including abuse and breaches of human rights, and where people, their families or staff are often not able to speak up. Whether the development of closed cultures is deliberate or unintentional, such as those arising from COVID-19 restrictions, they cause unacceptable harm to a person.

The NHS is committed to providing autistic children, young people and adults or those with a learning disability with the best possible care and treatment. NHSE would normally expect people to be admitted to services of suitable quality. NHSE will therefore strive to ensure that people with a learning disability and autistic people are not admitted to hospital settings rated inadequate by CQC, including people being moved from a unit that is closing. There may however be, occasions where it is in the best interests of the individual and their family to do so. Where, exceptionally, admissions to an inadequate hospital setting occur, this will be with the involvement of the patient (where they have capacity or based on a best interest decision making process where they do not) and their carer/family. It will also be based on an assessment of the risks and benefits that concludes this is the most favourable option for that individual patient. Additional mitigations and safeguards will be put in place to monitor their safety, wellbeing, and treatment.

NHSE will monitor this approach to admissions to inadequate rated services, by reviewing the number of any exceptional new admissions over the next six months, to ensure we are delivering this as intended. We will check progress on this approach to admissions to

mental health inpatient units rated inadequate by CQC. We will agree with NHSE and CQC the best way for this to be reported to the Building the Right Support Delivery Board.

This commitment is supported by other NHSE commitments to improving quality in mental health inpatient settings which is set out further in this action plan, as well as the NHS Long Term Plan. This includes embedding the HOPES model of care, commissioner oversight visits and provision of autism training. In addition, NHSE will support ICSs and provider collaboratives as they develop their local plans, to improve quality of services and localise care. Chapter 6 of this action plan sets this out further, including wider government aims to improve integration of health and care.

#### Safeguarding people from harm

Safeguarding is crucial in keeping people safe and respecting and protecting their needs, aspirations, and dignity. We know that there is variation in how local authorities carry out their adult safeguarding duties under the Care Act 2014. The Health and Care Act 2022 includes a provision for a new duty for CQC to assess local authorities' delivery of their adult social care duties under Part 1 of the Care Act 2014, such as adult safeguarding. DHSC is working closely with CQC and other key stakeholders to design a system that will drive the best possible outcomes for people.

We have published a range of guidance to encourage more consistent and high-quality safeguarding practice. The Chief Social Worker for Adults will be holding webinars with Principal Social Workers and sector partners to promote local adherence to this guidance (commitment 1b). In January 2022, the Chief Social Worker for Adults published an independent briefing 'Revisiting Safeguarding Practice' to support social workers and other safeguarding practitioners to carry out their duties under the Care Act 2014 effectively. This quidance will support health and care professionals to ask the right questions to identify any factors that may be preventing someone from feeling safe, and act on concerns that a person may be at risk of or experiencing harm or abuse. It highlights the importance of strengths based, person-centred safeguarding and provides practical resources for practitioners.

To encourage more effective partnership working across adult, children and family services across systems, the Chief Social Worker for Adults published a knowledge briefing on transitional safeguarding in June 2021. This briefing sets out why transitional safeguarding is a critical area of practice, and aims to support practitioners, senior leaders, and social care professionals to work better with one another to provide flexible and person-centred support for young people.

We know that more can be done to ensure effective partnership working and accountability at a local level. Under the Care Act 2014, local authorities are responsible for the establishment of Safeguarding Adult Boards (SABs). SABs play a key role in providing strategic oversight and leadership of local safeguarding practice and ensuring that local safeguarding arrangements and partners are acting to help and protect adults who they suspect are at risk of abuse or neglect. DHSC is considering how to strengthen practice in local SABs and encourage effective join-up with local partners. As part of this, it is considering the recommendations made in the Independent Review of the Mental Health Act which government responded to in 2021. The review recommended that local SABs should ensure that safeguarding arrangements support organisations, including inpatient

units, to discharge their safeguarding duties and ensure that there are effective processes in place to identify, investigate, and act on safeguarding issues.

#### Providing safe and effective care in mental health hospitals

We know that specialist inpatient care in a mental health hospital will be beneficial for some people, although not all. For example, where a mental health need escalates and cannot be safely treated in the community. Where this is the case, we are clear that admission should be for as short a time, as close to home and the least restrictive as possible. While people are in hospital, they should receive high-quality care and treatment that takes into account their individual needs, and they should be supported to return home as soon as possible. It should also be easier for people to leave hospital at the right time, into the right home, which is set out further in 'Chapter 2: Making it easier to leave hospital'. The quality and availability of community support likewise plays an important role in supporting people to leave hospital and preventing crisis which can lead to admission, which is set out further in 'Chapter 3: Living an ordinary life in the community'. We know that some people do not receive the quality of care that we would expect, and we are determined to prevent this.

People who have been admitted should receive regular Care (Education) and Treatment Reviews (C(E)TRs). C(E)TRs are formal reviews that intend to improve the quality of care that people receive in hospital by making recommendations for their safety, care, and treatment and to overcome barriers to the person's discharge. Partners in local authorities and education services are key to effective planning and delivery. The reviews should address barriers and make recommendations across systems. They should take place every 3 months for children and young people in hospital, every 6 months for adults in a non-secure mental health hospital, and every 12 months for adults in a secure mental health hospital.

Responsible clinicians should consider the findings and recommendations made from the C(E)TR of a person with a learning disability or autistic person, of any age, as part of their statutory care and treatment plan. To ensure this happens, we propose making it a statutory requirement for responsible clinicians to have regard to the findings and recommendations from C(E)TRs, as part of the person's care and treatment plan (commitment 1c). This will apply where a person is detained under certain sections of the Mental Health Act 1983. This is one of our proposals as part of reforms to the Mental Health Act 1983. The proposal includes placing a duty on relevant Integrated Care Boards (ICB) to have regard to recommendations that relate to services that are to be available on discharge. This will mean that if a responsible clinician or ICB deviated from the recommendations from a C(E)TR, they will be expected to justify this.

To check that people have safe experiences, people with a learning disability and autistic people in mental health inpatient care have received a safe and wellbeing review. This work is led by NHSE and applies to all people with a learning disability and autistic people who were inpatients as at 31 October 2021 (commitment 1d). The reviews form part of the NHS response to the safeguarding adults review (SAR) concerning the deaths of Joanna, Jon and Ben at Cawston Park hospital. The safe and wellbeing reviews included a requirement for the commissioner undertaking the review to talk to the person's family (with the consent of the person as required), and NHSE worked co-productively with family carers to produce the questionnaire for families. The majority of these reviews have now been completed and the outcomes are being shared with oversight panels for each ICS. NHSE will commission

an independent collation of the key national themes that emerged from the safe and wellbeing review programme and will consider any necessary actions resulting from this.

# Reducing restrictive practices in inpatient care

#### Monitoring the use of restrictive practices

Restrictive practices refer to actions or interventions that prevent a person's movement, freedom, or ability to act independently. Examples of this include enhanced observation, physical restraint, chemical restraint, seclusion, or long-term segregation. These practices are designed to be used when a person may be causing significant harm to themselves or to others. They should only ever be used as a last resort in line with best practice guidance, when all other attempts to de-escalate a situation have been made, and health and social care staff must always consider alternatives.

There are too many instances of restrictive practices being used for people with a learning disability and autistic people. We continue to focus on improving data quality and reporting compliance, in order to build a better understanding of the use of restrictive practice and to inform the actions that we need to take. For example, over time, Mental Health Services Data Set definitions regarding restrictive practices have changed to be more inclusive to support transparency and oversight. CQC is also developing and improving its monitoring of the use of restraint at a provider level.

#### Supporting people to move out of long-term segregation

As a result of the thematic review commissioned by the Secretary of State for Health and Social Care into restrictive practice, we know that a small proportion of people with a learning disability or autistic people in mental health hospitals are detained in long-term segregation. A person's environment should never be more restrictive than absolutely necessary to keep them or other people safe; staff must consider alternatives. When people are in long term segregation, treatment plans must aim to end the period of segregation as soon as possible. Independently chaired Care (Education) and Treatment Reviews (IC(E)TRs) are being carried out for people with a learning disability and autistic people in long term segregation (commitment 1e). Each review, for every individual, seeks to support a person to be discharged or to help them move to a less restrictive setting. As part of this work, long term segregation is understood as a person being in a period of enforced isolation for at least 48 hours and unable to have contact with people in their ward or unit on a long-term basis. It is still considered segregation even if the person is allowed periods of interaction with people.

Baroness Hollins was appointed to oversee the process of IC(E)TRs and chair an independent Oversight Panel in November 2019. By December 2020, 77 IC(E)TRs had been undertaken. The Oversight Panel published a thematic review of 26 of these IC(E)TRs, alongside recommendations to the government. In July 2021, we published our response to the Oversight Panel's review which included strong support for the recommendations. The Oversight Panel recommended that IC(E)TRs should continue. We agreed, and IC(E)TRs restarted in November 2021. We will continue to work with the Oversight Panel to implement the recommendations and carry out IC(E)TRs, in order to

improve the circumstances of people with a learning disability and autistic people who remain in long term segregation.

We know that some people in long term segregation face significant barriers to discharge and require specific support to leave segregation or hospital. We are extending our pilot of Senior Intervenor roles until March 2023, with the aim of reducing the length of time people with a learning disability or autistic people remain in segregation and supporting them to leave hospital (commitment 1f). Senior Intervenors are independent experts of health and social care practice who will work with people and systems, on a case-by-case basis, to find solutions to barriers that may be preventing the individual from moving to a less restrictive setting or into the community.

#### Increasing accountability

The Mental Health Units (Use of Force) Act, also known as Seni's Law, received Royal Assent in November 2018 and has been partially commenced. The purpose of the Act is to increase the oversight and management of the use of force (restraint) in mental health units so that force is only ever used proportionately and as a last resort. On 7 December 2021, we published the statutory guidance on the use of force in mental health settings and the government response to the consultation on the guidance. The majority of the provisions within the Act were brought into force on 31 March 2022 and the rest will be brought into force as soon as possible.

The statutory guidance sets out how we expect mental health units to meet the requirements of the Act. The Act makes it a legal requirement for providers to have a policy to reduce the use of force within their mental health unit, and the statutory guidance includes expectations of what the policy should include and how it should be developed and published. This policy should include the details of how patients, their families, carers, and independent advocates will be involved in care planning. As the regulator, if CQC considers the requirements of the Mental Health Units (Use of Force) Act 2018 and this statutory guidance are not being met, it may take action as appropriate in accordance with its statutory powers and policies.

The publication of the Use of Force Act statutory guidance represents an important step in increasing accountability and reporting of the use of force. It states that the Secretary of State for Health and Social Care must ensure that, at the end of each year, statistics are published regarding the use of force by staff. In addition, the NHS Standard Contract (2022 to 2023) necessitates providers of mental health services to submit data and information to commissioners on a quarterly basis as part of reporting requirements. The NHS Standard Contract also includes a condition for providers of mental health and learning disability services and mental health and learning disability secure services to have regard to the Standards for Inpatient Mental Health Services to encourage high quality service provision.

#### Improving culture, knowledge, and skills

In October 2020, CQC published its 'Out of Sight – who cares?' report following a review into the use of restraint, seclusion, and segregation, which was commissioned by the then Secretary of State for Health and Social Care. The report highlighted that there is a culture of restrictive practice and poor human rights approaches in many mental health hospitals across the country. This was followed by a progress report in March 2022. On 21 July 2021, we published our response to the recommendations made by CQC and work is underway

to implement these. In our response, we confirmed agreement, in full or in principle, to all of the recommendations made which named DHSC as the lead. As part of its role to bring together relevant work across systems and encourage effective partnership working, the Building the Right Support Delivery Board will have oversight of the work to implement these recommendations. This will ensure we are doing all we can to make progress across systems.

In order to effectively reduce restrictive practices, it is important to develop positive cultures in services and ensure the workforce has the right knowledge and skills. We have worked with partners to develop training standards and certification to minimise the use of restrictive practices. Services across health and social care are expected to only use training in restrictive practices that is delivered by an organisation with UKAS accreditation and therefore compliant with the Restraint Reduction Network (RRN) training Standards. The Use of Force Act statutory guidance sets out the requirements for staff training in the use of force. The NHS Standard Contract requires all providers of mental health and learning disability services to ensure all relevant staff have received training in restrictive practices that is delivered by an organisation with UKAS accreditation.

The HOPE(S) model is a national training model which follows a human-rights based framework and provides person-centred and trauma-informed approaches to working with people in long term segregation. The model was developed by Mersey Care NHS Foundation Trust. The model seeks to improve people's experiences and health outcomes, reduce length of stay, and support discharge. The HOPE(S) model will be delivered through NHS-led provider collaboratives to embed good practice across inpatient services with the aim of reducing the use of long term segregation and overall reliance on restrictive practices on a national scale. Recruitment is underway for HOPE(S) specialist practitioners as part of this work.

There is a range of other work underway in NHSE, which includes:

- co-produced family trauma training that has been commissioned to promote awareness and understanding of the impact of trauma – this training is running throughout all seven NHS regions
- introduction of human rights training and an assessment framework across children and young people inpatient services
- the Quality Improvement Taskforce is rolling out a Safe Wards programme across 20 wards with the aim to improve cultures and reduce the use of restrictive interventions

We are taking steps to reduce the inappropriate prescription of psychotropic medication. NHSE lead the STOMP and STAMP programme to make sure that people with a learning disability, autism or both are only prescribed the right medication, at the right time, and for the right reasons and in safe amounts. We know that people with a learning disability, and autistic people are more likely to be given psychotropic medicines than other people. These medicines affect how the brain works and include treatments for psychosis, depression, anxiety, epilepsy, or sleep problems. But they are sometimes given because services are required to provide care and treatment and to manage behaviour described as challenging when the person does not have a diagnosed mental health condition and where alternative interventions have not been provided in a timely and effective way. These medicines, which are supported by guidance from the National Institute for Care and Excellence (NICE) in particular circumstances, may be right for some people and can support them to stay safe and well. However, they must only be used together with or other treatments and supports

to help people to receive less medicine or none at all. The STOMP and STAMP team encourage clinical staff, together with the person, to carry out medication reviews that look at the whole of people's lives to identify the underlying causes and whether psychotropic medication is the right intervention for that person at that time.

In addition, the NHS Standard Contract states that in mental health and learning disability services and mental health and learning disability secure services, providers must monitor the cardiovascular and metabolic health of people with severe mental illness and people with a learning disability, autism or both who are receiving anti-psychotic medication, in accordance with relevant NICE clinical guidance.

### Being supported by the right people

Having the right workforce with the right skills and training to support people with a learning disability and autistic people is crucial in ensuring a person receives the best quality care and support. We know that there can be challenges recruiting and retaining staff with the right expertise and we are eager to support employers to lead and develop a confident and skilled workforce. We want to support staff to have the right knowledge and skills to provide personalised and compassionate care.

The People at the Heart of Care: Adult Social Care Reform white paper sets out our intention to invest in social work training routes and to improve the pre-qualification and post-qualification pathways in social work. We are committed to improving the quality of social work education and training and maintaining a sufficient supply of social workers with the right skills, knowledge, and values. Building on the post-qualifying standards for social workers, DHSC commissioned the British Association of Social Workers (BASW) to develop continuous professional development frameworks for social workers working with people with a learning disability and autistic people. We are taking further steps to build the capability of the social care workforce in the long term, which is set out further in 'Chapter 5: Working with changes to the system'.

Skills for Care are undertaking work to embed core skills for the social care and health workforces that support people with a learning disability and autistic people. This involves incorporating the Core Capability Frameworks for learning disability and autism, which were published in October 2019. Alongside the Institute for Apprenticeships, Skills for Care will support employers to consider specialist apprenticeship and diploma routes, recommending that they are linked to the core learning disability and autism capability frameworks (commitment 1g). In addition, Skills for Care plan to review the Level 4 adult social care diploma and use the findings to influence change to the associated apprenticeship standard by April 2023 to provide evidence of practice leadership that delivers high quality support for people in the community.

Skills for Care, alongside other partners, are leading on implementing a programme of personalised development for the workforce supporting people with a learning disability and autistic people who are at risk of being admitted to inpatient settings or who are ready to be discharged (commitment 1h). This involves providing funding through a personal workforce budget to deliver tailored learning and development for the people that support them. The budget does not fund learning and development that can be funded through other or usual routes, such as qualifications. It is designed to be customised to a person's needs which may involve bringing together people in their support network or arranging a series of

supervision sessions. Delivering this programme can have a positive impact in ensuring people are supported by a social care workforce that can better identify and understand their needs. Skills for Care will continue to evaluate this programme and use lessons learned to support employers and commissioners to trial the approach using their own commissioning resources.

Introducing mandatory training on learning disability and autism is an important way in which we can address persistent disparities in health and care outcomes for people with a learning disability and autistic people. That is why the government invested £1.4 million to test and trial the Oliver McGowan Mandatory Training (OMMT) on learning disability and autism, as set out in the 'Right to be Heard' publication (November 2019). This training is intended to ensure that health and social care staff have the skills and knowledge to provide safe, compassionate, and informed care. The OMMT was trialled in England during 2021 with over 8000 people. This training has been co-designed and co-delivered by autistic people, people with a learning disability, family carers and subject matter experts. By trialing the training and involving people with personal experience in its delivery, this ensures that the training is meaningful, sustainable, and not just a tick box exercise.

A robust evaluation of the trials has taken place, and a final evaluation report was published in June 2022, which will inform the next steps of the Oliver McGowan Mandatory Training programme (commitment 1i). The Health and Care Act 2022 introduces a new requirement for registered providers to ensure their staff receive specific training on learning disability and autism, which is appropriate to their role. It also creates a duty for the Secretary of State to publish a Code of Practice, which will make provisions about the nature of the training, including the content, delivery, and the ongoing evaluation of the training.

We want to ensure that the healthcare workforce have the right knowledge, skills, and capacity to support people to stay in their local communities. HEE and NHSE are working together to make this happen. This includes providing community learning disability teams and intensive support teams with the opportunity to commence advanced and consultant level practice training by April 2023 (commitment 1j). Community learning disability teams and intensive support should have a system in place to prioritise and provide timely support to people at risk of admission or who may be ready to be discharged. HEE encourage all community learning disability teams and intensive support teams to have the multidisciplinary workforce that best supports people's wide range of needs. Depending on local needs, this may include psychiatrists, clinical psychologists, physiotherapists, dieticians, occupational therapists, speech and language therapists and learning disability nurses. This will ensure people receive coordinated, specialist support when they need it.

NHSE are working with HEE on plans to further strengthen the health workforce that supports people with a learning disability and autistic people. In addition, NHSE are investing £1.5 million of funding into the development and trialling of autism training for staff working in adult inpatient mental health settings in 2022 to 2023 (commitment 1k). HEE will be developing autism training for staff working in mental health community and inpatient settings for all age groups (commitment 11).

#### Providing personalised support in action: Keith's story

Keith has a learning disability, complex autism, and related anxiety. He has been supported in his own home by the Lifeways Group for over ten years. He can sometimes display behaviours of distress and can find it difficult to find solutions to the thoughts he has which are building his anxieties. The Lifeways Group recognised that they have found it difficult to build the right communication with Keith. They wanted to ensure that the staff who support him have the right skills and experience to provide the best care and support for Keith. This included supporting Keith to build a daily lifestyle where he could cope with the unpredictability of certain situations, have structures and routines that he was comfortable with, and could take part in as many activities as possible.

Skills for Care provided funding to allow the time needed for Lifeways' multidisciplinary and behaviour team to work with Keith's team to develop a positive behaviour support plan and training for staff. They worked with Keith and his staff team to develop ways they could better understand each other, including strategies to encourage Keith to talk through his thoughts and problems. One example of this was using 'thought bubbles' in which Keith would write down his thoughts and feelings. He would discuss these with staff and talk through what the thoughts meant to him and would then decide himself if he wanted to keep them or discard them. He usually disposed of them once he was happy that the thought 'had been dealt with'. Often, he just needed an answer or solution and this would usually leave him feeling more relaxed and happy.

As a result, Keith now leads a more fulfilled life with reduced levels of anxiety. His behaviour patterns have changed, and he now talks with staff much more. Now that he's coming to terms with his thoughts, he's able to work through past experiences that have always troubled him. Because of these memories, he has often refused to return to places or meet people from the past. In his own words, he feels he is now able to confront issues with a view to moving on from them. Staff are also more confident in dealing with any issues and embracing positive risk taking, and turnover has reduced. The Lifeways Group fed back that the training allowed them to 'develop an understanding of how Keith was feeling, how his staff were feeling and how this impacted on everyone involved.'

# Chapter 2: Making it easier to leave hospital

#### 'I' statements

If I need to go to a mental health hospital for treatment:

I will be treated with respect and my rights will be upheld

I will have a plan in place if I, or the people around me, recognise that I may benefit from being in hospital. This plan will help me to avoid going into hospital where possible.

I know that the agreed action points written in my plan will happen and that I will get the things I need at the right time

I will be involved in the development of my plan to leave hospital as soon as I am able.

I will be central to regular reviews of my care and will participate in ways that work for me to make sure that I can leave hospital as soon as possible.

I will involve people that matter to me in my reviews in a way that I choose.

I will have access to good quality independent advocacy support to uphold my rights.

I am able to build a trusting relationship with an advocate who knows me and my family

I will have access to good support in the community and my own home post discharge to help me live well and avoid going back into hospital.

# Planning to leave hospital

As soon as a decision has been made that an individual would benefit from going into a mental health hospital for treatment, they should be involved in making a plan for how they will leave hospital once they are ready to do so. Ideally, this discharge plan should be started before they go into hospital. If not, it must be started as soon as possible and no longer than one week after admission. As part of the drive to make sure that this happens, NHSE are currently piloting the introduction of a 'clinical contract'. This clinical contract will set out expectations about the care of an individual during their stay in a mental health hospital, including the assessments that should be carried out and the requirement for a treatment plan, expected outcomes and plans for ongoing treatment in the community.

It is important that an individual's plan to leave hospital is reviewed regularly and that their family and or the people who matter to them are able to be involved in this process (with the individual's permission, as required). As planning for discharge should look at the whole person, it is important that plans include the input of professionals from every relevant part of an individual's life, be that their health, their home, the support they need to live a good life, and/or their education. This is why in 2020 to 2021 as part of our mental health recovery programme we invested £1.35 million into life planning, including piloting Senior Intervenor roles, to support autistic people and people with a learning disability (or both) who were in long-term segregation with discharge planning (commitment 1f).

In addition to this investment, there are a number of existing mechanisms in place to support people to leave hospital in the right way and at the right time. These include the 12point discharge plan which local NHS commissioners are expected to use for each person in inpatient care, and care room approaches (NHS regional regular reviews of care plans at an individual level) to ensure that a person's care and treatment in an inpatient unit is still right for them and that actions are happening to support the person to leave hospital as quickly as possible. The role of social care across children's and adults' services is vital in supporting these reviews and working in partnership to avoid admission, to support discharge planning, and to support safe provision of care and support to avoid readmission.

We recognise that high-quality, culturally appropriate advocacy support can make a big difference when planning for discharge, whether this is through a professional advocate, via a family member, or through peer support from a self-advocacy group. We will make recommendations to improve this support, based on the review of advocacy provision that was outlined in 'Chapter 1: Keeping people safe and ensuring high quality health and social care' (commitment 1a).

The support that someone receives after they have left hospital is vital to ensuring that they can continue to live a good life in the community. Section 117 of the Mental Health Act places a duty on both health and social services to provide free aftercare services to people who cease to be detained in hospital under certain sections of the Act and who leave hospital. Support could also be provided, where relevant, through Continuing Care (for children) and NHS Continuing Healthcare (for adults). 'Chapter 3: Living an ordinary life in the community' provides more detail on the actions we are taking to ensure that people who have left hospital have the right care, housing and support so that they can stay in their community.

# Helping people to leave hospital when they are ready

When someone needs to go to a mental health hospital to receive treatment, we are clear that they should only stay there for as long as is necessary for their treatment to be complete. For people with a learning disability and autistic people in hospital, commissioner oversight visits should be happening every 8 weeks for adults and every 6 weeks for children and young people to make sure that there is a reason for them to be in hospital, that they are being properly cared for, and to take action to tackle any barriers to discharge.

In addition to commissioner oversight visits, C(E)TRs should be happening every 3 months for children and young people in hospital, every 6 months for adults in a non-secure mental health hospital, and every 12 months for adults in a secure mental health hospital. We know that C(E)TRs can be an effective way to help support people to not go to hospital for their care, or support people to leave hospital, at the right time. NHSE is currently working on a refresh of the C(E)TR policy (commitment 2a). The refreshed policy will have an increased focus on the physical health of people in hospital and will include an increased emphasis on the importance of the actions that should follow from a C(E)TR. 'Chapter 1: Keeping people safe and ensuring high quality health and social care' includes further detail of work underway to ensure the findings and recommendations from C(E)TRs are considered as part of an individual's care and treatment plan. This will support us to ensure that progressing a person towards discharge is a priority from day one of being in hospital.

# Addressing the reasons for delays

To increase our understanding of why some people who are ready to leave hospital are not able to do so right away, NHS Digital has revised the Assuring Transformation dataset to include a greater level of detail about discharge planning, reported by commissioners at an individual level. While we recognise that there may be a complex range of reasons as to why an individual's discharge may be delayed, this data has shown that the most commonly reported reasons for a delayed discharge from inpatient care are the unavailability or waiting times for social care support and a suitable place to live (please note that there may be more than one reason given for a delay).

Another challenge can be funding, particularly the problem of 'double running' costs. This is where costs occur before a formal discharge when a person is still an inpatient requiring a bed, and a community care package is also being put in place. To address this and support the development of innovative solutions to enable people to leave hospital, we committed to £74 million in the UK (£62 million in England) for people with a learning disability and autistic people to support discharge from hospital into the community (commitment 2b). Of the £62 million Community Discharge Grant in England, £20 million was made available to local authorities during summer 2020, £21 million of funding was issued for 2021 to 2022, and the remaining £21 million will be issued for 2022 to 2023. In 'Chapter 3: Living an ordinary life in the community', we provide more detail on the actions we are taking to ensure that people have access to the right housing and support in their community.

To ensure oversight of local authority Community Discharge Grant expenditure, we have introduced the Community Discharge Grant data recording tool. Developed in conjunction with local government, this tool collates data to demonstrate the effectiveness of the grant. This evidence base will help the government to understand how the grant has been used and how effective it has been, ultimately informing future decision making.

#### Helping people to stay in their community: **Small Supports** Beyond Limits

Beyond Limits works with people who are at risk of a hospital admission or have been discharged from a period as an inpatient. It is a small supports provider which means that it provides a bespoke service to people in their home with staff chosen by them and in partnership with the person, their family, commissioners and other NHS and social care providers.

Beyond Limits has successfully supported people that have spent many years in and out of various inpatient settings and it does this by having a clear focus on their aspirations and strengths to ensure that everyone can have a good visible life - lived in their local community including having a job, friends, living in an ordinary house, and using universal services such as primary care.

All support is co-produced with the person, and they have the freedom to choose who works with them and the activities they do.

# Reducing the number of people with a learning disability and autistic people in inpatient care under Part III of the Mental Health Act

Part III of the Mental Health Act exists to manage the unique circumstances, needs, and risk profiles of patients in the criminal justice system. As such, it allows us to balance the interests of public safety with the care and support needs of the individual.

MoJ is mindful that for some people with a learning disability and autistic people in the criminal justice system, the only alternative to detention in hospital is detention in prison. In such cases, it is likely that detention in hospital may be a more appropriate environment to ensure that patients with a learning disability and autistic patients are able to access the specialist support they need.

However, we know that people with a learning disability and autistic people can face challenges at all stages of the criminal justice system, and detention in hospital comes with its own difficulties in terms of facilitating discharge. MoJ and DHSC are committed to working together to address these issues, including ensuring that our prison estate meets the needs of people with a learning disability and autistic people and that knowledge of best practice is shared amongst staff. In recognition of the importance and the complexity of this area, the Building the Right Support Delivery Board has made reducing the number of people in inpatient care under Part III restrictions one of its priority areas of work.

Restricted patients are offenders who are detained under Part III of the Act in hospital for treatment and who are subject to special controls by the Secretary of State for Justice. These controls include requiring permission for community leave, transfer to another hospital, discharge and recall to hospital, with decisions made by the Her Majesty's Prison and Probation Service (HMPPS) Mental Health Casework Section on behalf of the Justice Secretary. The overall aim of the restricted patient system is to protect the public from harm from offenders who have generally committed serious and violent offences, while at the same time recognising patients' rights to support and treatment.

To help facilitate the discharge of restricted patients who are ready to leave hospital but still present a risk to the public, MoJ is introducing a new power of Supervised Discharge to enable the discharge of restricted patients into conditions in the community which amount to a deprivation of liberty. This new power will apply to a very small number of restricted patients, some of whom may be people with a learning disability or autistic people, and it is part of our work to reform the Mental Health Act in legislation that will be introduced when parliamentary time allows (commitment 2c).

Following a call for evidence to find out what happens to neurodivergent people<sup>5</sup> when they come into contact with the criminal justice system and how they can be supported in future to realise better outcomes, MoJ published an action plan on 30 June 2022 on the recommendations in the Neurodiversity in the Criminal Justice System: A review of the evidence report (commitment 2d).

The findings of the call for evidence will also inform a national Neurodiversity Training Toolkit for frontline staff, as announced in the Sentencing White Paper (2020), which will enable frontline staff to manage people with neurodivergent conditions in the system more effectively. These measures seek to improve awareness of neurodiversity in the criminal justice system and provide staff with the tools and knowledge to better understand and identify neurodivergent individuals and support them to engage meaningfully with the rehabilitative aspect of their sentence. MoJ has committed to publish this toolkit by the end of 2022.

Furthermore, as part of the government's autism strategy, MoJ is working to improve the way in which the criminal and youth justice systems support autistic people. This includes supporting more prisons to become accredited by the National Autistic Society, to provide increased support for autistic people and to learn from the good practice of those already awarded accreditation.

NHS England Health and Justice have also recently published guidance for prison healthcare services concerning people with a learning disability and autistic people accessing these services. This includes reference to transfer to hospital from prison. They have also published updated guidance on the transfer of prisoners from prison to hospital under the Mental Health Act.

In addition to working closely with partners in Health and Justice to deliver these commitments, MoJ will continue to work collaboratively with Her Majesty's Prison and Probation Service, NHSE and DHSC on discharge planning to help identify barriers and progress individual cases as appropriate (commitment 2e).

<sup>&</sup>lt;sup>5</sup> As well as Learning Disability and Autism, Neurodivergence includes a range of conditions including Attention Deficit Disorders, Dyslexia and Dyspraxia.

# Chapter 3: Living an ordinary life in the community

### 'I' statements

I live an ordinary independent life in my community. I have good quality care and support in the way I want and need it to live my life the way I want to. I am respected as a citizen and have the freedom and opportunities to live my life the way I choose.

#### For me this means:

I live in my home, in my community with the people I love and who love me

I get the support I need when I need it from people who understand my rights and needs

I am treated like a whole person and my needs are met by professionals who work in a joined-up way

I have access to the right support commissioned by people who understand what works best for me

If I need support, that support is readily available and flexible and I have a choice of options for what works best for me

If I have an employer, I know they will make necessary reasonable adjustments to have an inclusive workforce

I have the right support if I have a time of crisis in my life, and I have a clear plan on what this looks like

If I come into contact with the police and criminal justice system, I know that they understand my needs, make reasonable adjustments, and divert me away from prosecution where possible.

# Having a good home

Good community provision supports people with a learning disability and autistic people to live the life they choose. Having a home, feeling involved in a local community, and having a reliable support network means that people live ordinary lives on ordinary streets.

#### Supported housing

Lack of suitable housing is considered a significant reason for delayed discharges. Assuring Transformation data shows that in April 2022, 45% of delayed discharges indicated a lack of suitable housing provision as one of the reasons for delay. Not having the right home, whether that is general needs housing, supported housing or residential care, can also contribute to people having unmet needs and being admitted into a mental health hospital. This is why the Building the Right Support Delivery Board has identified the need to address the adequacy and provision of housing as one of its priority areas of work. The adult social care reform white paper ('People at the Heart of Care') published in December 2021 stated the important role of suitable housing, including supported housing, in providing care and support. In the white paper, we committed to investing at least £300 million over the next 3 years to embed the strategic commitment in all local areas to connect housing with health and care, to increase local expenditure on services for those in supported housing, and to boost the supply of supported housing, including for people with a learning disability and autistic people (commitment 3a).

Since 2016, NHS capital has supported the development of community accommodation (both permanent homes and short-term accommodation) to support people with a learning disability and autistic people to be discharged from a mental health hospital or to prevent admission. £15 million has been made available for 2022 to 2023 with a further annual commitment of NHS capital funding, to be prioritised according to need, made up to 2024 to 2025.

Capital funding programmes are underway to incentivise new supply of specialist and supported housing and to increase the availability and choice of specialist and supported housing, including for people with a learning disability and autistic people (commitment 3b). The £11.5 billion Affordable Homes Programme (2021 to 2026) includes delivery within the programme of new supported housing. In addition, we will continue to invest in the Care and Support Specialised Housing (CASSH) Fund over the next 3 years to continue to deliver specialised housing, including for people with a learning disability and/or autism or mental ill-health.

Building the Right Home sets out guidance and principles for housing for people with a learning disability and autistic people that need specialist and supported housing. Local authorities should understand and share information with council housing and development colleagues about the specialist housing needs for their area and engaging with and actively supported by partners across systems, should facilitate close working arrangements between health, care, and housing services to provide person-centred housing, care and support for people, facilitate discharge and prevent readmission, and enable people to live positive, self-determined, healthy lives in the community.

To support with providing a range of housing options, Home Ownership for People with Long-Term Disabilities (HOLD) exists as a form of shared ownership designed to assist people with long-term disabilities, including people with a learning disability and autistic

people, to purchase a property that meets their needs on the open market. This enables people to live in a home of their own within a house and street that is ordinary and near their family and friends, as well as necessary support services.

DLUHC, are working with colleagues across government on supported housing. This includes representatives from DHSC and the Department for Work and Pensions (DWP). In October 2020, DLUHC and DWP published a National Statement of Expectations (NSE) for supported housing which sets out the government's vision for what good looks like in supported housing, with examples of best practice and beneficial ways of working in the sector. The guidance brings together accommodation standards in supported housing, setting out legal requirements as well as recommended standards for 'minimum' and 'going further'.

In addition, DLUHC are commissioning independent research to understand the size, cost, and demand of the supported housing sector, including that which meets the needs of people with a learning disability and autistic people, with the final findings report due at the end of 2023 (commitment 3c). This will help to develop an up-to-date evidence base on supported housing supply to support policy development and local system decision making.

#### **Disabled Facilities Grant**

Many people benefit from home adaptations to meet their needs. We have committed £573 million per year (2022 to 2023 and 2024 to 2025) to provide funding to local areas to deliver the Disabled Facilities Grant (DFG). This locally administered grant is open to people of all ages and tenures, including people with a learning disability and autistic people. It can help them live safely and independently at home, including in the existing family home (commitment 3d).

While the DFG is means tested, children and young people aged 17 and under as well as those in receipt of some income related benefits are exempt. Foundations, the national body for home improvement agencies funded by DLUHC, published a Guide to Adaptations for Children and Young People With Behaviours That Challenge in April 2021 which includes advice for local authorities on delivering adaptations for autistic children and young people and children and young people with a learning disability.

Through the <u>adult social care reform white paper</u>, there will also be a reform of the DFG. This will include increasing the maximum amount for a grant application, considering how best to align the DFG means test with adult social care charging reforms, and looking at the way DFG funding is allocated to local authorities.

#### Having a good home: siblings live the life they choose

Trafford Clinical Commissioning Group submitted a bid for complex case funding to NHSE for £12,500 to buy specialist equipment and furniture to support two young siblings to move into their new shared home. Using a planned, proactive, and highly personcentred approach, the siblings were able to move into their new shared home. To make the moves possible, it was essential that high quality, bespoke, toughened equipment and furniture were installed into the property.

As a result of this proactive intervention, the siblings live in a comfortable home of their own with furniture that would keep them safe and their house looks like any well looked after home. The siblings were used to this furniture in the family home and in respite settings, so it was familiar to them.

The parent has said that the furniture is specifically built to support people with challenging behaviour. It means that it won't break if it is thrown or jumped on. All the furniture is easy to wipe and keep clean. This is especially important because if you don't have furniture that can be easily cleaned, rooms can smell. This doesn't happen with Tough Furniture, and it provides them with the dignity to live in a house that doesn't smell.

Trafford Community Learning Disability Team noted the resounding success of the move which meant the siblings could thrive, adding that this was in no small part due to the NHSE award which meant the tough furniture which was essential for the placement to function was bought and installed in a timely way. Trafford Community Learning Disability Team noted that the risk of carer and placement breakdown was high whilst the siblings were living at home with parents and would have no doubt resulted in the splitting up of the siblings. The use of assessment and treatment units and/or out of area placements was averted.

# Investing in community support

The NHS Long Term Plan commits to investment into the development of community health services which will help people to live their lives in the community, help prevent people going into mental health hospitals and support timely discharge.

In 2022 to 2023, over £90 million will be invested in community services and support for discharges, specifically for people with a learning disability and autistic people.

This comprises of £40 million investment as part of the NHS Long Term Plan to continue 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, £30 million of funding to continue putting keyworkers in place for children and young people with the most complex needs, and £21 million for the Community Discharge Grant.

More broadly, the NHS Long Term Plan commits to an extra £4.5 billion a year for primary care and community health services by March 2024. Increased investment in intensive, crisis and forensic community support will enable more people to receive personalised care in the community, closer to home and reduce preventable admissions to inpatient services.

# Good community support

Everyone who uses care services should feel confident that they will receive the support they need in the community when they need it. Local authorities are best placed to understand, plan, and provide for the housing, support, and care needs of local people, and to develop and build local care markets. Under the Care Act 2014, local authorities must promote the efficient and effective operation of a market in services for meeting care and support needs. This should be with a view to ensuring that people have a variety of providers to choose from, and that people have enough information to access the services that best meet their needs.

We must build upon our understanding of what good community support looks like. Evidence for this must be disseminated widely so that this can be embedded by all Integrated Care Boards and providers to ensure a wide range of support is available that can meet people's needs. As described in the opening section of this action plan, we are working closely with the Building the Right Support Advisory Group, the LGA and ADASS to understand the best practice models of care needed for the right support to be provided and for better local and national solutions to be developed. This work is one of the priority areas of the Building the Right Support Delivery Board.

#### The 'What Good Looks Like' project

ADASS and LGA have been working with the Building the Right Support Advisory Group to identify 'What Good Looks Like' and produce a report that includes best practice examples, with an emphasis on initiatives that support citizenship and human rights (commitment 3e). This report is coproduced and will include focusing on 'What Good Looks Like' to people with personal experience, and their families and carers. Identification of the conditions that enabled good practice to happen will be noted as part of the process and will improve our understanding of what the barriers to people accessing high-quality community support are and how we can overcome them. Initial work on identifying these best practice models was completed in March 2022, and consultations on the draft report will be undertaken in July 2022. It is expected that the final report will be available in September 2022.

The Advisory Group is made up of people who have a wealth of knowledge in this area, including first-hand experience of the current system. Advisory Group members include people with a learning disability, autistic people, and families.

Co-production has been the main foundation that has enabled the Advisory Group to create the 'What Good Looks Like' report. This reciprocal and equal partnership has supported learning from each other and demonstrates that co-production is vital for good change to happen.

The objective of this project is to develop an evidence base, principles, and examples of good practice for 'What Good Looks Like' in terms of local health and care systems and community and voluntary services for autistic children and adults and or children and adults who have a learning disability. This includes crisis support across England.

By identifying the best practice within local systems that enabled 'good' projects to thrive, and by understanding known barriers and how to overcome them, a summary of how to embed this within local authorities and wider community services will be developed and shared. The final report findings should influence how we adapt our shared improvement programme to make positive change happen together.

Work on the 'What Good Looks Like' project has identified 7 key principles ('must-haves') that underpin good community-based services, including services that support people if they experience a time of crisis. Good support and good services are:

Ethical: they use rights-based approaches to working with individuals and they protect **Human Rights** 

Personalised: they use conversations (not standardised assessments) based on asking "What matters to you?" rather than "What is the matter with you?"

Creative: they are confident at finding solutions that work for individuals by listening to their aspirations. These services work with families as true partners

Agile: they make systems work for individuals rather making people fit into organisational silos, and they are confident working with individuals to find solutions because they understand legislative requirements, financial frameworks, and national guidance

Focused on valuing people. They listen and show that challenge is always welcomed. Workers at all levels are confident in making decisions because they have had good training and are supported by their managers to be open and honest.

Pragmatic: they work with partners to quickly put in place what an individual needs to keep safe and well in their own home. They will question the value of an admission or continued stay in a mental health hospital and will always bring community alternatives to these discussions.

Well Led: they are led by people who model best practice and take positive risks. These leaders trust their teams and will sometimes work outside the 'rules' and have a learning culture within the organisation.

The final report on 'What Good Looks Like' will also outline the "must do" actions that are needed now to ensure that good change happens.

#### **Supporting local systems**

In this action plan, NHSE, along with a range of partners, commit to continuing to roll out a programme across England that enables the development of small (supporting less than 30 people with a learning disability and autistic people) community driven organisations to deliver high quality, bespoke support, wrapped around an individual that promotes choice, control, human rights and citizenship (commitment 3f). This supports market development within local systems. As set out in the case study in 'Chapter 2: Making it easier to leave hospital', this programme involves addressing commissioning structures that limit creativity and innovation and working with and encouraging the establishment of small providers that promote individual choice and control within communities. 12 ICSs have been through the process and a further 8 ICSs will be recruited by the end of March 2023. This programme of work aims to help councils and systems to think differently about how they develop and increase the local market of regulated, high quality bespoke providers for people with a learning disability and autistic people and supports systems to engage with values driven individuals who may not have considered how they could become a local support provider. The programme will nurture systems and people to create small, bespoke community organisations to support people and families.

NHSE will continue to commission funded peer reviews (commitment 3g). This is a voluntary process available to the local systems and key partners who support an area to deliver the commitments set out in Building the Right Support and the NHS Long Term Plan. It involves a small group of peers spending time in another area as 'critical friends' to support an area to develop and improve service delivery. This process involves a wide range of stakeholders, including people with personal experience, and reflects to the system where they need to focus attention. It helps to create an environment where system leaders, commissioners and service providers are able to collaboratively take responsibility for their own improvement.

#### Help to stay well

Being able to stay well is important to all of us and being able to access healthcare effectively is something we take for granted. People with a learning disability are more likely than the general population to have at least one long term condition, which means that being supported to have their health checked annually by their local primary healthcare team, and have their health monitored with a health action plan, is fundamental to enabling people to stay well. We want to encourage more people with a learning disability to request an annual health check, which can improve people's health by spotting problems earlier, and will work with NHSE to support actions for those most vulnerable in ethnic minority groups and isolated communities.

#### Sport and physical activity

Access to regular sport and physical activity provides a range of social, physical, and mental health benefits, and is key in supporting living a full and ordinary life. Benefits include reducing the risk of disease, managing existing conditions, and developing and maintaining physical and mental function. We are working with Sport England, our arm's length body for grassroots sport in England, to engage people with a learning disability and autistic people and ensure they have the same opportunities to experience the positive impact of sport and physical activity.

# Better commissioning

Evidence from work such as the independent reviews of people in long term segregation and CQC's 'Out of Sight' report indicate that commissioners would benefit from additional support to build knowledge and design creative commissioning solutions that best meet the needs of people with a learning disability and autistic people of all ages.

Skills for Care have committed to continue to roll out an accredited commissioning qualification for current and aspiring commissioners by April 2023 (commitment 3h). This commissioning qualification has been developed to support the commissioning workforce to develop their skills, knowledge, and expertise in commissioning for people's lives and not just for a service. Training providers for the commissioning qualification engage families and people with personal experience as co-trainers. Furthermore, by April 2023, a training programme for senior leaders will be rolled out to increase their skills and knowledge to support local commissioners (commitment 3i).

In addition to this, we are developing commissioning guidance to build the capability and knowledge of the commissioning workforce, designed to complement qualifications and

training programmes (commitment 3j). Autism specific commissioning guidance is already available and guidance specifically written to support commissioning for people of all ages with a learning disability was published in July 2022.

Health, social care, education, and housing commissioners are responsible for the diversity of housing, care, and support services in their local area. This includes the service's adequacy and quality for people with a learning disability and autistic people of all ages. As part of our proposals to reform the Mental Health Act, we propose to introduce new duties on commissioners to ensure that there are adequate community-based services in their local area to support people with a learning disability and autistic people (commitment 3k).

In addition to this, we propose to introduce a new duty for commissioners to hold a dynamic support register (DSR), including an 'at risk of admission' component, that would ensure that commissioners understand and monitor the risk of crisis at an individual level for children, voung people, and adults with a learning disability and autistic children, young people, and adults in their local population (commitment 31).

# Getting and keeping a job

Good work helps people to live healthier and more independent lives. Disabled people and people with long term health conditions have been more likely to leave work than nondisabled people, and then face additional barriers compared with non-disabled people when returning to work. This is particularly true of people with a learning disability and autistic people, only about a quarter of people with a learning disability and autistic people of working age are currently in employment.

Not all disabled people or people with health conditions feel able to work at any given time, but with the right employment conditions many say they could do some work. For example, DWP research with people in the Support Group and with Limited Capability for Work Related Activity (LCWRA) showed that one in five people (20%) felt work could be possible in the future, and 4% felt they could work now, if the right job and the right support were available.

Progress has been made since 2017 when government published Improving lives: the future of work, health, and disability. In 2017, the government set a goal to see a million more disabled people in employment between 2017 and 2027. The latest figures released for Q1 2022 show that between Q1 2017 and Q1 2022 the number of disabled people in employment increased by 1.3m – meaning the goal has been met after only five years.

Good and appropriate careers advice can help people with a learning disability and autistic people move into and stay in employment. DfE is developing a careers system that will support anyone to go as far as their talents will take them and have a rewarding career. The Gatsby Benchmarks of Good Career Guidance defines world-class careers education, and DfE expects all secondary schools and colleges to use the Gatsby Benchmarks to develop and improve their careers programmes. The benchmarks can be used for all young people, but specialist implementation support is available through the Careers & Enterprise Company (CEC) to assist delivery of the benchmarks for young people with Special Educational Needs and Disabilities (SEND). The CEC work with special schools across England, as well as with Careers Leaders, who design and deliver careers education programmes tailored to the needs of young people with SEND, regardless of their

educational setting. They undertake targeted work with employers to stimulate more employer engagement that will support young people with SEND, and they will continue to make the case for employers to provide work experience and Supported Internships for young people with SEND.

Supported Internships provide young people with Education, Health and Care plans with the skills to secure and sustain employment. DfE are committed to strengthening the Supported Internships programme and have worked with the Education and Training Foundation to publish a Quality Assurance Framework to support providers to review and improve the quality of internship provision. DfE have recently announced up to £18 million funding over the next three years, aiming to build capacity of the programme to support more young people with Education, Health and Care plans into sustained, paid employment (commitment 3m). DWP have secured increased Access to Work funding to support this expansion and help pay for workplace adjustments where necessary.

For those people with a learning disability and autistic people who do find themselves excluded from the workplace, starting this autumn, DWP will invest £7.2 million in Local Supported Employment services, working with around 20 Local Authorities to enable more social care users with a learning disability and autistic social care users to access the support needed to help them get into work and remain in employment. DWP have also strengthened their Disability Employment Adviser role, delivering direct support to claimants who require additional work-related support and supporting all work coaches to deliver tailored, personalised support to claimants with a disability or health condition, including those who are autistic.

Access to Work offers disabled customers, including those with a learning disability, tailored packages of support and advice to help them access or remain in work. DWP are also piloting an Adjustments Passport supporting disabled people with the transition to employment and the move between employers, and are also piloting Access to Work Plus which can deliver more support to those with the greatest needs.

Furthermore, the Intensive Personalised Employment Support programme provides highly personalised packages of employment support for disabled people who want to work but have complex needs or barriers and require specialist support to achieve sustained employment. In addition to this direct action, DWP is engaging with employers through the Disability Confident scheme and helping to promote the value people with learning disabilities can bring to their businesses.

Alongside this work being undertaken by DfE and DWP, the Department for Business, Energy and Industrial Strategy (BEIS) launched an online advice hub offering accessible information and advice on rights for disabled people.

# The right support at a time of crisis

We want the right support to be in place so that people are less likely to reach a point of crisis. For times that pose a particular risk of crisis, such as a time of transition, health, social care, and education services must work together to support people and their families. It is important that local NHS services and local authority social care and education services understand the needs of people with a learning disability and autistic people of all ages in their area. This is so that they can make sure people receive the right support. It is

important that services know the people who are likely to need additional support and when people might need it so that they don't end up being admitted to mental health hospitals unnecessarily. It is important to understand what the right support looks like for each person. The right support might include access to reasonably adjusted services such as psychological therapy.

People with a learning disability and autistic people who are at risk of admission should be offered a community C(E)TR to see whether they are safe, in the right place, and to understand their plans for the future. Recommendations from community C(E)TRs can involve support from specialist health teams, local authority respite care, voluntary agencies, short breaks, and self-advocacy and carer organisations providing support.

We want every local area to understand and monitor the risk of crisis at an individual level for people with a learning disability and autistic people in the local population. This is why NHSE will work with partners to strengthen the use of DSRs to identify children, young people and adults most at risk of admission. In summer 2022, NHSE will update guidance on DSRs (commitment 3n). The guidance sets out to support local areas to increase the use of DSRs and aims to support consistency of use. The guidance supports the sharing of intelligence from DSRs to inform the individual's care. It will serve as a guide to professionals working in all parts of the health and social care system on their roles to make sure there is an up to date and consistent DSR that is linked to local support offers. DSRs should result in proactive action and additional support for a person of all ages.

The guidance says that there should be clear information for people and their families about what they should expect from a DSR where they live. As a minimum, this should include a clear link between people being included on the register and the facilitation of Community C(E)TRs prior to admission and a route to access the learning disability and autism keyworker service for children and young people, where appropriate. We say more about the keyworker service in 'Chapter 4: A good start to life'. The guidance aims to ensure there is a level of consistency in DSRs so that families/carers are clear what they can expect, wherever they live. It also aims to support local areas to make sure there are robust processes in place to use the intelligence from DSRs to inform commissioning and provision of adult health and social care and children's services.

For those in mental health crisis, NHSE recently moved to ensure that all mental health crisis services are 'open access', via 24/7 urgent mental health helplines. This means that anyone can self-refer and there should be no exclusions to who can seek to access support. As part of the implementation programme to support the ambition to make all NHS urgent mental health services more accessible via NHS 111 by 2023 to 2024, NHSE will share guidance on adjustments and principles for people with a learning disability and autistic people who might call these lines to ensure they get more appropriate support.

# Having the right support at all stages of the criminal justice system

It is important to improve our understanding of patients with a learning disability or autistic patients under restrictions in mental health hospitals, which we set out in 'Chapter 2: Making it easier to leave hospital'.

MoJ is working closely with NHSE on discharge planning to help identify barriers and progress individual cases, as appropriate, and also to better understand the role that liaison and diversion services can play for people at the initial stages of the criminal justice pathway. Liaison and diversion services identify people who have mental health conditions, learning disability, substance misuse or other vulnerabilities when they first encounter the criminal justice system. The service can then support people through the early stages of criminal system pathway, refer for appropriate health or social care or enable people to be diverted away from the criminal justice system into a more appropriate setting, if required.

The national Liaison and Diversion service specification was updated in 2019. It outlines how services can provide a consistent and high-quality approach across England. The rollout of NHS England commissioned Liaison and Diversion services achieved 100% coverage across England in March 2020. In addition, NHS England Health and Justice's Mental Health Treatment Requirement (MHTR) programme of work has employed a neurodiversity lead to help ensure all MHTR services are able to provide treatment services to neurodiverse people with mental health conditions (that form part of their community court order).

# Chapter 4: A good start to life

#### 'I' statements

As a child or young person, I want good opportunities and experiences as I grow up. For me, this means:

I have a timely autism diagnosis that enables me to access the support I need to live an ordinary life

If I have a learning disability, I can access the support I need to live an ordinary life

I feel safe and supported in a school that understands and meets my needs, without living in fear of exclusion and restraint

My school enables me to reach my potential by building on my strengths

If I need one, I have an Education, Health and Care Plan that me and my family are involved in developing, and my education setting is confident in delivering the support it sets out

# Early identification of need

Making sure that children and their families get identification of any disability and additional needs at the earliest stage is essential, as it means that they can access the right support as soon as possible. Whilst having a learning disability may be identified in early years, for some autistic children and young people, this may not be identified until later in childhood, or adulthood for some people. Accessing timely pre-diagnostic and post-diagnostic support is essential. Without a diagnosis, the support that a child or young person needs may not be provided. This can have significant consequences on a child or young person's life and may cause difficulties in school or in accessing education.

We know that in many areas children and young people face long waits for autism assessments and diagnosis. The Autism Act 2009 was a catalyst for a substantial increase in public awareness of autism, which has been positive in improving inclusion of autistic people in society and helping more people recognise they may be autistic. However, as more people recognise that their child or someone they care for could be autistic, demand on diagnostic services is continuing to increase, an issue which has been exacerbated by the pandemic because some assessment and diagnosis services were paused.

Too many autistic children and young 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. NICE guidelines state that if you are referred for an assessment, it should be done within 3 months and be carried out by a team of people who are specialists in autism

Building on the £10.5 million COVID-19 Mental Health Recovery Fund and £2.5 million NHS Long Term Plan investment, in 2022 to 2023, we are investing a further £2.5 million to support delivery of the Long Term Plan commitment to improve autism diagnostic pathways for children and young people. NHSE will continue to develop guidance and support to embed effective diagnostic pathways building on our investment which tested and carried out research into the best diagnostic models last year for children, young people and adults (commitment 4a).

We know that there are considerable benefits in identifying children and young people as early as possible in life, as this enables them to get the support they need to thrive. This is why DfE are investing £600,000 into significantly expanding an autism early identification pilot in Bradford (commitment 4b). This pilot will be tested in at least 100 schools over the next three years, to assess if new approaches can achieve diagnosis faster. The pilot involves teams screening children and young people who are likely autistic and bringing multidisciplinary teams together in school settings to diagnose children more rapidly. This assessment complies with the NICE guideline on the diagnosis of autism.

The early findings are positive. Education staff report that they are better able to identify and put in place the support children need to thrive in their education. A further £1.6 million is being invested this academic year (2021 to 2022) to test and develop the pilot across other local areas with different demographics and commissioning models (commitment 4c). These local areas will also look at upskilling the mainstream school workforce to better identify need, develop screening tools to better identify girls, and test out an 'out-sourcing' model for the multi-disciplinary team members. In one area, health services did not have the capacity to be involved in this, so this left a 'gap' within the multi-disciplinary team aspect of the process. We are working with a private company who have a range of clinicians to draw upon to provide robust assessments for those pupils identified. This can be done in person or remotely. They are already working in this way, as some regions are commissioning them to undertake ASD assessments as a matter of course, to reduce waiting lists.

It is vital that families can access the support and services they need to help them to effectively navigate the system when supporting their young child. We know that this is not always easy. At the Budget in 2021, the Chancellor announced a £300 million package to transform 'Start for Life' services and create a network of family hubs in half of the council areas across England. The package includes £82 million over three years to support 75 areas to create a network of family hubs, in addition to the £39.5 million already committed to champion family hubs. These hubs will offer improved access to services with better connections between families, professional services, and providers. Hubs will be expected to help families who have a child with SEND to navigate support by signposting and referring them to appropriate services within the Hub network and to incorporate evidencebased support for children with SEND into their provision where appropriate. Local authorities receiving funding to develop family hubs through the £12 million Transformation Fund will be expected to integrate SEND provision into their 0-2 year old offer, offering children the best start to life.

All of this work will make a difference to children, young people and their families. As well as reducing waiting lists, variation in practice and complexity in navigating pathways, it will also improve the speed and quality of diagnosis.

# Improving experiences in education

Apart from home, school is often the single most important place in the lives of most children. When children have a special educational need or disability, their experience of school can be very different, and accessing the right support they need to make this a positive experience and enable them to meet their outcomes is vital.

The government recognises that the current SEND system does not always deliver the outcomes we want and expect for children and young people with SEND, including being able to access support early enough from health and social care, as well as education.

We want to improve outcomes for children and young people with SEND within a financially sustainable system. The SEND Review aims to reform the system so that we can realise the benefits of aligned education, health and care provision and ensure children and young people with SEND access the right support, in the right place, at the right time (commitment 4d). The SEND and alternative provision green paper was published on 29 March 2022. It sets out its vision for a single, national SEND and alternative provision (AP) system that will introduce new standards in the quality of support given to children across education, health and care following the SEND Review.

In 2022 to 2023, High Needs funding for children and young people with complex needs is increasing by £1 billion to over £9.1 billion. This unprecedented increase of 13% comes on top of the £1.5 billion increase over the last two years and will continue to support local authorities and schools with the increasing costs they are facing.

An additional £2.6 billion has been made available over the next three years to deliver new places and improve existing provision for pupils with SEND or who require alternative provision (commitment 4e). This funding represents a significant, transformational investment in new High Needs provision and will help deliver tens of thousands of new places, supporting learning in both mainstream and special provision. It will also be used to improve the suitability and accessibility of existing buildings. The funding will be distributed through a combination of local authority grant allocations, further tranches of the 'safety valve' programme, and new waves of centrally delivered special schools

Following a successful project funded by NHSE in North Cumbria and the North East, the scale up of the 'Autism in Schools' project was supported in 2021 to 2022 with an investment of £4 million. To sustain this work, a further £2.5 million will be invested by NHSE in 2022 to 2023 (commitment 4f). This investment enables the Clinical Commissioning Group, local authority and Parent Carer Forum in a local area to partner and work with schools to ensure a shared understanding about the needs of autistic children and young people is held across school settings. This should ensure accessibility and reasonable adjustments in schools are considered at early stages to support autistic children and young people. This project has been rolled out in at least two areas in each region across England. Impact has demonstrated that children and young people have been supported to stay in school and reductions in both crisis and inappropriate admissions to mental health hospitals.

# Supporting children when there are difficulties at school

All children should have a good education where they are able to reach their potential. We know that some children will need additional support in school and that a positive and supportive school environment can often be crucial to enabling autistic children and those with a learning disability to succeed.

We know that a positive school environment is important for autistic children and those with a learning disability to learn effectively. DfE has consulted on the Behaviour in Schools guidance (formerly the Behaviour and Discipline in Schools guidance) which has been updated and will be published shortly. It better develops and communicates the role and expectations of school leaders, staff, and pupils to help create and maintain good standards in schools.

The updated Behaviour in Schools guidance will consider the needs of pupils with SEND and how vulnerable children will be supported. It will provide practical advice to schools on how best to encourage good behaviour and a positive environment in and out of the classroom. It will also give guidance on the use of removal rooms in schools.

Schools and colleges should be positive and respectful environments, where everyone is treated with dignity, where all pupils, students, and staff feel safe, and where all children and young people can learn and reach their potential.

# Supporting children and young people when they need extra help and support

Some children and young people will need more support than a reasonably adjusted offer or support offered through the SEND system. Some children and young people's needs may mean they need a support offer from social care or specialist health services from early in life, and some children and young people may require this throughout their childhood and into adulthood.

For many children and families, access to short break or respite care services and provision can provide essential support that prevents wider crisis and family breakdown. In 2020 to 2021 and 2021 to 2022, NHSE provided additional funding to each local health system to support access to short breaks for children and young people with a learning disability and autistic children and young people.

On 1 February 2022, the government announced a new £30 million fund to support local authorities in developing innovative approaches to the delivery of respite care and short breaks (commitment 4g). This fund will allow local areas to develop and test new approaches to respite, targeting those children and young people who may need a different model of delivery from what is currently available in their area. Successful bids will enable local authorities to work closely with health partners to deliver services which address unmet needs so that families get the best support, and children and young people can achieve the best possible outcomes. In the first year, we expect to fund a minimum of 5 local areas (total investment of up to £5 million) to trial different approaches.

Evidence demonstrates that children with SEND are more likely to experience mental health crises than other children and young people. Ensuring timely and reasonably adjusted access to mental health services is essential.

As part of its Long Term Plan commitment to ensure that by 2023 to 2024 at least a further 345,000 children and young people aged 0 to 25 can access mental health care, NHSE is working with education and third sector partners to deliver Mental Health Support Teams (MHSTs) in schools and colleges. These school and college-based services build on the support already available and help to provide a 'whole school approach' to mental health and wellbeing, build resilience, support earlier intervention, enable appropriate signposting, and deliver evidence-based support, care, and interventions. We have made good progress in rolling out MHSTs. There are now over 280 MHSTs set up or in training, 183 are operational and ready to support children and young people in around 3,000 schools and colleges, covering 15% of pupils in England. A further 112 teams are to be established in 2021 to 2022. MHSTs will cover 20-25% of pupils in England by 2022, a year earlier than originally planned.

NHSE are investing in the development of community intensive support provision to better support children, young people and adults with a learning disability or autistic children, young people and adults as part of the NHS Long Term Plan commitment. In 2021 to 2022, £25 million has been invested in local systems with a focus on autistic young people aged 14 to 25. In 2022 to 2023, this increases to £40 million for people of all ages.

As referenced in 'Chapter 3: Living an ordinary life in the community', for autistic children and young people and those with a learning disability who may also be experiencing mental health crisis, NHS England expect local systems to utilise their Dynamic Support Registers and Systems to identify those children and young people whose needs may be escalating and where a strong multi agency response is required. New guidance about Dynamic Support Registers will be published in summer 2022 (commitment 3n).

If there is concern that a person may be at risk of admission to a mental health hospital, local health commissioners should convene a C(E)TR. For over 80% of community C(E)TRs; the decision is not to admit the person to a mental health hospital.

The NHS Long Term Plan made a commitment that by 2023 to 2024 children and young people with a learning disability and autistic children with the most complex needs at risk of admission or in hospital will have a designated keyworker. 13 pilot areas were funded in each of the regions for 2020 to 2021 and an additional 14 early adopters have now been funded with a full ICS footprint roll out of designated keyworkers for children and young people with a learning disability and autistic children and young people is expected next year (commitment 4h).

# Supporting children and young people who may need to live away from home

For some children and young people, needs change and increase as they get older, or their family circumstances change, and they may not always be able to remain living at home. For children and young people with a learning disability and autistic children and young

people, this may mean that they live either in a residential special school, or a care setting, including sometimes in secure welfare provision.

Some children and young people who experience a mental health crisis where care and treatment cannot be provided in the community may find themselves admitted to a mental health hospital. Some young people may find themselves involved with the youth justice system.

Historically, many children when living away from home may find themselves placed in a setting or home that is far from their family and geographical home. This can be very distressing and can limit opportunities for regular contact and visits. There are also often financial difficulties for families because of needing to travel long distances (transport costs) and taking time off work to do so.

NHSE funded guidance developed by the Challenging Behaviour Foundation (CBF) and Mencap called "Keeping in touch with home" which remains relevant and important in these instances. Through the Provider Collaborative Programme, NHSE are committed to reducing the number of children and young people who are placed in mental health hospitals that are a long way from home.

In some instances, children in mental health hospitals can experience variations in the quality of education provision. This may have a detrimental impact on their education when they return to a mainstream setting. Where an inpatient unit is registered as a school, it is subject to Ofsted inspection. Where a hospital setting does not have an on-site school, provision would be commissioned by the local authority under their section 19 duty to secure education for those unable to attend school. Further detail is in the guidance on education for Children with Health Needs Who Cannot Attend School.

DfE have updated the National Minimum Standards (NMS) for Residential Special Schools (the new standards come into force on 5 September 2022) and engaged with Ofsted and other stakeholders on this update (commitment 4i). Placement decisions based on education (not those who are looked after children) are made with the family involved, and parents can express a preference for the setting they would want their child to attend. A local authority is then under a conditional duty to name that setting. The NMS contain arrangements to safeguard and promote the welfare of children for whom accommodation is provided.

Local authorities' experience of funding suitable placements for those children who become looked after can be variable. The Competition and Markets Authority (CMA) carried out a market study into the children's social care market and the final report was published in March 2022. The CMA found a lack of placements of the right kind, in the right places, meant that children were not consistently getting access to care and accommodation that meets their needs; the largest private providers of placements were making materially higher profits, and charging materially higher prices, than would be expected if the market were functioning effectively; and some of the largest private providers were carrying very high levels of debt. They made recommendations which seek to improve commissioning, reduce barriers to providers creating and maintaining provision and reduce the risk of children's homes providers exiting the market in a disorderly way. The Independent Review of Children's Social Care also made recommendations in relation to placements for looked after children ensure the right type of homes are in the right places, offering a loving environment for children. The government is now considering the recommendations from

both reviews and will publish a children's social care implementation strategy by the end of the year.

In recognition of the fact that there are sufficiency challenges in the placement market for all looked after children in England, the government is supporting local authorities through providing £259 million of capital funding to maintain capacity and expand provision in both secure and open residential children's homes. This will provide high quality, safe homes for some of our most vulnerable children and young people, including autistic children, children with a learning disability and those with mental health needs.

In terms of promoting high quality experiences for those children who are looked after, or who are placed in residential educational settings, Ofsted has recently published refreshed guidance on 'Positive environments where children can flourish', which is a guide for inspectors about physical intervention and restrictions of liberty in social care settings and education.

The 2015 Guide to the Children's Homes Regulations addresses the use of restrictive practice in those settings. The requirements and expectations of schools recognise that behaviours can be a manifestation of a special educational need or disability, that schools have duties to put appropriate support in place to help prevent inappropriate behaviour, and that the school's use of sanctions may need to take account of any SEND a child may have.

# Preparing for adulthood

Points of change and transition, such as education, housing, employment and from children's health and care services to adult services, can cause young people to be anxious and upset. Planning and preparation for these transition points should be proactive and sufficiently in advance to prevent the escalation of needs. When supporting young people with a learning disability and autistic young people to prepare for adulthood, it is important to use a 'strengths based' approach so that they are supported to live full, independent lives within the communities they choose.

As stated earlier in this chapter, a timely autism diagnosis can be important. Upon diagnosis, practical support must be put in place for a child or young person.

Planning for transition to adult services should begin when a child is in Year 9 at school (13 or 14 years old) at the latest. Transition should be an ongoing process rather than a single event and be tailored to the needs of the child. The assessment should provide advice and information about what can be done to meet or reduce the individual's needs, as well as what they can do to stay well and prevent or delay the development of needs. The local authority has a duty to carry out this assessment and the child will continue to receive children's services during the assessment process, either until the adult care and support is in place to take over, or until it's clear after the assessment that adult care and support doesn't need to be provided. Transition assessments could also become part of a young person's Education Health and Care Plan. It is important that everyone involved understands the process and feels supported and prepared to try to ensure that the transition is as smooth as possible.

In addition, as children get older and start to become more independent, parents, families, schools, and other people around them can all help to convey messages about healthy lifestyles. We want to encourage good habits, to give everyone the best start to life, so that by the time a child or young person reaches the age of 14 and is ready for their first annual health check, this is as ordinary as going to school.

As we mention in 'Chapter 3: Living an ordinary life in the community', Supported Internships for young people aged 14 to 16 with SEND, who have an Education Health and Care Plan can play an important role in helping these young people as they move to adulthood by providing the opportunity to achieve sustained, paid employment by equipping them with the skills they need for work, through learning in the workplace.

Supported interns are enrolled and supported by a learning provider, for example, a school or college, but spend most of their learning time in a workplace. Supported interns are in full-time education and their supported internship work placements are part of their course.

# Building the skills and knowledge of the education workforce

Education settings can be important places for people to be provided with early and appropriate information and advice, so it is vital that the workforce has a strong understanding of the needs of children and young people with a learning disability and autistic children and young people to ensure they are better able to meet these needs.

DfE committed to continue support for autism awareness training for education staff in early years, schools, and further education settings (commitment 4j). Since 2011, this training has reached more than 305,000 people and has developed good autism practice guidance and practice frameworks aimed at supporting and improving practice within education settings.

DfE continues to include preparation for adulthood in its programme of school and college workforce training and development on SEND. This will ensure that the education workforce has the right skills and knowledge to support children and young people who may be autistic and or have a learning disability through their education journey and their entry to higher education or employment. In February 2022, DfE announced funding of more than £45 million over the next three financial years (commitment 4k) to:

- target support to improve monitoring, support and intervention for local authorities and local health and care partners' delivery of statutory SEND services, with a focus on underperforming areas and sharing best practice
- improve participation and access for parents and young people for high quality advice and support
- directly support schools and colleges to work with pupils with SEND, for example through training on specific needs like autism

As part of the first year of the national autism strategy, the government is taking a number of steps to improve understanding of autism among educational professionals. In addition, DfE will embed autism as a priority for educational leadership as this is important in developing autism-inclusive cultures and 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.

DfE continues to include preparation for adulthood in its programme of school and college workforce training and development on Special Educational Needs and Disability (SEND). This will ensure that the education workforce has the right skills and knowledge to support children and young people who may be autistic and or have a learning disability through their education journey and their entry to higher education or employment.

Children and young people's experiences of accessing support for SEND can be variable. Ofsted and CQC carry out joint area inspections of SEND services to provide assurance and drive improvement. These inspections cover local authority education and care, and health commissioning bodies. Working in partnership with DHSC, the Department for Education has commissioned Ofsted and CQC to develop and transition to a new joint Ofsted / CQC Area SEND Inspection framework which will provide a much clearer picture of improvement needs and will focus more on the experiences of children, young people and their families (commitment 41). This will support ongoing improvement activity across all parts of the SEND system.

#### The power of the keyworker programme: Luke's story<sup>6</sup>

The NHS Long Term Plan included a commitment that 'by 2023 to 2024, children and young people with a learning disability and/or who are autistic with the most complex needs will have a designated Keyworker'.

Heywood, Middleton and Rochdale Keyworking service began as one of 13 areas across the country to be chosen to pilot a service in their area. In this area, two keyworkers are currently working with nine families. A third keyworker began work in December 2021 with a plan to have three keyworkers supporting up to 30 families by mid-2022.

One young person who is benefitting from the service is Luke\* who is 15 years old and autistic. Living at home with his parents and a younger sibling, Luke was struggling to manage his increasingly aggressive behaviour at home. A variety of medication had been tried and Luke had spent some time living at his grandparent's house to provide his family with some respite. Luke was engaging well in school but struggling with impulse control. He was in a class with a very supportive teacher who communicated regularly with Luke's mental health worker who had known Luke for several years.

Speech and language therapy support had been offered and Luke had been referred to children's social care. However, the family were reaching crisis and wanted support so that Luke could remain with them in the family home. Luke was referred to the DSR, with a red level of risk, and was allocated a Keyworker.

<sup>&</sup>lt;sup>6</sup> Name changed to protect identity

The keyworker said: "Having the opportunity to have an overarching view of the support being offered and to explore the impact of this on the young person enables a different level of understanding regarding what is working, could be improved upon or is missing".

The allocation of a Keyworker ensured that Luke's feelings were captured and supported. Luke responded positively to the support and was able to continue living at home.

# Chapter 5: Working with changes to the system

#### 'I' statements

We want people to be able to say:

The services that support me understand my needs, value what I have to say, and support me to realise my aspirations and wishes.

I am confident I will receive the health, social care, and education support I need to lead a good, ordinary life

I am confident that the health, social care, and education systems work for me in a joined up way and protect my rights.

# Reforming the Mental Health Act

We are taking action to ensure that people living with mental health conditions who may require treatment under the Mental Health Act have greater control over their treatment and are treated with dignity and respect.

The Independent Review of the Mental Health Act, chaired by Professor Sir Simon Wessely, which reported in December 2018, concluded that the Act does not always work as well as it should for patients, nor for their families and carers. It proposed recommendations for change.

In response to the Independent Review, the government published a White Paper in January 2021, which accepted the vast majority of the review's recommendations and sought views on the impact of these recommendations and how best to implement them in practice. We published our response to this consultation in July 2021.

The proposed reforms to the Mental Health Act support the objectives of Building the Right Support and the aims of the NHS Long Term Plan so that more people with a learning disability and autistic people are supported in the community and fewer in mental health hospitals. The draft Mental Health Bill was published on 27 June 2022 and will go through pre-legislative scrutiny ahead of being introduced when parliamentary time allows.

We know that the majority of people with a learning disability and autistic people who are in mental health hospitals are detained under the Mental Health Act. The Assuring Transformation data set shows that in March 2022, 92% of people with a learning disability and autistic people were detained under the Mental Health Act (52% under Part 2 civil sections, 27% under Part 3 forensic sections with restrictions, 12% under Part 3 without restrictions, and 2% under other parts of the Act). For some people, being detained under the Mental Health Act can lead to prolonged detention which may worsen their condition. particularly if the inpatient environment fails to meet their sensory or communication needs. This means our proposed changes to the Act should play a meaningful role in delivering Building the Right Support.

We propose to reform the Mental Health Act so that neither a learning disability nor autism can be considered to be conditions for which a person can be subject to compulsory treatment under section 3 of the Act (commitment 5a). This will limit the scope to detain people with a learning disability or autistic people under the Mental Health Act. This is because learning disabilities and autism are conditions which cannot be removed through treatment, although some autistic people and people with learning disabilities may, at times, require treatment for a co-occurring mental illness. When this is the case, they may require admission, but this should always have a clear therapeutic benefit and be for the shortest time possible. 'Chapter 1: Keeping people safe and ensuring high quality health and social care' sets out the quality of care we expect of inpatient settings, and 'Chapter 2: Making it easier to leave hospital' sets out how people should be supported to be discharged when ready.

Under the proposals, people with a learning disability and autistic people could be detained for assessment under section 2 of the Act when their behaviour is so distressed that there is a substantial risk of significant harm to self or others (as for all detentions). The maximum time somebody can be detained under section 2 is 28 days. They will only be able to be detained for treatment under section 3 of the Act if a mental health condition which would benefit from hospital treatment is identified. If no mental health condition is identified, then detention will end.

It is important that, in such circumstances, someone is only detained in hospital under the Mental Health Act after all community alternatives have been considered. A C(E)TR should take place before a decision to admit someone to a mental health hospital and form part of decision-making. Although C(E)TRs should already be taking place, we know that the way they are carried out and how far their recommendations are implemented in practice can vary. To improve this, where patients are detained, we set out in 'Chapter 1: Keeping people safe and ensuring high quality health and social care' that we are proposing that recommendations from C(E)TRs, which are carried out within a set period of time after admission, are placed on a statutory footing (commitment 1c). This will mean that Responsible Clinicians must have regard to recommendations and include them in those patients' Care and Treatment Plan, unless there are good reasons not to do so. There will also be duties on the relevant ICB to have regard to recommendations that relate to services that may be available on discharge, unless there are good reasons not to do so. In 'Chapter 2: Making it easier to leave hospital', we set out how this will make it easier for people to leave hospital and ensure that discharge is considered from the outset of planning care and treatment.

The patient's new statutory Care and Treatment Plan should be developed in direct collaboration with the patient and those close to them, to ensure that it reflects their wishes, preferences, beliefs and values and their individual needs, including how they will be met. As well as setting out how the patient will be progressed to a timely discharge, the patient's Care and Treatment Plan should provide a record of why detention under the MHA is considered necessary, as well as the rationale behind any restrictive elements to the patient's care, where applicable. This is to ensure greater transparency around clinical decision making and to enable independent scrutiny by the First Tier Tribunal (Mental Health).

Under the proposed reforms, patients will have enhanced rights to challenge their detention at the Tribunal and, where detention to administer treatment under the MHA is considered appropriate and therapeutically beneficial, patients will have enhanced rights to shape what their care and treatment looks like. Patients will also receive increased support to enable them to access these rights through independent mental health advocacy and the new 'Nominated Person' model, which will replace the outmoded Nearest Relative system.

We recognise the importance of ensuring the right services are available for people to have their needs met in a timely way in their community, and we know that more must be done. Providing the right support in the community will prevent admission to mental health hospitals, and support people who are currently inpatients to be discharged at the right time and with the right support in place. We are proposing to create new duties on commissioners to ensure that there are adequate community-based services in their local area to support people with a learning disability and autistic people (commitment 3k). In addition, we are proposing a related duty for commissioners to hold a local 'at risk' register which allows them to work with local authorities to understand, monitor and respond to the risk of crisis at an individual level for people with a learning disability and autistic people in their population (commitment 31).

# Reforming adult social care

The government is reforming adult social care through £5.4 billion over three years to accelerate a comprehensive reform programme, building on the measures in the Health and Care Bill. This includes £3.6 billion to reform the social care charging system and enable all local authorities to move towards paying providers a fair cost of care; and a further £1.7 billion to begin major improvements across the social care system in England. Our white paper, People at the Heart of Care, sets out an ambitious 10-year vision for reforming adult social care and our priorities for investment.

Our 10-year vision for adult social care applies to everyone who draws on care and support including autistic people and people with a learning disability. The vision puts personalised care and support at the heart of adult social care. We want to ensure that people have the choice, control, and support they need to live independent lives, that they can access outstanding quality care and tailored support, and that they find adult social care fair and accessible so they can get the support they need. This is an ambitious vision, but we are already taking steps towards it.

Personalised and flexible care, delivered innovatively, can be adapted to address specific unmet needs, and can often be combined with care in their own community, to better support people with a learning disability and autistic people and promote their wellbeing. By introducing more models of care that support people in their own homes and in their local communities, local places will be able to deliver greater personalisation and better meet

complex care and support needs. To help us achieve this, we will maximise our use of the latest innovations and best practice in the commissioning, planning, and delivery of care, as well as in provider business models. In our white paper, we announced we will provide up to £30 million to build the capacity, capability and ambition of local places to scale and embed innovative models of care into practice. This will better support a changing population and provide more options that suit people's needs and circumstances.

We are also taking steps to build the capability of the social care workforce. Our white paper set out our commitment to invest at least £500 million in learning and development for the adult social care workforce. Our programmes will include a Knowledge and Skills Framework, careers pathways and linked investment in learning and development for care workers. New continuous professional development budgets will be introduced for registered nurses, nursing associates, occupational therapists, and other allied health professionals to support them in their development, to meet re-validation requirements and to specialise. These reforms will ensure that the adult social care workforce have the right skills and knowledge to provide the best possible care and support for the needs of the people for whom they care, many of whom are people with a learning disability and autistic people.

We know that people with a learning disability and autistic people can face barriers when trying to access the labour market. In 'Chapter 3: Living an ordinary life in the community', we set out some of the ways that we are supporting people to find the right job and maximise independence. In our adult social care reform white paper, DWP committed to funding Local Supported Employment with 20 local authorities to identify effective ways local authorities can support autistic people and people with a learning disability into employment. The initiative will support approximately 1,200 participants with a learning disability or autistic people who use local authority social services.

'People at the Heart of Care' also sets out that we are investing up to £25 million to work with the sector to drive change in the services provided to support unpaid carers, so that unpaid carers, including those of autistic people and people with a learning disability, are adequately supported. This is in addition to providing dedicated funding worth at least £5 million for local organisations to pilot and evaluate new ways to provide personalised advice to help people navigate local adult social care systems.

Also amongst our package of reforms is new investment in housing and a strategy for the adult social care workforce. In 'Chapter 3: Living an ordinary life in the community', we set out the reforms which will enable more people to live independently and lead the lives they want to lead through improved housing. In 'Chapter 1: Keeping people safe and ensuring high quality health and social care', we set out how we will support the adult social care workforce to deliver consistent, person-centred care.

# Integrating health and social care

On 9 February 2022, we published the health and social care integration white paper. This white paper outlines the government's vision for health and care integration. It sets out policies to improve the delivery of joined up and seamless services to support people including those with learning disabilities and autistic people to live healthy, independent, and dignified lives and which improve outcomes for the population as a whole.

Specifically, the government has committed to:

- consult stakeholders and set out a framework with a concise number of national priorities and approach for developing additional local shared outcomes, by spring 2023
- set an expectation that by spring 2023, all places should adopt a model of accountability and provide clear responsibilities for decision making including over how services should be shaped to best meet the needs of people in their local area
- review section 75 of the 2006 National Health Service Act which underpins pooled budgets, to simplify and update the regulations and publish guidance on the scope of pooled budgets spring 2023
- develop a national leadership programme, addressing the skills required to deliver effective system transformation and place-based partnerships, subject to the outcomes of the upcoming leadership review
- ensure all professionals have access to a functionally single health and adult social care record for each citizen (by 2024) with work underway to put these in the hands of citizens to view and contribute to
- develop a national delegation framework of appropriate clinical interventions to be used in care settings
- increase the number of clinical practice placements in social care during training for other health professionals

By introducing shared outcomes, which a single person will be responsible for delivering locally, the white paper commits to better integration across primary care, community health, adult social care, acute, mental health, public health, and housing services which relate to health and social care.

By building on the Health and Care Act 2022, which focuses on system-level changes, the commitments in the Integration white paper will enable more integrated place-based working, by ensuring that local authorities and the NHS have the tools to increase their cooperation to address their population health and care needs at the most appropriate level.

The white paper is also aligned with our progress on adult social care reform, having published the People at the Heart of Care white paper which sets out a 10-year vision for personalised care and support for everyone who draws on adult social care. We want people including those with learning disabilities and autistic people to have the choice. control and support they need to live independent lives; to be able to access outstanding quality and tailored care and support; and to find adult social care fair and accessible.

# Making money work for people

We recognise that the way that funding flows through and across the health and social care system can impact on the provision of support and people's overall experiences of care. We are taking steps as part of wider reforms to improve how this happens.

To support this, we commissioned an independent consultancy organisation (RedQuadrant) to undertake a rapid review of funding flows. This rapid review sought to identify and understand any financial barriers and (dis)incentives to discharge and admission to

inpatient care (commitment 5b). This review concluded in March 2022 and its report has been published.

The report's primary recommendation focused on the need for comprehensive financial monitoring both in terms of costs relating to people admitted to inpatient care and costs of post-discharge care over time, and investment levels in preventative and crisis services. Both should capture the share of funding between NHS and councils.

Amongst other aspects, RedQuadrant also considered the use of pooled budgets and factors relevant to ensuring the success of joint funding arrangements, and local policies and practices around personal budgets, personal health budgets and core support costs. We say more about existing wider activity on these below.

We will consider RedQuadrant's primary recommendation, alongside other findings from the report, through the Building the Right Support Delivery Board and a related, focused task and finish group. The task and finish group will report to the Delivery Board which is chaired by the Minister of State for Care and Mental Health.

### **Pooled budgets**

Pooled or aligned budgets can be an effective way to plan for a person's care and support throughout their lives, aiding good decision making with funding. Section 75 of the NHS Act 2006 is the existing mechanism and enabling tool for pooling budgets. It enables an NHS body and a local authority to enter a partnership arrangement. This may be for the purposes of jointly exercising the functions of the NHS body or the health-related functions of the local authority if the arrangements lead to an improvement in the way in which those functions are exercised.

As set out in the February 2022 white paper on health and social care integration, we want to build on progress in recent years to go further and faster in pooling and aligning funding to enable delivery at place level. Our expectation is that aligned financial arrangements and pooled budgets will become more widespread and grow to support more integrated models of service delivery, eventually covering much of funding for health and social care services at place level. These should be supported by robust frameworks to manage risk and deliver value for money. We will not at this point mandate how this is achieved, but our expectation is that funding should be aligned and pooled around pathways where the case for joined up care is most pressing.

To support this, we are reviewing section 75 of the NHS Act 2006 (which allows partners such as NHS bodies and councils to pool and align budgets) to simplify and update the underlying regulations. Post review, in Spring 2023 DHSC will publish revised guidance on the use of pooled budgets (commitment 5c).

#### **Personal budgets**

We are reaffirming our commitment to personal health budgets, personal budgets, and integrated personal budgets as a means for supporting integration around individual patients and people who draw on care services. As set out in the white paper on health and social care integration, we want to build on the roll-out of personal budgets and personal health budgets across health and social care.

Direct payments and personal budgets are a vital way in which people can have more choice and control over their care and wellbeing. A personal budget is the total amount of money a person receives for their care and support, which is allocated to them following an assessment of their needs. A person can choose to take their personal budget as a direct payment, which means that they can personally buy services that will meet their agreed care and support needs. This offers people greater flexibility and independence. In line with the Care and Support (Direct Payments) Regulations 2014, we want to ensure that local authorities offer people direct payments, including advice and support in using their direct payments. We know that some people may not wish to have a direct payment, though they should be informed of the choices available to them in relation to personal budgets.

Therefore, as part of our 10-year vision for adult social care, set out in the 'People at the Heart of Care' white paper, we will work with the sector, including Think Local Act Personal (TLAP), to explore how we can encourage greater use of direct payments and consider what changes could be made. Also, as part of our reforms to the adult social care charging system, we will explore how direct payments could be used as a mechanism for making payments once the cap on care costs has been reached. If we get this right, we can make the most of the expertise, capacity and potential of people, families, and communities to deliver better health and wellbeing outcomes and experiences for everyone who interacts with the care and support system.

In order to successfully implement Building the Right Support in the long term, Integrated Care Boards (ICBs) should commission in a more effective way for people with a learning disability and autistic people. This includes moving money from some services, such as high-cost inpatient care, into others, such as community health services. New Pathway Fund guidance provides a framework for local systems to work in partnership with NHS-led provider collaboratives to ensure that money released from specialist hospital provision can be reinvested in alternatives to hospital care.

#### Having choice and flexibility through personal budgets: Katy and Jackie's story

Katy, aged 24, lives in Dorset with her parents. She has profound learning disabilities with complex health needs. She needs support 24 hours per day for seven days a week. Katy's personal health budget was used to prevent her moving into permanent residential care, and to pay for person-centred care at home. Katy's health, including psychological wellbeing, weight, and vulnerability to infections, has improved dramatically, says Katy's mother, Jackie.

Before Katy was offered the option of a personal health budget, she attended a day centre five days per week. Agency carers would also visit one hour in the evening Monday to Fridays to help bathe Katy who uses a wheelchair and put her to bed. However, Katy did not like the day centre as staff there had neither the knowledge nor resources to provide the 24-hour support she needs. Jackie felt that Katy's healthcare needs were not being met, but with her profound disabilities there was nowhere else for her to go. When Katy was not at the day centre, Jackie and her husband would provide the care she required at home. This included giving Katy all her medical treatment.

Through Katy's social worker, Katy and her family were informed about personal health budgets and carried out an assessment of Katy's needs. They were granted a personal health budget for two carers to provide eight hours care per day, Monday to Friday, and one hour evening and morning care seven days per week. For three days a week, they decided the carers should be with Katy at home, and the other two days at the day centre, so she can keep in contact with other people. The day centre is also where Katy can have sessions with a physiotherapist, hydrotherapist, and dietician.

Jackie immediately found it positive that she and Katy could choose and employ Katy's carers. In Jackie's own words – 'A personal health budget has given us control over who cares for Katy, how and when.'

Jackie reflected that the personal health budget was 'the best thing to have happened for Katy for many years. Katy is now calm and happy. We've now got our Katy back'. It also proved a positive step for Katy's family as they were able to go on holiday for the first time in 10 years, were able to have more respite and sleep, and overall found themselves 'better carers'.

# Chapter 6: National and local accountability to deliver

As outlined in the 'Partnership Statement', no one organisation can achieve the objectives of Building the Right Support on their own. In this section, we outline how Building the Right Support Delivery Board members will work with one another to support national and local level implementation and hold themselves and each other accountable.

# Promoting accountability within the system

We want to join up care around a person's needs so that, from their perspective, their experience of care is seamless. It is critical we stop individuals, their families, and unpaid carers from falling through the gaps or being bounced around the system.

The new Health and Care Act 2022 will increase integration between health and social care. Greater integration between health and social care and prevention has the potential to generate significant health benefits for people with a learning disability and autistic people. This includes increased independence, improved quality of care, reduced avoidable admissions into hospitals, and better overall experiences of care due to the removal of barriers to joint-decision making between systems.

The new legislation intends to remove silos that exist within the NHS to join-up healthcare, social care, and public health services. We are doing this by building on the work of existing non-statutory ICSs, establishing new NHS bodies known as ICBs, and requiring the creation of Integrated Care Partnerships (ICPs) in each local system area. An ICB will take on the commissioning functions currently being carried out by a Clinical Commissioning Group and some aspects of NHSE's commissioning function. This will put more power and autonomy in the hands of local system partners, to plan and deliver seamless health and social care services.

Each ICB and each local authority whose area coincides with or falls within the ICB's area will be required to establish an ICP. Each ICP will be responsible for preparing the integrated care strategy for their areas, setting out how ICBs and local authorities will address the needs in their local area through the exercise of their functions, bringing together local partners to allow them to do so.

The NHS Long Term Plan Implementation Framework (2019) sets out the approach ICSs are asked to take to create their strategic system plans. System plans should set out how ICSs will deliver the Long-Term Plan commitments to improve services and outcomes for people with a learning disability and autistic people, reducing reliance on inpatient provision in mental health hospitals and increasing community capacity. To do this effectively, systems must ensure that they understand their local unmet need and gaps in care. including local health inequalities. It is expected that all ICSs will have a named senior responsible officer to oversee local implementation of NHS Long Term Plan ambitions for people with a learning disability and autistic people, and their families.

During the passage of the Health and Care Act 2022, we committed to go further by expecting all ICBs to have a named lead for learning disability and autism through the issuing of statutory guidance by NHSE. This will ensure that every ICB has an expert with knowledge and understanding of what good health and support looks like for people with a learning disability and autistic people of all ages.

As set out in 'About This Plan', we want this action plan to complement and support achievement of the NHS Long Term Plan target that by March 2024 mental health inpatient provision for people with a learning disability and autistic people will reduce to less than half of 2015 levels (on a like for like basis and taking into account population growth). Along with other clinical and service delivery areas of the NHS, the NHS Long Term Plan commitments for learning disability and autism were made prior to the COVID-19 pandemic. It is well understood and accepted that the pandemic has disrupted existing services, detracted potential patients from seeking help, and required staff to work flexibly, often across areas of clinical expertise and disciplines, away from their core responsibilities. NHSE is undertaking a review of the NHS Long Term Plan, including plans for learning disabilities and autism, which will take account of the impact of COVID-19 to review existing commitments and set out the next steps on delivery against targets.

Our long-term aim is to support improved outcomes and a better experience of care for people and their families. The Health and Care Act 2022 includes provisions for a new duty for CQC to assess local authorities' delivery of their adult social care functions under Part 1 of the Care Act 2014. Where the Secretary of State for Health is satisfied that a local authority is failing, or has failed, to discharge any of its functions under Part 1 of the Care Act 2014 to an acceptable standard, the Secretary of State will be able to give to the local authority any directions that the Secretary of State considers appropriate for the purpose of addressing the failure.

In the adult social care white paper, we provided further detail on how we will develop an enhanced assurance framework for adult social care. This will allow us to understand where adult social care is working well and where support is needed. This includes looking at how local authorities can work best with partners to improve the care provided for adults with complex needs. This will build on work we are doing to improve the quality, timeliness, and accessibility of adult social care data. To help drive improvement in the system, it will also be important to highlight and share good practice and innovation. CQC and DHSC will work closely with local authorities, people who draw on care and support and other stakeholders to develop this assurance framework, alongside more support tools to enable local authorities to improve performance as needed. Our intention is that the CQC assessment function will roll-out from 2023 to 2024 and we will work with the sector to support a smooth implementation of the new process.

On 7 September 2021, the government announced that we will work further with citizens and other key stakeholders to produce a comprehensive national plan for supporting

integration between health and social care, and for empowering local leaders. This will bring together partners in health and social care, alongside local and voluntary partners, to support people to retain their independence, health, and wellbeing for longer.

### Governance

Building the Right Support is overseen by the Minister of State for Care and Mental Health in the Department of Health and Social Care. The governance structure comprises of a Delivery Board, an Advisory Group of people with personal experience, and a stakeholder update forum.

### **Delivery Board**

The Delivery Board is responsible for overseeing the implementation of this action plan. Chaired by the Minister of State for Care and Mental Health, the Building the Right Support Delivery Board consists of government departments and the delivery partners who hold the levers to make change happen and deliver the ambitions of this Action Plan. The Board provides a point of single Ministerial oversight under the Minister of State for Care and Mental Health.

Representatives from expert groups are part of the Delivery Board to ensure necessary links are made and that work is joined up. The Learning Disability and Autism Children and Young People's Steering Group, chaired by Anne Longfield OBE, feeds into the Delivery Board to ensure that the needs of children and young people are regularly brought to the Board's attention and reflected in ongoing workstreams. Baroness Hollins is a member of the Board, as the chair of the Oversight Panel on IC(E)TRs.

### **Advisory Group**

The representatives of the Advisory Group are a key part of the Board's membership, involving people with personal experience and their families. The Advisory Group has been established to improve meaningful engagement of people with personal experience and their families in delivering Building the Right Support. It works with the Board to shape and deliver on its commitments, ensuring that a person-centered focus is maintained throughout the Board's work.

### Stakeholder update forum

A stakeholder update forum is held on a quarterly basis which brings together a wider group of stakeholders than the Delivery Board and Advisory Group. The forum ensures that interested parties can be kept updated on the Delivery Board's progress and wider work and policy developments related to Building the Right Support. It provides an additional opportunity for feedback and challenge.

# Implementation and assurance

As outlined in 'About this Plan', the Building the Right Support Delivery Board will formally review progress on the commitments in this action plan regularly and ongoing monitoring will take place alongside this.

In addition to the Delivery Board's accountability for the commitments in this action plan, we know that different organisations and systems responsible for delivering aspects of this action plan are already being held to account through their existing governance and reporting mechanisms. As stated in the 'Partnership Statement', the Delivery Board are committed to using the levers in their power to drive progress on Building the Right Support. This includes using the following mechanisms to support national and local level implementation of this action plan:

Organisation	Role in driving implementation of Building the Right Support
Department of Health and Social Care (DHSC)	DHSC will continue to work with partners across systems and across government to drive further and faster progress on Building the Right Support.
	As set out in this chapter, the Building the Right Support Programme is overseen by the Minister of State for Care and Mental Health in DHSC. DHSC oversee the governance mechanisms of the programme, which include the Delivery Board, the Advisory Group, and the stakeholder update forum.
	DHSC will deliver on commitments it owns within this action plan, ensuring collaboration with relevant partners as appropriate.
	DHSC officials will ensure join-up within the department by ensuring that the needs of people with a learning disability and autistic people remain an important focus of relevant policy developments and wider reforms.
Department for Education (DfE)	DfE is responsible for the SEND system and for national policy for children's social care in England. The commitments outlined above in relation to education for autistic children and young people, and those with a learning disability, form part of our ongoing programmes of improvement, which are monitored by the SEND Leadership Board. The SEND and alternative provision green paper which was published on the 29 March 2022 sets out proposals for further reform and improvement and is open to a full public consultation.
	Our commitments around children's social care, including the capital funding outlined in chapter 4, will support Local Authorities in addressing sufficiency issues with funding targeted to areas of greatest need. The government is considering the recommendations from the Independent Review of Children's Social Care, which published its <u>final report</u> in May 2022.
	We continue to work closely with DHSC and our partners across government, to improve the lives of autistic children and young people, and those with a learning disability, and their families.

# Department for Levelling Up, Housing, and Communities (DLUHC)

As part of this Action Plan's housing commitments, DLUHC are working with DHSC (via the adult social care reform white paper) to ensure housing in local areas connects with health and care.

The Disabled Facilities Grant (DFG) is administered locally by local authorities (LAs). Foundations (the National Body for Home Improvement Agencies) support local delivery and are aware of the commitment to raise awareness and have provided guidance on delivery of DFGs for people with challenging behaviours, including people with a learning disability and autistic people.

### Department for Work and Pensions (DWP)

Recognising that good work can help people with a learning disability and autistic people to live healthier and more independent lives, DWP is committed to helping more of them secure and retain employment.

We will ensure our Jobcentre Plus work coaches and Disability Employment Advisors are knowledgeable and can deliver appropriate support.

We will pilot and deliver specialist employment programmes such as Local Supported Employment and Access to Work.

We will work through Disability Confident and other mechanisms to ensure employers recognize the value that people with a learning disability and autistic people can bring to their businesses and can offer appropriate support and adjustments.

And we will work with other government departments, voluntary sector organisations and other stakeholders to continue to drive change and progress.

## **Ministry of Justice** (MoJ)

MoJ will support implementation of this action plan to improve support for individuals with a learning disability and/or autistic people that come into contact with the criminal justice system.

Work to reform the Mental Health Act and share best practice across the criminal justice system is being conducted in partnership with health, justice and policing partners, including: DHSC, NHSE, Her Majesty's Prison and Probation Service, Her Majesty's Courts and Tribunal Service, the Home Office, Police and Welsh Government. There are established governance structures in place to bring together all the relevant stakeholders to drive forward delivery.

In addition, MoJ is committed to working with other government departments to publish a neurodiversity action plan to improve outcomes and increase support for neurodivergent people in Spring 2022.

## A cross-government working group has been established to support the delivery of this work and ensure the actions set out in the autism strategy's implementation plan are progressed in a timely way. Local Government The LGA is a membership organisation and a national voice of Association (LGA) local government in England, representing around 350 local and the Association authorities. It is led by a Board of elected councillors, supported by officers. Alongside its policy and communication and of Directors of Adult representation functions, it also provides support to local Social Services (ADASS) authorities to improve. The LGA is a unique delivery partner for Building the Right Support as it has a broad reach across public health, housing, and community safety, as well as local authority membership. ADASS are a membership charity; a leading, independent voice of adult social care. ADASS promotes higher standards of social care services and influences policies and decision-makers to transform the lives of people needing and providing care - so that everyone needing care and support can live the lives they want, regardless of age, disability, status, and social background. The membership is drawn from serving directors of adult social care employed by local authorities and their direct reports. Associate members are past directors and, since 2019, our wider membership includes principal social workers. Both the LGA and ADASS support social care systems for young people and adults which cover a wide range of areas, including commissioning, practice, work with partners, and enabling functions such as technology, information, and value for money. We do this with a wide range of partners, including those who access social care. Due to the nature of our organisations, our role as a delivery partner is supporting others to achieve the objectives of Building the Right Support, both strategically at Board level and also through delivery in communities. **Health Education** HEE will continue to work co-productively with people with England (HEE) personal experience, alongside delivery partners and government departments, to meet the education and training needs of the existing and future workforce. We will use our expertise, influence and identified funding to meet our actions set out in this plan and that contribute to the NHS Long Term Plan. Working collaboratively with delivery partners to support local NHS England (NHSE) systems, NHSE will deliver our actions set out in the Building the Right Support Action Plan and relevant commitments in the NHS

	Long Term Plan to reduce reliance on mental health inpatient care for people with a learning disability and autistic people.
Skills for Care	Skills for Care's National Learning Disability and Autism Lead will facilitate and support implementation at a national and local level in partnership with regional leads and strategic partners. The learning disability and autism internal group directly links to Skills for Care's operational team and leadership and has established lines of accountability.
	In addition, Skills for Care utilises specific groups to disseminate good practice and delivery work programmes such as the Autism Workforce Strategy group, the WAGE (Workforce Autism Group England), the Commissioning Implementation group, and the workforce experts by experience group. All these groups bring together relevant partners for delivery.
Care Quality Commission (CQC)	As the independent regulator, CQC are not responsible for delivering specific actions in the Action Plan but will use their regulatory levers to stop poor care and their improvement function to galvanize action and hold delivery partners to account.  'Chapter 1: Keeping people safe and ensuring high quality health and social care' sets out CQC's role in more detail.
Ofsted	Ofsted is the regulator and inspector of children's social care provision and the inspector of local authority children's services and education settings. We work in partnership with CQC on dually registered provision. We will advise government and local areas on regulatory matters including where regulatory changes are needed to reflect the changing nature of provision in the community.

While the Building the Right Support Delivery Board's primary focus is at a national level, we know that regional and local level implementation are important to successful delivery. We know that some local areas have had greater success in reducing the number of inpatients than others, and we are keen to learn more about this regional variation and promote good practice. We want to build on what works well, particularly encouraging greater partnership at a local level which will support making this action plan a reality. One example is outlined below.

### Working together to improve access to the right support: NHS South East London **Integrated Care System**

A new £60,000 scheme to help people with a learning disability or severe mental illness access GP services digitally has been launched in South East London as a result of local health and care partners working together to secure funding. Working with residents with a learning disability and severe mental illness, a pilot has been developed to improve their access to healthcare and is being delivered by Mind in Bexley and Bexley Mencap. The voice of residents was crucial in designing the full project and its delivery.

Mind in Bexley have set up a non-clinical peer-led monthly group for clients as part of a Recovery College. This has been running since October 2021 with Annual Health Checks available. An online webinar has been held, featuring a local GP and Mental Health Lead for South East London, themed around self-care. There has been good feedback and content has been offered to GP practices to increase reach. A webinar attendee said: "All the presenters were great, explaining in a simple and slow way so you could understand. At present I am struggling and found it very, very useful".

A Digital Health Skills Training Network went live in November 2021 with referrals starting to come in. This is offering one on one digital training onsite and can help people solve any number of digital challenges.

Bexley Mencap are supporting people with a learning disability to plan, make and share three short films. The films are about the Learning Disability Register, Annual Health Check, and winter messaging and the importance of community pharmacy. These new resources will be available via easy read web pages currently in design. This will consolidate local easy read information and other resources available via GP websites.

Bexley Mencap are also supporting the development of easier GP websites by giving feedback on immediate changes to create greater accessibility and include a link to easy read health information. This will be tested amongst a self-selecting group of Practices with a view to mainstreaming in 2022.

We know that progress has not been as fast as we had hoped; however, we do not want to lose sight of the positive outcomes that have been achieved with the right support and structures in place. Some of these outcomes have been presented through stories throughout this action plan. It is these stories that motivate us and others to make this action plan a reality, so that people with a learning disability and autistic people, of all ages, live an ordinary life in their community in a way that we know is possible.

# Where we are now: glossary of terms used

This section provides further information on charts A-J as set out in the section 'Where we are now' of this action plan.

Please note the following about the language used in the charts:

- when used in this section, 'people' refers to people with a learning disability and autistic people who are in a mental health hospital
- CYP refers to children and young people aged under 18
- adults are people aged 18 and over
- MHA refers to the Mental Health Act, 1983. The MHA is the main piece of legislation which determines when people need to go into a mental health hospital for assessment and or treatment.
- 'MHA status' refers to the MHA legal status classification of the person

The MHA status is important to understand when navigating the charts. It states that:

- 'voluntary' means a person has voluntarily agreed to come into hospital and so they are not detained under the MHA
- 'detained' means a person who is being detained in hospital under a section of the MHA and is therefore not free to leave

Powers for compulsory admission under the MHA (i.e. for those who are detained) are set out in Part II and Part III, as follows:

- Part II of the MHA deals with patients who are detained in hospital and have no criminal proceedings against them. These patients are generally referred to as 'civil patients'.
- Part III of the MHA is concerned with patients who are involved in criminal proceedings or are under sentence. These patients are referred to as 'forensic patients. There are two types of patients who fall under this category – restricted and unrestricted patients - which are defined as:
  - 'restricted patients' refers to offenders with severe mental health needs who have been detained in hospital for treatment and are subject to special controls by the Secretary of State for Justice. These special controls exist to protect the public from serious harm whilst at the same time recognising patients' right to access treatment in an appropriate setting.
  - 'unrestricted patients' refers to defendants and offenders who are not subject to these restrictions. The Secretary of State for Justice does not have involvement in these cases, unless the patient falls under their remit in another way, such as multi

agency public protection cases where additional arrangements are needed to protect the public from harm.

#### 'other' refers to:

- people detained under Acts other than the MHA
- people in hospital where a 'temporary holding' section of the MHA is being used,
- people whose MHA legal status is reported as 'not applicable' or 'not known'

Most data presented in the charts is from the NHS Digital Assuring Transformation (AT) dataset, January 2022, and is England-level data. Chart F, Chart H and Chart J contain data provided by NHSE. Please note that:

- all values have been rounded to the nearest five
- where counts were less than five, values are given as zero as they have been suppressed so individuals cannot be identified
- figures may not sum to 100% due to rounding



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