

# Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition



Service model for commissioners of health and social care services

**October 2015**





# Contents

<b>Introduction</b>	<b>4</b>
<b>About this document</b>	<b>5</b>
<b>Who this service model is about</b>	<b>8</b>
<b>Good services for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition</b>	<b>10</b>
<b>Annex A – terminology</b>	<b>30</b>
<b>Annex B – common needs and common shifts in service response</b>	<b>33</b>
<b>Annex C – understanding the local population</b>	<b>38</b>
<b>Annex D – reference group membership</b>	<b>39</b>

# Introduction

## Service model vision statement

Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition\* have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.

**“The success in this lies not within systems and processes but within human connections, commitments, accountability and sustainable relationships that are non-adversarial.”**

### **Commissioner**

The principles which underpin this service model build on what have been described before, including in [Valuing People](#) and [Valuing People Now](#), all of which focus on rights, independence, choice and inclusion for people with a learning disability and/or autism.

Good practice guidance around the commissioning of services for people with a learning disability and/or autism who display behaviour that challenges, including the [1993](#) and [2007 Mansell reports](#), describe the need to develop high quality local services that understand and support people, and reduce the reliance on out-of-area placements. They focus on ensuring the best outcomes for people by working in partnership with individuals and families/carers and through adopting person-centred approaches – vital to delivering independence and control for people and ensuring that the person’s wishes and aspirations for their own life are at the centre of their care and support arrangements.

There has been a renewed commitment to transforming the way in which care and support is delivered to people with a learning disability and/or autism who display behaviour that challenges. In line with the provisions of the [Children and Families Act](#) and the [Care Act](#), which focus on outcomes, personalisation and wellbeing, this commitment focuses on strengthening support in the community by building on the provision of preventative support that will avoid crises and help support people to be active members of their communities, with all the benefits that brings.

This service model brings together the current good practice taking place in local areas, and that which has previously been described for this group of people. It recognises that improvements are typically underpinned by visionary leadership, a focus on human rights based approaches, workforce development, co-production and a preparedness to reflect and learn. It aims to support commissioners across health and social care to work together to commission the range of services and support required to meet the needs of this diverse group.

\* Hereafter people with a learning disability and/or autism

# About this document

Since the investigation into the abuse at Winterbourne View and other similar hospitals<sup>1</sup>, there has been a cross-government commitment to transform care and support for people with a learning disability and/or autism who display behaviour that challenges, including behaviour that can lead to contact with the criminal justice system. This is focused on building up community capacity and reducing inappropriate hospital admissions.

Services will not look the same all over the country. Each local area is different: local populations have different needs, and their range of providers have different strengths and weaknesses. Each local area will therefore need to draw up its own model for how services should look in future, based on an agreed service model.

However, there will be some national consistency in what services should look like across local areas, based on established best practice. This document seeks to describe that national consistency, while giving commissioners the flexibility to design services that best fit the needs of their local population. It sets out to provide clarity on 'what good looks like' for health, social care and housing services for people with a learning disability and/or autism.

## Who this service model is for

This service model is for all health and social care commissioners – not just learning disability commissioners; in particular, this includes mental health commissioners, Continuing Health Care (CHC) commissioners, public health and children's commissioners. It covers the full range of commissioning – strategic, operational and individual/micro commissioning.

## Different types of commissioning



<sup>1</sup> 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients.

Commissioners should ensure that plans impacting on people of all ages with a learning disability and/or autism align with related initiatives, and identify opportunities for joint working. This should include commissioners seeking to align these plans with the development of their Local Transformation Plans for Children and Young People's Health and Wellbeing, local action plans under the Mental Health Crisis Concordat and the 'local offer' for personal health budgets.

## Scope of the service model

This service model focuses on services and packages of care and support funded by the NHS and local government, as well as NHS/local government interfaces with other services (e.g. education), but not those services funded by other public sector agencies themselves (e.g. schools).

This does not mean, however, that other public services and organisations do not also need to review and improve the way they support and provide services for children, young people and adults with a learning disability and/or autism. It is essential that links across all local system partners are established both to ensure a joined-up and effective approach to supporting people, with clearly identified care and support pathways, and to maximise opportunities for sharing knowledge, skills and support across agencies and systems. This is in line with existing NICE guidelines (see below) on challenging behaviour and learning disabilities which recommends the need for leadership teams across health, social care and education to develop care pathways for people including transitions between and within services.

## How the service model was developed

A reference group<sup>2</sup> was set up to provide expert advice on the development of the model, bringing together a range of stakeholders. In addition, six 'fast-track' areas<sup>3</sup> used a draft version of the service model as they developed plans to transform services for people with a learning disability and/or autism over the summer of 2015 and provided feedback. Through a process of engagement, NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS), sought the views of clinicians, commissioners, providers, families and people with a learning disability and/or autism.

This service model is intended for a particular juncture in the transformation of services for people with a learning disability and/or autism. It builds on existing NICE guidance (such as that on [challenging behaviour](#) and learning disabilities and that on [autism](#) and will be superseded as good practice develops and in particular once [NICE service model guidance](#) is published in 2017.

We do not expect the services and support described here to be put in place over night, but we do expect all areas to implement this service model over the next three years.

<sup>2</sup> See Annex D for reference group membership.

<sup>3</sup> The 'fast-track' areas are Greater Manchester; Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire.

## The transforming care programme

The service model forms part of a national plan to support commissioners across the country to formulate joint transformation plans. This in turn is part of a much broader programme of work led by the Department of Health, NHS England, the LGA, ADASS, the Care Quality Commission (CQC), and Health Education England (HEE) to transform services.

[The national plan](#) describes in further detail the mechanisms for achieving transformation, including the financial underpinnings and commissioning arrangements, which are key to delivering on the vision outlined in this service model. Other aspects of the wider transforming care programme will also support its delivery, including the development of effective assurance metrics; robust inspection/regulation; and development of the workforce.



# Who this service model is about

## Who this is about<sup>4</sup>

This service model is about those people with a learning disability and/or autism who display behaviour that challenges, including behaviour which is attributable to a mental health condition<sup>5</sup>.

This includes people of all ages and those with autism<sup>6</sup> (including Asperger's syndrome) who do not also have a learning disability (as well as those who have both a learning disability and autism), and includes those people with a learning disability and/or autism whose behaviour can lead to contact with the criminal justice system.<sup>7</sup>

## Services to meet diverse and complex needs

This is an extremely diverse group of people and the support they require will be highly individualised - tailored to their particular needs, strengths, interests and in some cases the risks they pose to others (all of which might change over time).

However, there are some common needs that services in any one local area need to ensure they have the capacity to address. There are also some common deficiencies in how services currently address those needs in the community, with the result that, too often, people may end up in hospital (including through diversion from the criminal justice system) at great human cost to themselves and their families/carers<sup>8</sup>, and when those circumstances could have been avoided. There are therefore, also some common shifts that services will often need to make.

<sup>4</sup> For simplicity, henceforth when we refer to 'everyone' or 'people' in this document, we are referring to this defined group of people (children, young people and adults) unless otherwise stated and when we refer to 'people with learning disabilities and/or autism', we are referring to 'people with learning disabilities and/or autism who display behaviour that challenges, including those with a mental health condition.

<sup>5</sup> See Annex A for definitions: behaviour that challenges, learning disability and autism.

<sup>6</sup> Throughout this document we use the term 'autism' as an umbrella term for all Autistic Spectrum Conditions, including Asperger Syndrome.

<sup>7</sup> A small percentage of people with a learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting. They are included as a distinct group within this service model because their specific needs have not always been recognised; the model presents an opportunity to develop the support and services they may require.

<sup>8</sup> In this document we use the term 'carer' to mean those people who provide unpaid support to someone. This is often a family member, but not always. We refer to people who provide paid support as 'paid support and care staff'.



The following groupings help to illustrate some common needs amongst the diversity of the population that this service model is about:

- Children, young people or adults with a learning disability and/or autism who have a mental health condition such as severe anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- Children, young people or adults with an (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.
- Children, young people or adults with a learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).
- Children, young people or adults with a learning disability and/or autism, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family backgrounds) who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.
- Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in hospital settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

This is not an exhaustive list. These groupings cannot cover the complexities of every individual, nor all the causes of certain behaviours. Individuals do not 'slot neatly' into any single grouping – they overlap, people's needs change over time, and often a large part of the challenge for local services will be to understand what combination of factors lies behind an individual's behaviour.

These groupings are a means of demonstrating the range and complexity of the group described within the service model and some common themes and needs that will require consideration by commissioners. Annex B provides further detail on these common needs and the common shifts in service responses that are required.

# Good services for people with a learning disability and/or autism

This section describes what good services and support look like for people with a learning disability and/or autism who display behaviour that challenges, including behaviours which may result in contact with the criminal justice system.

It is structured around **nine core principles** that are stated from the perspective of the reasonable expectations of someone who might use such services. Additional [supplementary information](#) for commissioners has been published alongside this to provide further detail on each aspect of the model outlined.

The human rights of people who use services are incontrovertible and must be upheld at all times; consequently there are a number of **'golden threads'** that run consistently through the nine principles described and which should therefore be reflected in local commissioning strategies:

- **Quality of life** – people should be treated with dignity and respect. Care and support should be personalised, enabling the person to achieve their hopes, goals and aspirations; it should be about maximising the person's quality of life regardless of the nature of their behaviours that challenge. There should be a focus on supporting people to live in their own homes within the community, supported by local services.
- **Keeping people safe** – people should be supported to take positive risks whilst ensuring that they are protected from potential harm, remembering that abuse and neglect can take place in a range of different environments and settings. There should be a culture of transparent and open reporting, ensuring lessons are learned and acted upon.
- **Choice and control** – people should have choice and control over their own health and care services; it is they who should make decisions about every aspect of their life. There is a need to 'shift the balance of power' away from more paternalistic services which are 'doing to' rather than 'working with' people, to a recognition that individuals, their families and carers are experts in their own lives and are able to make informed decisions about the support they receive. Any decisions about care and support should be in line with the [Mental Capacity Act](#). People should be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interests involving them as much as possible and those who know them well.
- **Support and interventions** should always be provided in the least restrictive manner. Where an individual needs to be restrained in any way – either for their own protection or the protection of others, restrictive interventions should be for the shortest time possible and using the least restrictive means possible, in line with [Positive and Proactive Care](#).

- **Equitable outcomes**, comparable with the general population, by addressing the determinants of health inequalities outlined in the [Health Equalities Framework](#). The starting point should be for mainstream services, which are expected to be available to all individuals, to support people with a learning disability and/or autism, making reasonable adjustments where necessary, in line with Equality Act legislation, with access to specialist multi-disciplinary community based health and social care expertise as appropriate.

## The vision described in this service model

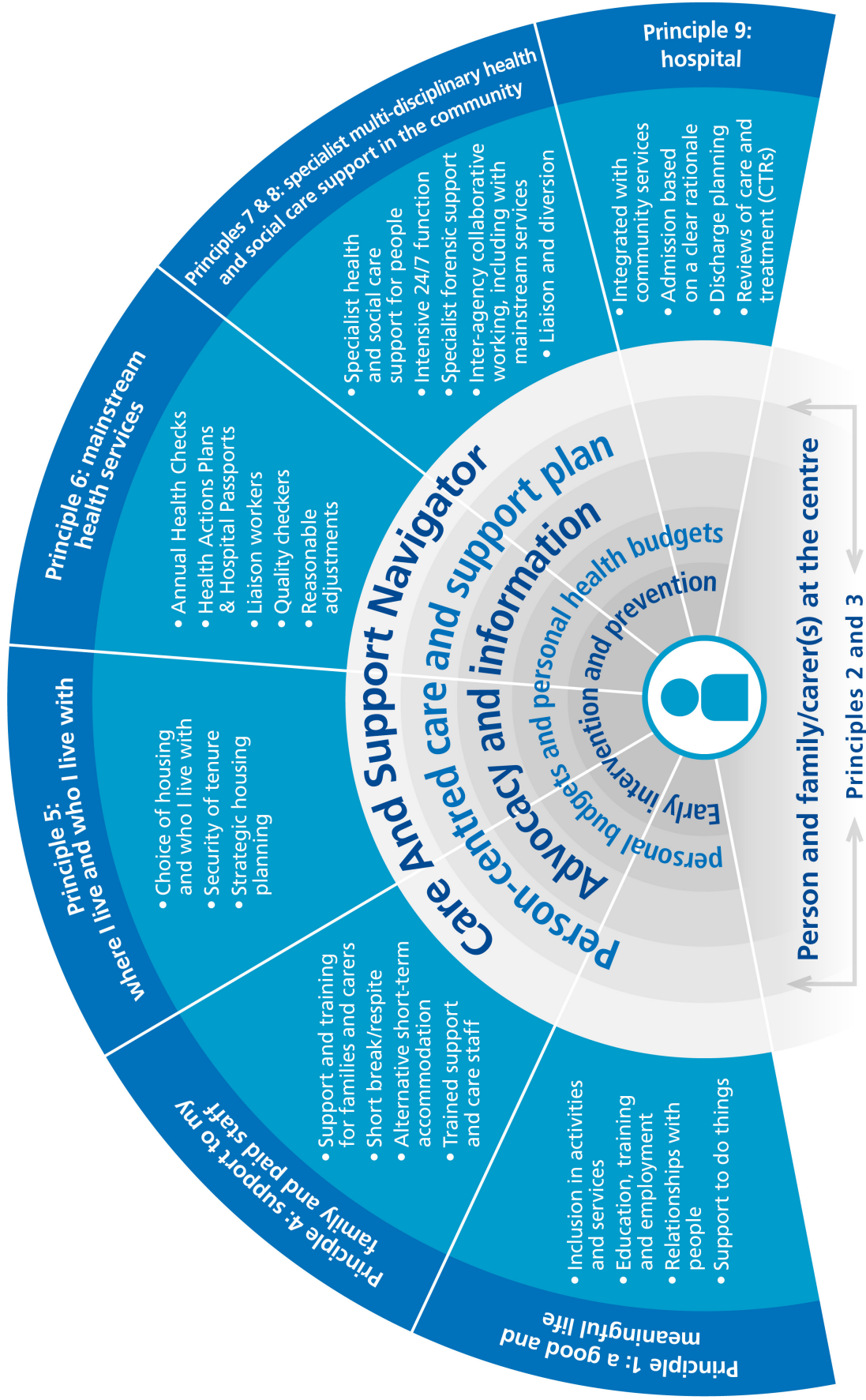
A whole-system response is the key to delivering high quality services and support for people. For this to be a reality, services need to demonstrate a strong commitment to a shared value base which places individuals and their quality of life at the heart of all they do. This value base should reflect the 'golden threads' and be evident on the basis of the [capable environments](#)<sup>9</sup> within which care and support is delivered. Capable environments are characterised by: positive social interactions, support for meaningful activity, opportunities for choice, encouragement of greater independence, support to establish and maintain relationships and mindful and skilled family/carers and paid support and care staff.

The service model describes a range of services and supports that should be in place within any local area. Depending on their needs and circumstances, people with a learning disability and/or autism and their families/carers should be able to draw upon the support described in the model in a way that is right for them. They should also be supported to navigate their way through an often complex and anxiety provoking system.

Just as people's situations and experiences vary (for example, some may have a long history of behaviour that challenges, whilst others may develop such behaviours as a result of transient physical or mental health problems), they will become known to different local services in different ways and at different points in their lives. What works and is needed for each individual will look different, and not all aspects of the service model will apply, or be required by everyone.

However, the starting point for everyone should be about **access to support that is based on individual need**, through establishing an understanding of the factors, both historic and current, that have contributed to the individual's behaviour. Care and support should then be delivered with the aim of improving the person's quality of life. In order for this to be successful, it will require **multi-disciplinary** and **multi-agency** working, as well as skilled informed responses from specialist health and social care services, in partnership with the person and those who provide day-to-day support.

<sup>9</sup> See: <http://www.kcl.ac.uk/sspp/policy-institute/scwru/news/2014/newsfolder/McGill-et-al-Capable-environments.pdf>



## Service Model

Commissioners understand their local population now and in the future

## 1. I have a good and meaningful everyday life.

“When I move to my flat, the most important thing is friends.”

“It’s all about relationships – with my friends, my family and my staff.”

### Individuals with a learning disability in a secure hospital

- 1.1** Children, young people and adults with a learning disability and/or autism who display<sup>10</sup>, should be included in **activities and services (such as early years services, education, employment, social and sports/leisure) that enable them to lead a good and meaningful everyday life.** They should have choice and control over the activities in which they participate, facilitated through person-centred care and support plans/ Education, Health and Care (EHC) plans and personal budgets/personal health budgets (see principles 2 and 3) – any restrictions imposed (Ministry of Justice/MAPPA)<sup>11</sup> will need to be considered but should not adversely affect the individual experiencing, where possible and under appropriate supervision, a fulfilling and purposeful everyday life.
- 1.2** Everyone should have access to **education, training and employment (including supported internships)** which they can access within their local area. To enable this, support providers and multi-disciplinary specialist health and social care teams (see principle 7) should provide training and support to mainstream service staff and/or provide support to individuals and their families/carers that enables them to participate in mainstream services, and to access education and training within local schools and colleges. Commissioners should also seek to ensure that supported employment/ training services meet the needs of this group.
- 1.3** Everyone should have the opportunity to **develop and maintain good relationships** with people. Commissioners should be mindful of the importance of relationships to keep people safe and well, and should therefore seek to offer good support to families/ carers, friends and others (see principle 4). This should form a key part of people’s person-centred care and support plans (see principle 2).

### Key actions for health and social care commissioners:

- Strategic learning disability commissioners should work with those that commission and manage mainstream activities/services to find ways to make them accessible, in line with [Equality Act](#) duties.
- Operational commissioners will need to work with mainstream services to enable people with a learning disability and/or autism who display behaviour that challenges to be included.
- Local authorities should commission supported employment services that can meet the needs of this group.
- Commissioners should ensure that service specifications are based on person-centred outcomes.

<sup>10</sup> For simplicity, henceforth when we refer to ‘everyone’ or ‘people’ in this document, we are referring to this defined group of people (children, young people and adults) unless otherwise stated.

<sup>11</sup> Multi agency public protection arrangements

## 2. My care and support is person-centred, planned, proactive and coordinated.

“We know about person-centred planning. Now we want to see the person-centred doing.”

**Family carer**

- 2.1** Local health and care services should develop a **dynamic register** based on sophisticated risk stratification of their local populations. This will enable local services to anticipate and meet the needs of those people with a learning disability and/or autism.
- 2.2** Everyone should have a **single person centred care and support plan**, incorporating a range of other plans, including behaviour support plans where appropriate, as well as crisis and contingency plans, which they have been involved in drawing up and which they have a copy of. Plans should focus on what is important to the individual. For children and young people up to the age of 25 with a special educational need (SEN), this should take the form of an Education, Health and Care (EHC) plan.
- 2.3** Everyone should be offered a named **local care and support navigator or keyworker** to coordinate and ensure timely delivery of a wide range of services set out in the person centred care and support plan, working closely with the person and their families/carers where appropriate and ensuring a consistent point of contact.

### Key actions for health and social care commissioners:

- Strategic learning disability commissioners should risk stratify their local population of people with a learning disability and/or autism see Annex C.
- Micro-commissioners should ensure that the person they are supporting has a single person-centred care and support plan, not just those on the [Care Programme Approach \(CPA\)](#).
- Commissioners should ensure that everyone is offered a local care and support navigator or key worker.
- Commissioners should ensure a multi-disciplinary approach to EHC plans, not leaving this only to education.

### Relevant guidance and standards:

- [NHS England guidance on personalised care and support planning](#).
- [Think Local Act Personal \(TLAP\) guidance on personalised care and support planning](#).
- [National Institute for Health and Care Excellence \(NICE\) guidance on challenging behaviour and learning disabilities, section on understanding the risks of developing behaviour that challenges](#).
- [Preparing for adulthood programme, including information and guidance on EHC plans](#).



### 3. I have choice and control over how my health and care needs are met.

“My advocate spoke for me after I told her what I wanted to say. I didn’t have the courage to speak myself [in review meeting].”

#### Individual with a learning disability

- 3.1** Everyone should receive information about their care and support in formats that they can understand and should receive appropriate support to help them communicate, in keeping with the new Accessible Information Standard.
- 3.2** Individuals, and where appropriate families/carers, should be integral partners in care and support planning discussions (see principle 2). Even where people lack capacity to make specific decisions, they should be involved in care and support planning discussions wherever possible and any decisions taken on their behalf should be made in their best interests. These discussions and the final plan should be person-centred and focused on what is important to the individual. Increasingly, people should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care, and should have access to information advice and support to help them understand the choices available to them, exercise these choices and to help them plan how to use and manage their budget. Many will already have a right by law to personal budgets or personal health budgets, but commissioners should be rapidly and ambitiously extending this offer beyond rights guaranteed in law.
- 3.3** At key points in their interaction with health, education and care services, people should have access to different types of **independent advocacy**. In addition to the legal right to advocacy, people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives. This will include in preparation for and on leaving a specialist hospital. Both statutory and non-statutory advocacy should be delivered by services that are independent of the organisations providing the person’s care and support.

#### Key actions for health and social care commissioners:

- Commissioners should be planning for, and delivering the offer of, personal budgets, personal health budgets and integrated personal budgets beyond rights guaranteed in law.
- By April 2016, every CCG will be expected to have a ‘local offer’ for how to expand the use of personal health budgets; this must include people with a learning disability.
- Commissioners should work with the local voluntary sector to consider what additional or different local services are needed to ensure that people with personal budgets have a range of services to choose from.



- Commissioners should be extending the offer of advocacy through investment in non-statutory advocacy services and should ensure statutory and non-statutory advocacy is available to people who are leaving a hospital setting.
- Commissioners should ensure that advocacy services are independent and provided separately from care and support providers

**Relevant guidance and standards:**

- [NHS England's Accessible Information Standard.](#)
- [NHS planning guidance, section on Personal Health Budgets : Forward view into action: Planning for 2015/16.](#)
- [NHS England's Personal Health Budgets Right to Have guidance.](#)
- [TLAP guide to personal health budgets for people with learning disabilities.](#)

#### 4. My family and paid support and care staff get the help they need to support me to live in the community.

“It is paramount that families get support especially when their child has complex needs. Support rarely arrives until there is a crisis...by which time it's too late to remedy.”

**Family carer**

- 4.1** All families or carers who are providing care and support for people who display behaviour that challenges should be offered **practical and emotional support** and access to **early intervention programmes**, including evidence-based parent training programmes, and other skills training, in line with NICE guidance and which is targeted to meet their specific strengths, challenges and needs.
- 4.2** All families or carers who are providing care and support for people who display behaviour that challenges should be offered information about a **carers assessment and advocacy support** in their own right, **access to short breaks/respite** suitable for people whose behaviour challenges and which meets their own needs, and support to care for the person from specialist multi-disciplinary health and social care teams (see principle 7).
- 4.3** **Alternative short term accommodation** (available for a few weeks) should be available to people, as and when it is needed, to be used in times of crisis or potential crisis as a place where they can go for a short period, preventing an avoidable admission into a hospital setting. It might also provide a setting for assessment from teams providing intensive multi-disciplinary health and care support (see principle 7) where that assessment cannot be carried out in the individual's home.
- 4.4** Everyone who is getting a social care package should have access to paid support and care staff **trained and experienced** in supporting people who display behaviour that challenges, and those who may have come into contact with or are at risk of coming into contact with the criminal justice system. These staff should be able to deliver proactive and reactive strategies to reduce the risk of behaviour that challenges, in line with NICE guidelines.
- 4.5** Local authorities should use **Market Position Statements** with an explicit focus on people with a learning disability and/or autism. **They should identify a group of preferred providers**, which can demonstrate minimum quality standards and competencies. These providers should be seen as genuine partners of specialist multi-disciplinary health and social care teams (see principles 7 and 8.3) as part of multi-agency working. Commissioners, along with the providers, should develop competency frameworks, such as that provided by Health Education England. These competency frameworks need to include requirements for staff training, for example person-centred approaches, communication and Positive Behaviour Support (PBS), in line with the PBS competency framework.

### **Key actions for health and social care commissioners:**

- Children's and strategic learning disability commissioners should ensure availability of early intervention programmes, including evidence-based parent training programmes.
- Children's and strategic learning disability commissioners should ensure availability of a range of support and training for families and carers.
- Children's and strategic learning disability commissioners should provide flexible and creative short break/respite options.
- Children's and strategic learning disability commissioners should work with their local providers to develop models of alternative short-term accommodation.
- Commissioners should develop a group of social care preferred providers that meet the needs of people with a learning disability and/or autism.
- Local authorities should develop Market Position Statements with an explicit focus on this group.

### **Relevant guidance and standards**

- [NICE guidance on challenging behaviour and learning disabilities, sections on parent-training programmes and proactive and reactive strategies.](#)
- [Positive Behaviour Support \(PBS\) competency framework.](#)
- [Health Education England's learning disability skills and competency framework.](#)
- [Department of Education guidance on short breaks for carers of disabled children.](#)

## 5. I have a choice about where I live and who I live with.

“I don’t want to lose my home again if I go back to hospital.”

**Individual with autism**

“Help people to see what their housing options are and what it really means to them.”

**Feedback from a discussion forum on housing**

- 5.1** People should be offered a **choice of housing, including small-scale supported living**. This choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the individual is on an offender pathway. Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person’s person-centred care and support plan (see principle 2). Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning.
- 5.2** Everyone should be offered **settled accommodation**. This should include exploring home ownership, or ensuring security of tenure.
- 5.3** Commissioners need to work closely with housing strategy colleagues to ensure that the future needs of this group are understood, considered and planned for strategically and form part of **local housing strategies**.

### **Actions for health and social care commissioners:**

- Commissioners should co-produce local housing solutions leading to security of tenure, that enable people to live as independently as possible, rather than in institutionalised settings
- CCGs could consider allowing individuals with a personal health budget to use some of their budget to contribute to housing costs if this meets a health need and is agreed as part of the individual’s care and support plan.
- Strategic commissioners need to work with housing strategy colleagues to ensure strategic housing planning

### **Relevant guidance and standards:**

- [Communities and local government guidance on Disabled Facilities Grants](#)

## 6. I get good care and support from mainstream health services.

“Professionals working with people with autism and not knowing that autism is a ‘triad’ of social impairments is a bit like finding a builder who does not know how to mix cement.

### Feedback from people with lived experience

- 6.1** Everyone with a learning disability over the age of 14, should be offered an **Annual Health Check**. This is particularly important for those with communication difficulties. Everyone should have a **Health Action Plan**, which identifies how any physical and mental health needs will be met, and this should form an integral component of a person’s person-centred care and support plan (see principle 2). Where appropriate it should include a **‘Hospital Passport’** to help mainstream NHS services make the reasonable adjustments required by law (including meeting the needs of people who display behaviour that challenges) and ensure equity of health outcomes for people.
- 6.2** Everyone should expect universal NHS services to employ clearly identified and readily accessible primary and secondary healthcare **‘liaison’ workers** who have specialist knowledge and specific skills in working with people with a learning disability and/or autism which enable them to advise those services on how to make effective adjustments.
- 6.3** Everyone should expect **‘quality checker’** schemes to be in place ensuring that mainstream services serve them appropriately.
- 6.4** Everyone should expect mainstream mental health services to regularly audit how effective they are at meeting the needs of people with a learning disability and/or autism. The Green Light Toolkit should be used to both **evaluate services and to agree local actions** to deliver real improvements. In many instances this will require investment in mainstream mental health services (such as Child and Adult Mental Health (CAMHS) Services, Improving Access to Psychological Therapies (IAPT) and services that are helping to deliver against the Crisis Care Concordat). In other instances there will be new initiatives to support mainstream mental health services to make reasonable adjustments to their pathways of care and support, and to improve access to those services.

**Actions for health and social care commissioners:**

- Health commissioners should ensure that people with a learning disability are offered Annual Health Checks.
- Health commissioners should ensure that everyone has the option of a Health Action Plan, and are promoting the use of Hospital Passports.
- Mental Health commissioners should ensure that the Green Light Toolkit audit is completed annually, and an action plan developed.
- Commissioners should ensure that practices and care and support pathways within mainstream primary and secondary NHS services are 'reasonably adjusted' to meet the needs of this group, in line with Equality Act duties, and are routinely monitoring equality of outcomes.

**Relevant guidance and standards:**

- [Green Light toolkit: reasonable adjustments in mental health services.](#)
- [Improving Health and Lives \(IHAL\) resources on making reasonable adjustments for people who need mental health services and support.](#)
- [IHAL Working Together guidance for improving support for people with learning disabilities in hospital.](#)
- [NHS England Quality Checkers initiative.](#)
- [IAPT Positive Practice guidance for people with learning disabilities.](#)
- [2015 Directions on Annual Health Checks.](#)

## 7. I can access specialist health and social care support in the community.

"It is important for them to stick with the person."

**Family carer and a consultant psychiatrist**

- 7.1** Everyone should have access to **integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community** that is readily accessible, when needed, by children, young people and adults with a learning disability and/or autism, including those who may have come into contact with or are at risk of coming into contact with the criminal justice system (see principle 8). Key functions of this specialist support should include: support to enable people to access mainstream health and social care services, work with mainstream services to develop their ability to deliver individualised reasonable adjustments, support to commissioners in service development and quality monitoring, and the delivery of direct assessment and therapeutic support.
- 7.2** Specialist support might be provided by a range of services, and often across services (e.g. children's services, Child and Adult Mental Health Services (CAMHS), learning disability CAMHS teams and specialist community learning disability teams). Support should be built around the needs of the individual through a **'Collaborative Care' model, or by combined teams** (e.g. all age, learning disability and autism). Individuals should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services. Access to and provision of support should be based on need.
- 7.3** Anyone who requires additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and social care support** at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be delivered by members of highly-skilled and experienced multi-disciplinary/agency teams with specialist knowledge in managing behaviours that challenge. The interface between specialist routine multi-disciplinary support services (described above) and this type of intensive support service should be seamless.



**Actions for health and social care commissioners:**

- Commissioners should ensure the availability of specialist integrated multi-disciplinary health and social care support in the community for people with a learning disability and/or autism, covering all ages.
- Commissioners should ensure this specialist health and social care support includes an intensive 24/7 support function.
- Commissioners should ensure inter-agency collaborative working, including between specialist and mainstream services.

**Relevant guidance and standards:**

- [Mansell Report: Services for people with learning disabilities and challenging behaviour or mental health needs report of a project group.](#)
- [Royal College of Psychiatrists: Challenging Behaviour a Unified Approach.](#)

## 8. If I need it, I get support to stay out of trouble.<sup>12</sup>

“There was too much focus on mental health reports and a lack of learning disability awareness.”

### Individual with a learning disability

- 8.1** People who have come into contact with, or may be at risk of coming into contact with the criminal justice system, should have **access to the same services aimed at preventing or reducing anti-social or ‘offending’ behaviour<sup>13</sup> as the rest of the population**. They should expect services (including those provided by youth offending teams, liaison and diversion schemes, as well as troubled family schemes and programmes such as those for drug and alcohol misuse) to identify people with a learning disability and/or autism amongst the people they support, and to make reasonable adjustments so they can effectively support those people. This should be achieved through collaboration with specialist multi-disciplinary health and social care services for people with a learning disability and/or autism (see principle 7, and 8.3 below).
- 8.2 Liaison and diversion schemes** should seek to support people through the youth or criminal justice system ‘pathway’ enabling people to exercise their rights and/or where appropriate, diverting people to appropriate support from health and social care services. Clear pathways for diversion to appropriate health and social care services should be established through local multi-agency protocols.
- 8.3** When required, people should have access to **specialist multidisciplinary health and social care support for people who have come into contact with or may be at risk of coming into contact with the criminal justice system** (i.e. offering a community forensic function for people with a learning disability and/or autism) including the expertise to manage risks posed to others in the community. The interventions offered by these services will depend on the needs of the individual and the level of risk they pose, from individual and group offence-specific interventions, to specialist assessment and established links with other services aimed at facilitating appropriate pathways away from the criminal justice system. It is likely that some people will be best served by mainstream forensic services able to work with people with a learning disability and/or autism, and some by specialist multi-disciplinary health and social care services for people with a learning disability and/or autism. In some areas, specialist community forensic learning disability and autism teams or hospital outreach teams work with small numbers of people who pose a more significant risk to others, usually spanning several localities.

<sup>12</sup> A small percentage of people with a (cont.) learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting. They are included as a distinct group within this service model because their specific needs have not always been recognised; the model presents an opportunity to develop the support and services they may require.

<sup>13</sup> The term ‘offending’ behaviour is used in this way to encompass those people whose behaviour has brought them into contact with the criminal justice system, even if they have not been convicted of an offence.

**Actions for health and social care commissioners:**

- Commissioners should ensure that mainstream services aimed at preventing or reducing anti-social or 'offending' behaviour are making reasonable adjustments to meet the needs of people with a learning disability and/or autism, in line with Equality Act duties, and are routinely monitoring equality of outcomes.
- Commissioners should ensure the availability of specialist health and social care support for people with a learning disability and/or autism who may be at risk of or have come into contact with the criminal justice system, offering a community forensic function for this group.

**Relevant guidance and standards:**

- [NHS England - Liaison and Diversion Services](#).

9. If I am admitted for assessment and treatment in a hospital<sup>14</sup> setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to.

"Being in hospital helped me understand my mental health needs and I am now living in my own home."

"Sometimes I feel I need a safe place to go every now and again. I stay in hospital for a long time and I have to rebuild my life each time."

**Two individuals with recent experience of being in hospital**

- 9.1** Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be **integrated into their broader care and support pathway**, with hospitals working closely with community mental health, learning disability/autism and other services, including those providing intensive community and/or forensic support (see principles 7 and 8).
- 9.2** When people are admitted for assessment and treatment in a hospital setting they should expect support to focus on **proactively encouraging independence and recovery**. Services should seek to minimise patients' length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment with measurable outcomes. Hospitals should not become de facto homes; discharge planning should start from the point of admission - or earlier for a planned admission. Care and treatment should be regularly reviewed, in line with NHS England Care and Treatment Review guidance and CPA requirements. Services should be as close to home as possible and provide care and treatment in the least restrictive setting.
- 9.3** People who present an immediate risk to those around them and/or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment and/or treatment is temporarily required that cannot be provided safely and effectively in the community. They should have access to high quality assessment and treatment in **non-secure hospital services** with the clear goal of returning them to live in their home. Sometimes people will be detained under the Mental Health Act if the necessary conditions are met. People with a learning disability and/or autism should be assessed and treated in mainstream inpatient services where this is the most appropriate option. This is likely to be the case for people with a mild learning disability and/or autism who have a mental health problem of a type and severity that warrants inpatient care. Providers should make the reasonable adjustments to enable this (e.g. liaison nurses and collaborative working with learning

(cont.)

<sup>14</sup> 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients

disability and/or autism specialists). This might require providers to designate particular wards as suitable for this purpose. People whose learning disability and/or autism is more significant and who require an adapted environment and/or intensive specialist treatment and care should be admitted to a specialist unit if they require inpatient care. These specialist beds should be increasingly co-located within mainstream hospital settings as part of integrated specialist inpatient services, rather than in isolated stand-alone units. With the right support at the right time in the community, use of inpatient services should be rare and only for clearly defined purposes.

- 9.4** Admission to **secure inpatient services** should only occur when a patient is assessed as posing a significant risk to others. Often they will be detained under Part III of the Mental Health Act ('patients concerned in criminal proceedings or under sentence') and in contact with the criminal justice system, with or without restrictions from the Ministry of Justice. Some patients, however, may be detained in secure settings under Part II of the Mental Health Act where they pose an equivalent level of risk to others and this risk cannot be managed safely in less secure settings. For example, those who have been diverted away from the criminal justice system as a result of criminal justice agencies not taking the case through the courts, or discontinuing proceedings once it is seen that the person is already in hospital. In line with the Mental Health Code of Practice, only patients who require a combination of enhanced physical, procedural and relational security should be placed in secure services.
- 9.5** Everyone, other than those following diversion or direction from the criminal justice system, should expect a **community (pre-admission) CTR**. In urgent situations where there is not time to convene a CTR then there should be a 'Blue Light' meeting, in line with NHS England policy and guidance. Admissions should always be with a clear stated purpose and set of expected outcomes. In the event of an urgent admission, where a CTR has not been carried out, then this should take place within 10 working days of their admission. After six months they should expect a mandatory CTR. Additionally, at any stage in hospital, should there be concerns about care and treatment, the person themselves, their family, advocate, commissioner or clinical team have a 'right to request' a CTR.
- 9.6** For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education. For adults, provision of single-sex accommodation is essential.

### **Actions for health and social care commissioners**

- Health commissioners should ensure that hospital admissions are supported by a clear rationale of assessment and treatment, and desired outcomes, and that services are as close to home as possible.
- Micro-commissioners should be working with individuals, families/carers, clinicians and local community services to ensure that the discharge planning process starts from the point of admission, or before.

- Health commissioners should be ensuring the appropriate CTR are taking place and are of a high quality, in line with NHS England policy.
- Commissioners should ensure that support for families and carers are part of any commissioning framework.

**Relevant guidance and standards**

- [NHS England Care and Treatment Review \(CTR\) guidance.](#)
- [NICE guidance on challenging behaviour and learning disabilities.](#)

# Services to meet complex and diverse needs

When designing the service commissioners should also take into account their legal duties under the Equality Act 2010 and with regard to reducing health inequalities, their duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities. See further guidance for NHS commissioners on Equality and Health Inequalities legal duties.

## Personal Information

Recording and sharing confidential personal information is a vital part of implementing the principles and procedures set out in this document. It should be done with the explicit informed consent of the person the information is about (or when appropriate someone with parental responsibility for them); or, if they lack capacity, an assessment is needed to ensure sharing their information is in their best interests within the framework set out by the Mental Capacity Act 2005 and its Code of Practice. It is particularly important in the context of people with a learning disability and/or autism to make sure that consent is freely given.

The above paragraph above applies to all recording and sharing of confidential personal information for the purposes set out in this and the related documents, including: registers, risk stratification tools, personal health budgets, care plans, communication passports, 'quality checkers' and quality assessment.

However, confidential personal information can be recorded and shared in the public interest to help a child or young person who is or may be at risk of harm, or anyone who is or may be at risk of offending or of suffering harm or loss from offending. In each case the information recorded or shared should be in proportion to the risk.

Clear and robust information sharing protocols or agreements will always be beneficial. However they do not form a legal basis for sharing in themselves. Moreover the absence of a protocol should never be an obstacle to information sharing. Staff should be supported by adequate training and procedures to ensure they share information appropriately and are able to make informed judgements about overriding confidentiality when required.



# Annex A

## Terminology

### Learning disability<sup>15</sup>

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning), and;
- which is apparent before adulthood is reached and has a lasting effect on development.

Each of these three criteria must be met before someone can be said to have a learning disability; Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability. In terms of intellectual functioning, learning disability is conventionally defined as an IQ score in the region of 70 or below. However, it is not appropriate to use a 'cut off' figure of 70, as the results of a recognised IQ test require skilled interpretation. There should also be significant difficulties in adaptive and/or social functioning, for example in relation to conceptual, social and practical skills (such as language, interpersonal skills and activities of daily living).

The level of support someone needs depends on individual factors, including the severity of their learning disability, which can range from someone with a mild or moderate learning disability to someone with a severe or profound learning disability. The extent and nature of a person's learning disability may be determined by the presence or not of a single major genetic or environmental cause or by multiple factors interacting with educational and social opportunities that facilitate learning and the development of functional and social skills.

Learning disability is different from a specific learning difficulty, such as dyslexia, or a mental health condition.

### Autism<sup>16</sup>

Also referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC).

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.

<sup>15</sup> Adapted from Valuing People, Department of Health, 2001. See: [Valuing People – A New Strategy for Learning Disability for the 21st Century](#)

<sup>16</sup> Adapted from Fulfilling and rewarding lives, Department of Health, 2010. See: [Fulfilling and rewarding lives: the strategy for adults with autism in England](#)

The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice);
- social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own);
- social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with.

Autism is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, while others (including those who also have a learning disability) may need more support. It is estimated that around 50% of people with autism also have a learning disability.

## Behaviour that challenges

**"Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion."**<sup>17</sup>

Some people with a learning disability and/or autism display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and does not in itself imply any understanding as to the causes of the behaviour. The behaviour may be a way for someone to let people know what they want or how they feel, or to try and control what is going on around them, or be a response to physical or mental distress.

A variety of factors are likely to contribute towards the development and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical ill-health, impaired communication difficulties, mental ill-health, the impact of poverty and social disadvantage, quality of support and exposure to adversities. Some care and support environments may increase the likelihood of behaviour that challenges, including those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, as well as environments where physical health needs and pain go unrecognised or are not managed.

<sup>17</sup> Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007). See: [Challenging Behaviour: A Unified Approach](#).

Behaviour that challenges can often result from the interaction between personal and environmental factors, and can include self-injury or physical aggression, severe agitation and extreme withdrawal, as well as behaviours that can result in contact with the criminal justice system – in some cases leading to someone being arrested, charged and convicted of an offence.

Some people may have a long and persistent history of behaviour that challenges, perhaps starting in childhood. In others, it may be highly episodic – arising only under specific circumstances of stress or when the individual has a physical or mental health condition. In others still, it can be traced to a specific life event, such as a bereavement. This means that even if someone does not display behaviour that challenges today, they may do so in the future.

# Annex B

## Common needs and common shifts in service responses

**Children, young people or adults with a learning disability and/or autism who have a mental health condition, such as severe anxiety, depression or a psychotic illness, and those people with personality disorders, which may result in them displaying behaviour that challenges.**

### **Now**

Too often, mental health conditions may not be picked up or appropriately treated at an early stage in the community.

Difficulties accessing appropriate treatment for mental health conditions sometimes mean that people's conditions, once recognised, are so severe or acute that the person needs admission to hospital.

Specialist care and support is too often provided only in reaction to a crisis. The care and support being provided by multiple agencies is typically poorly coordinated and not joined up.

People often feel they have little or no control or choice over the nature of their care and support and are often excluded from mainstream services/activities.

### **In the future**

There is better and earlier identification and treatment of mental health conditions in the community, including through reasonable adjustments to mainstream health services.

Care and support is more proactive, planned and coordinated; there is multi-agency person-centred planning to meet mental health needs resulting in a person-centred care and support plan; planning takes place in partnership with individuals and families/carers who have more choice and control.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their plan.

Care and support is focused on promoting mental health and wellbeing. People have access to activities and services within the community; they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Where a person needs to be admitted to hospital for a mental health condition, it will be for no longer than is necessary and based on a clear treatment plan; it will be form part of an integrated care and support pathway of mental health support that spans hospital and community.

**Children, young people or adults with an (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill-health, some of whom will have a specific neurodevelopmental syndrome with often complex life-long health needs and where there may be an increased likelihood of displaying behaviour that challenges.**

### **Now**

Too often poorly constructed care and support packages fail to fully or adequately meet people's needs.

People may be exposed to living environments that contribute to the development or maintenance of behaviours that challenge. Often the impact of physical health conditions are not fully recognised.

At important points of life transitions, care and support is often poorly coordinated. Foreseeable difficulties are not anticipated and ongoing needs are not fully understood or met immediately following transition.

Specialist care and support may not be readily available to people who are not presenting in acute crisis and there is poor coordination between agencies delivering care and support.

A failure to recognise and meet the person's needs often contributes to families/carers or paid support and care staff struggling to support the individual. This can lead to people being admitted to hospital.

People often struggle to access mainstream activities/services.

### **In the future**

Care and support is highly personalised; there is multi-agency person-centred planning and a proactive approach to the identification/treatment of physical and mental health problems.

Individuals and families/carers are fully involved in the development of their person-centred care and support plans and have more choice and control over what their housing, care and support looks like, including through increased use of personal budgets/personal health budgets.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their plan.

Highly skilled and resilient families/carers and paid support and care staff are able to deliver proactive and reactive strategies for managing behaviour that is challenging, and services are actively supporting and enhancing the knowledge and skills of families/carers and paid support and care staff.

People, and those who support them, will be able to readily access advice and support from specialist multi-disciplinary health and/or social care teams. Specialist support will be provided more intensively and flexibly at times of crisis.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

**Children, young people or adults with a learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive, aggressive or sexually inappropriate behaviour)**

### **Now**

Often, evidence-based interventions that, if delivered at an early age would minimise or reduce the development of challenging or risky behaviours, are not available.

Staff working in social care services may struggle to cope with the person's behaviour or effectively support the person.

Involvement with the criminal justice system (which then struggles to recognise and meet people's needs) can lead to people being admitted to hospital.

Specialist care and support may not be readily available to people who are not presenting in acute crisis.

There is often poor coordination between agencies delivering care and support.

People often struggle to access mainstream activities/services.

### **In the future**

Care and support is more proactive, planned and coordinated; there is multi-agency person-centred planning resulting in a person-centred care and support plan.

Services/agencies are working together to deliver evidence-based interventions, from an early age, and people and families/carers are supported by a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their person-centred care and support plan.

People, and those who support them, are able to readily access advice and support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services and are supported to manage risks to others in the community.

There is multi-agency and collaborative working. Liaison and diversion schemes, where appropriate, divert people away from the criminal justice system to appropriate specialist health and social care services or provide support throughout the criminal justice pathway in collaboration with these health and social care partners.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

**Children, young people or adults with a learning disability and/or autism, often with lower level support needs, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family background), who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.**

### **Now**

Too often, people may have displayed behaviour that challenged as a child or young adult, but their learning disability, autism or mental health condition was not diagnosed (possibly masked by the multiple nature of the child/family's difficulties).

People may be unknown to/not eligible for support from specialist community teams for people with a learning disability (or equivalent), and yet mainstream services struggle to provide the right support.

The person may commit an offence before being diverted to secure hospital settings (which may be where their learning disability and/or autism is first diagnosed or the point at which they are first known to health and social care services).

The individual may be excluded from programmes to address 'offending' behaviours or struggle to participate. Services that are not familiar with the combination of learning disability and/or autism with 'offending' behaviour may struggle to meet their needs and to assess and manage risk effectively.

Care and support is too often provided in reaction to a crisis and is fragmented, with the individual having little choice or control.

### **In the future**

Services that are aimed at preventing or reducing anti-social/or 'offending' behaviours are able to meet the needs of people with a learning disability and/or autism, including through support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services.

Adapted programmes are available and local services are competent to deliver them.

Local multi-agency working means that a person's health and social care needs are identified earlier and addressed within ordinary community services/settings.

People, and those who support them, are able to readily access advice and support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services and are supported to manage risk to others in the community.

Care and support is more proactive, planned and coordinated, and the individual has more choice and control over what this looks like.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.



**Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in inpatient settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.**

### **Now**

Too many people have been in hospital for very many years (in some cases decades).

Care and support is often delivered to people in this situation in a way that isolates them from friends and family; affords them little or no control over their care and support; is not individualised; and is impersonal.

They will often be excluded from mainstream services/activities.

### **In the future**

People are not effectively 'living' in hospitals.

People are resettled in the community; they have highly personalised packages of care and support, through careful planning with the individual, their family/carers and an independent advocate.

People are supported by an independent advocate to help in the transition from a hospital setting.

Care and support is proactive, planned and coordinated, and the individual has more choice and control over what this looks like, including through increased use of personal budgets/ personal health budgets.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their person-centred care and support plan.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

# Annex C

## Understanding the local population

Commissioners need to have an understanding of different types of need (see Annex B) in order to ensure the availability of the right sorts of support and services in their area. They will need to establish in one place, who their local people are through increasingly sophisticated risk stratification of their local population.

This needs to be included within the Joint Strategic Needs Assessment's ensuring they are an integral part of the whole system assessments of the current and future health and social care needs of the local community and are informing commissioning decisions. The risk stratification will inform local evidence-based priorities for commissioning which will improve the public's health and reduce inequalities.

The starting point should be a focus on those who are most at risk of inappropriate responses by services.

Commissioners should identify and provide enhanced vigilance and service coordination for people who are displaying behaviours which may result in significant harm to themselves/ others/ the environment, and/or are at risk of abuse/exploitation.

This should include (for children, young people and adults):

- anyone currently in a hospital setting;
- anyone referred for or accessing specialised services for challenging behaviour (e.g. intensive support services, specialist short breaks, special schools, residential care and supported living);
- anyone subject to the provisions of the Mental Health Act or subject to Deprivation of Liberty safeguards;
- anyone with a previous hospital stay (for example, with the last 5 years);
- anyone with involvement with the youth or criminal justice system (for example, within the last 12 months);
- those children in 52 week educational placements;
- those in receipt of NHS Continuing Healthcare (CHC) funding;
- those in receipt of services from youth offending teams (YOT).

This will enable commissioners to start to quantify their populations and establish capacity to meet need.

Commissioners will need to work across commissioning and organisations to improve transparency and accountability across the whole system, being clear about how resources are being used in each area and providing evidence to support collaborative decision making.

# Annex D

## Service model reference group membership

The reference group was co-chaired by Professor Tony Holland (CBE), Department of Psychiatry, University of Cambridge, and Scott Watkin, from national charity SeeAbility and former national learning disability co-tsar for learning disabilities for the Department of Health.

The reference group was set up to provide expert advice and to bring together perspectives from a range of stakeholders.

### Individuals represented:

Dominic Tumelty	Association of Directors of Children's Services (ADCS)
Steve James	Avenues Group
Sam Sly	Centre for Welfare Reform
Viv Cooper	The Challenging Behaviour Foundation
Mark Humble	Darlington Borough Council
Stuart Miller	Department for Education (DfE)
Helen Toker-Lester	Devon Clinical Commissioning Group (CCG)
Daniel Dalton	Hertfordshire Partnership University NHS Foundation Trust
Sue Turner	Improving Health and Lives (IHAL)
Susan Harrison	London Borough of Camden
William Wormell	Ministry of Justice (MOJ)
Mark Lever	The National Autistic Society
Rob Greig	National Development Team for Inclusion (NDTi)
Karen Flood	National Forum of People with a Learning Disability

Vicki Raphael	National Valuing Families Forum
Shaun Clee	NHS Confederation
Michael Mellors	National Institute for Health Care and Excellence (NICE)
Gill Bell	Northumberland Tyne and Wear NHS Foundation Trust
Nick Hindley	Oxford Health, NHS Foundation Trust
Ashok Roy	Royal College of Psychiatry
Jean Riley	People hub
Alison Giraud-Saunders	Policy into Practice
Gyles Glover	Public Health England
Jan Tregelles	Royal Mencap Society
Rhodri Hannan	Sheffield Health and Social Care NHS Foundation Trust
Angela Hassiotis, Susan Harrson	University College London (UCL)
Peter Langdon, Glynis Murphy	University of Kent
Richard Hastings	Independent academic
Karen Dodd	Learning Disability Professional Senate

Transforming Care national delivery partners represented: NHS England, Local Government Association, Association of Directors of Adult Social Services, Department of Health, Care Quality Commission and Health Education England.

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

**October 2015**

Association of Directors of Adult Social Services (ADASS)

Local Government Association (LGA)

NHS England