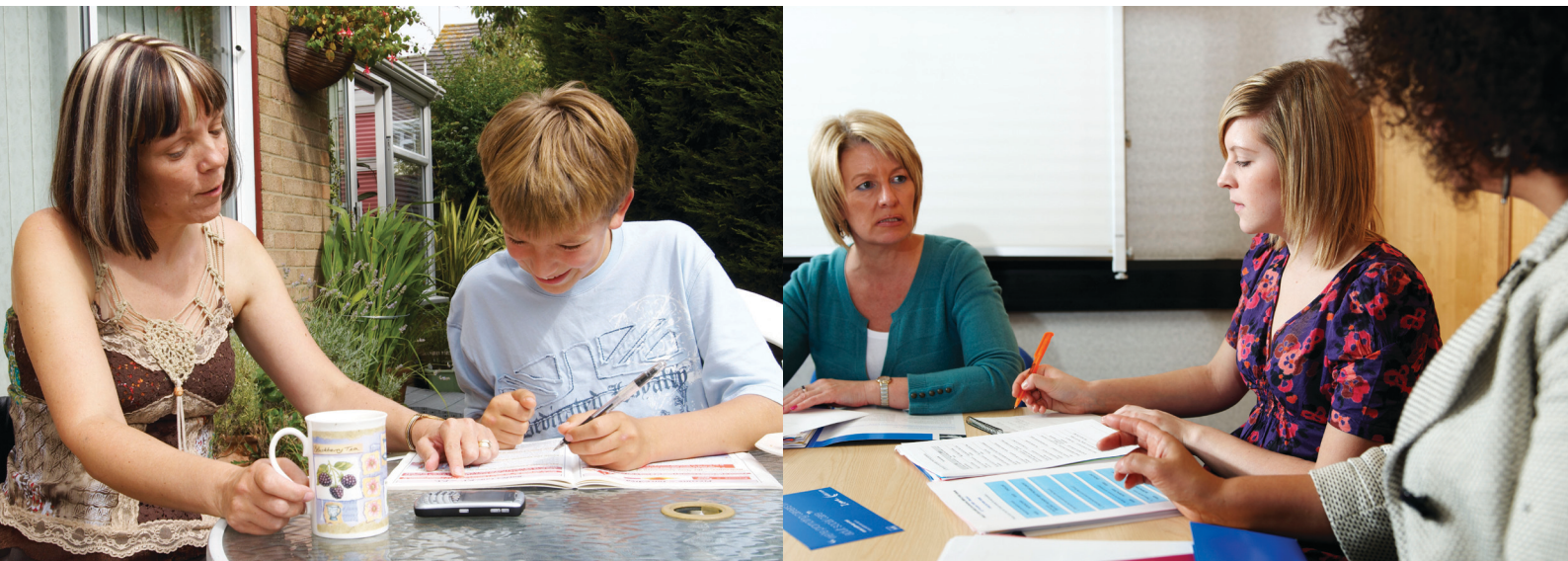


# Supporting people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges



DRAFT service model for commissioners  
of health and social care services  
**July 2015**



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# About this document

Since the investigation into the abuse at Winterbourne View and other similar hospitals, there has been a cross-government commitment to transform care and support for people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges, including behaviour that can lead to contact with the criminal justice system.

Over the coming months, local areas across England will receive extra support to draw up plans to transform the services they provide for people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges. Transformation will mean closing some inpatient beds and strengthening support in the community.

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 and a mental illness or behaviour that challenges. It 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 document is a draft. A reference group<sup>1</sup> was set up to provide expert advice on the development of the Model, bringing together a range of stakeholders. We will be continuing to work with this group in the development of the final version of the Service Model. In addition, five 'Fast Track' areas<sup>2</sup> will be able to use it as they draw up their transformation plans over the summer of 2015 and they will also test it against the reality on the ground. NHS England, the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS) will refine this service model in response to their feedback. We will also continue to seek the views of clinicians, commissioners, providers, people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges and their families. We will publish a final version in autumn 2015. You can see more about how to give us your views via a survey that you can access on [NHS England's website](#).

<sup>1</sup> See Appendix C for reference group membership.

<sup>2</sup> This summer, NHS England, the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS) will be working closely together with five 'fast track' areas - Greater Manchester and Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire - to help them draw up transformation plans. We will then apply what we have learned from working with these areas to support others to draw up their plans.

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 will be superseded as good practice develops and in particular once [NICE service model guidance](#) is published in 2017.

It is also one part of a much broader programme of work led by the Government, NHS England, the LGA, ADASS, the Care Quality Commission (CQC), and Health Education England (HEE) to transform services<sup>3</sup>. That programme includes work on issues such as workforce and funding flows (e.g. commissioning arrangements and pooled budgets) which will be key to making this service model work. More detail on this broader programme of work can be found in the [July 2015 Progress Report](#) from the Transforming Care Delivery Board.

<sup>3</sup> A commitment to demonstrating improvement by meeting our legal duties to address inequalities (the Equality Act 2010 and Health and Social Care Act 2012) underpins all our work.

# Who this Service Model is about

## Who this is about

This Service Model is about those people with a learning disability and / or autism who also have, or are at risk of developing, a mental health condition or behaviours described as challenging. This includes people of all ages and those with autism<sup>4</sup> (including Asperger's syndrome) who do not also have a learning disability, as well as those people with a learning disability and / or autism whose behaviour can lead to contact with the criminal justice system.<sup>5</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).

That said: 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 at great human cost to themselves when those circumstances could have been avoided. There are therefore also some common shifts that services will often need to make. The table below sets out some of these common needs, common problems now, and some examples of the shifts that services will need to make in future.

This table is not exhaustive. The groupings below cannot cover the complexities of every individual, nor all the causes of certain behaviours. Individuals do not 'slot neatly' into these groupings - 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. Instead the table below is intended to illustrate common needs amongst the diversity of people with a learning disability and / or autism who have a mental health condition or whose behaviour challenges, and some common shifts in service responses that commissioners should be aiming to achieve and that this Service Model is intended to support.

<sup>4</sup> Throughout this document we use the term "autism" as an umbrella term for all autistic spectrum conditions, including Asperger Syndrome.

<sup>5</sup> For simplicity, when we refer to 'everyone' or 'all people' in this document, we are referring to this defined group of people unless otherwise stated.

## Common needs, and common shifts in service response required

**Children or adults with a learning disability and / or autism who have a mental health problem, such as severe anxiety, depression or a psychotic illness which may result in them displaying behaviours that challenge.**

### **Now**

Too often mental health problems may not be picked up or appropriately treated at an early stage in the community, with the result that they deteriorate and the individual ends up in hospital. Care and support is too often provided in reaction to a crisis and is fragmented, with the individual having little choice or control. The individual is often excluded from mainstream services/activities.

### **Future**

Better identification and treatment of mental health problems amongst children and adults with learning disabilities and / or autism in the community. Care and support is more proactive, planned and coordinated, and the individual and their families has more choice and control over what this looks like. Where a hospital admission is needed it is as short as possible, part of an integrated care pathway, and delivered in local generic mental health inpatient services or local specialist inpatient services, according to individual need. Access to mainstream services / activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

**Children 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 behaviour that challenges.**

### **Now**

Too often, poorly constructed care and support packages, including specific living environments, or poorly managed transitions / transitory health problems, result in behaviours that can challenge services, leading to families being unable to cope or placement breakdown, with the individual ending up in hospital. Care and support is too often provided in reaction to a crisis and is fragmented, with the individual, and their families, having little choice or control. The individual is often excluded from mainstream services / activities.

### **Future**

Highly-personalised, life-long person-centred plans and care and support packages, with highly skilled and resilient families / staff able to deliver proactive / reactive strategies for managing challenging behaviour in the community. Proactive identification / treatment of physical and mental health problems, and the individual's day-to-day support in the community is informed by the expertise provided from multi-disciplinary specialist health/social care teams (stepped up in intensity at times of crisis). Care and support is more proactive, planned and coordinated, and the individual and their families has more choice and control over what this looks like. Access to mainstream services / activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.



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

### **Now**

Too often, evidence-based interventions to minimise / reduce risky behaviour from a young age are not made available; social care staff struggle to manage the behaviour, individuals may get involved with a criminal justice system which then struggles to deal with their needs, and the individual can end up in hospital. Care and support is too often provided in reaction to a crisis and is fragmented, with the individual and their families having little choice or control. The individual is often excluded from mainstream services / activities.

### **Future**

Evidence-based interventions, from a young age, to minimise 'risky' behaviours, care and support packages with the right skills to manage behaviours and risk to others in the community (including through support from multi-disciplinary specialist health/social care teams and specialist forensic health services), liaison and diversion schemes to divert individuals (where appropriate) away from the criminal justice system to appropriate health and social care support or provide support throughout the criminal justice pathway, working in collaboration with health and social care partners. Care and support is more proactive, planned and coordinated, and the individual has more choice and control over what this looks like. Access to mainstream services/activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

**Children or adults with a learning disability and / or autism, often with lower level health or social care needs and 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 problems are not diagnosed (possibly masked by multiple nature of the child/family's difficulties). Unlikely to be eligible for support from a Community Learning Disability Team (or equivalent), they may also have struggled to access mainstream services. The individual might commit an offence before being diverted to secure hospital settings (which may be where their learning disability or autism is first diagnosed. or the point at which they are first known to health and social care services). Care and support is too often provided in reaction to a crisis and is fragmented, with the individual having little choice or control.

#### **Future**

Those at risk are identified earlier, mainstream services working to prevent anti-social / or 'offending' behaviours are better supported to work with people with a learning disability / autism, health and social care needs are identified earlier and addressed in the community, care and support packages manage risk to others in the community with support from multi-disciplinary specialist health / social care teams and specialist forensic health services. Care is more proactive, planned and coordinated, and the individual has more choice and control over what this looks like. Access to mainstream services/activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

**Adults with a learning disability and / or autism with a mental health condition or whose behaviour challenges who have been in inpatient care 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). They may be highly institutionalised, with little choice or control over their care and support. They will often be excluded from mainstream services/activities.

#### **Future**

Individuals are resettled in the community, with a highly personalised health, care and housing package put in place through careful planning with the individual, their family and independent advocate. Care and support is proactive, planned and coordinated, and the individual has more choice and control over what this looks like. Access to mainstream services / activities means the individual lives a purposeful and fulfilling life.

# Good services for people with a learning disability and / or autism who have a mental health condition or whose behaviour challenges

This section describes what good services look like for a person with a learning disability and / or autism who has a mental health condition or behaviour that challenges.

It is structured around nine overarching principles for people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges (including behaviours which may result in contact with the criminal justice system). The principles are framed from the perspective of one such person. Further explanatory notes on each paragraph are available in subsequent sections of the document.

## **In commissioning these services a number of 'default positions' should be taken:**

- A person must be assumed to have the mental capacity to make decisions about their care, unless it is established that they lack capacity for that specific decision - and all practicable steps should be taken to support them to make their own decisions.
- 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.
- People's homes should be in the community, supported by local services.
- 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, with access to specialist multi-disciplinary community-based expertise as appropriate.

## 1 My care is planned, proactive and coordinated.

- 1.1 Children and adults with a learning disability and / or autism who have a mental health condition or behaviour that challenges<sup>6</sup> who, at times, might need extra support to remain in the community, should expect local health and care services to be using increasingly sophisticated risk stratification to anticipate and meet their needs. This should include an **'at risk of admission' register** to provide those most at risk of admission to hospital with proactive, preventative support. (See p18 for further notes)
- 1.2 Everyone<sup>7</sup> should have a **person centred care and support plan**, which they have been involved in drawing up and which they have a copy of. For children and young people up to the age of 25 with a special educational need and / or disability, this should take the form of an Education, Health and Care (EHC) plan. (See p19)
- 1.3 Everyone should be offered a named **local care coordinator** 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 child or adult and their family where appropriate. (See p20)

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

- 2.1 Everyone should receive information about their care in formats that they can understand and should receive appropriate support to help them communicate, in keeping with the new **Accessible Information Standard**. (See p21)
- 2.2 Increasingly, people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care. 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. (See p21)
- 2.3 At key points in their interaction with health and care services, people should have access to different types of **independent advocacy**. In addition to the legal right to advocacy, people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges 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. (See p23)

<sup>6</sup> For simplicity, henceforth when we refer to 'everyone' or 'all people' in this document, we are referring to this defined group of people unless otherwise stated.

<sup>7</sup> See footnote above.

### 3 I live in the community with support from and for my family and paid carers.

- 3.1 All parents caring for children (of whatever age) who have a learning disability and / or autism and who are at risk of developing or are beginning to develop a mental health condition or behaviour that challenges should be offered practical and emotional support and **evidence-based parenting training**, in line with NICE guidance, which are targeted to their specific challenges and needs. (See p24)
- 3.2 All parents caring for children (of whatever age) with a learning disability and / or autism who have a mental health condition or display behaviour that challenges should have **access to short breaks** suitable for people whose behaviour challenges, and support to care for their child from specialist multidisciplinary teams. (See p25)
- 3.3 **Alternative short term accommodation** (available for a few weeks), which open as and when is needed, can be used in times of crisis or potential crisis as a place where people can go for a short period, preventing an avoidable admission into an inpatient setting. They might also provide a setting for assessment from intensive multi-disciplinary health and care teams (see section 7 below) where that assessment cannot be carried out in the individual's home. (See p26)
- 3.4 Everyone who is getting a social care package who has a learning disability and / or autism and who has a mental health condition or behaviour that challenges should have access to paid **care staff trained and experienced in supporting people with behaviours that challenge**, mental health conditions 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. Local authorities should use Market Position Statements and "strategic provider"/ "preferred provider" frameworks with specific service specifications including requirement for staff training in Positive Behaviour Support (PBS) to develop a market of providers with these skilled staff. (See p26)

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

- 4.1 People should be offered a **choice of housing, including small-scale supported living** - in accordance with REACH standards. 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). (See p27)
- 4.2 People should be offered **settled accommodation**. This should include exploring home ownership, or ensuring security of tenure. (See p28)
- 4.3 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 the **local housing strategies**. (See p29)

## 5 I have a fulfilling and purposeful everyday life.

- 5.1** Everyone should have **access to activities / services (such as early years services, education, employment, social, sports / leisure) that enable them to lead a fulfilling and purposeful everyday life**. They should have as much choice and control as possible over the activities in which they participate, facilitated through person-centred plans / EHC plans and personal budgets / personal health budgets - any restrictions posed (MOJ / Multi Agency Public Protection Arrangements - MAPPA) 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. (See p29).
- 5.2** People should have access to **education, training and employment which addresses their needs** and which they can access within their local area. To enable this, support providers and multi-disciplinary specialist health and social care teams should provide training to mainstream service staff and / or provide support to individuals that enables them to participate in mainstream services and to access education and training within local schools and colleges. (See p29).

## 6 I get good care from mainstream NHS services.

- 6.1** Everyone with a learning disability over the age of 14 should have an **Annual Health Check**. This is particularly important for those with communication difficulties. This should result in a **Health Action Plan** integrated into a single person-centred care and support plan (as above). Where appropriate it should include a **'Hospital Passport'** to help staff in mainstream NHS services make the reasonable adjustments for the individual (including to accommodate behaviour that challenges) that are required by law. (See p30)
- 6.2** Everyone should expect universal NHS services to employ clearly identified and readily accessible **'liaison' staff** who have specific skills in working with people with a learning disability and / or autism, and are able to advise those services on reasonable adjustments. (See p31)
- 6.3** Everyone should expect **'quality checker'** schemes to be in place ensuring that mainstream services serve them appropriately. (See p32)
- 6.4** In **mainstream mental health services**, everyone should be able to expect services to regularly audit how they serve people with a learning disability and / or autism and make improvements as a result, using the [Green Light Toolkit](#). They should be able to expect new initiatives and investment in mainstream mental health services (such as new investment in Children and Adolescent Mental Health Services (CAMHS), Improving Access to Psychological Therapies (IAPT) and the Crisis Concordat) to improve their access to those services. (See p32)

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

- 7.1** Everyone should have access to **integrated specialist multidisciplinary health and care support for people with a learning disability and / or autism in their community** when required. This needs to include children, young people (particularly at the point of transition between childhood and adulthood), and adults, as well as those children and adults who may have come into contact with or be at risk of coming into contact with the criminal justice system, including people with lower level social care and / or health needs. (See p33)
- 7.2** The support available should include: supporting people with a learning disability and / or autism who have a mental health condition or behaviour that challenges to access mainstream services (including wider health and social care services and services for people who may have come into contact with the criminal justice system) or enabling those services and families to support this cohort, and providing direct assessment and specialist clinical therapeutic support. The support might be provided by children's services, child and adult mental health services and specialist community learning disability teams working together through a 'Collaborative Care' model; or by combined teams (e.g. all age, learning disability and autism). (See p33)
- 7.3** Anyone with a learning disability and / or autism who at any one point 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 short breaks services, to help prevent family or support package breakdown. This support should be provided by a highly-skilled and experienced multi-disciplinary / agency team with specialist knowledge in managing behaviours that challenge. The 'step up' and 'step down' between specialist multidisciplinary support (above) and this intensive support needs to be seamless. (See p35)

## 8 I am supported to stay out of trouble.

- 8.1** People with a learning disability and / or autism 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 as the rest of the population**. Through collaboration with multi-disciplinary specialist health and social care services for people with a learning disability and / or autism (see above), 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 make reasonable adjustments such that they can effectively support people with a learning disability and / or autism, and to identify learning disabilities or autism amongst the people they support. (See p36)
- 8.2 Liaison and diversion schemes** should seek to support people through the criminal system 'pathway' enabling people to exercise their rights and / or where appropriate, diverting people to appropriate support from health and care services; clear pathways for diversion to health and social care services should be established through local multi-agency protocols (See p37)
- 8.3** When required, anyone with a learning disability and / or autism should have access to **specialist health and care services that support people who have come into contact with or are at risk of coming into contact with the criminal justice system (i.e. offering a community 'forensic' function) including the expertise to manage risk posed to others in the community**. The interventions offered by those services will depend on the needs of the individual and the level of risk they pose, from circles of support to individual and group offence-specific interventions aimed at reducing offending, 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 learning disabilities and / or autism (likely to include people with more mild-moderate learning disabilities); some by multidisciplinary specialist health and social care services for people with learning disabilities and / or autism (see above). In some areas, specialist forensic learning disability and / or autism (see above). In some areas, specialist forensic learning disability and / or autism teams or hospital outreach teams work with small numbers of people who pose a more significant risk to others, usually spanning several localities. (See p37)



## 9 If I need assessment and treatment in a hospital 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.

- 9.1** People with a learning disability and / or autism who present a severe and 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 intensive support and assessment is temporarily required that cannot be provided in the community because of the risk to their own health and safety or that of others. They should have access to assessment and treatment of mental health and behaviour disorders 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. With the right support at the right time in the community, use of these inpatient services should be very rare and for defined purposes: in the region of England where people with a learning disability are most likely to be supported in the community rather than hospital, at any one time approximately 20 beds per 10,000 people with a learning disability on GP registers will be occupied by people with a learning disability. (See p39)
- 9.2** People with a learning disability and / or autism who need assessment and treatment for a mental disorder whilst preventing harm to the public (and whose behaviour has often resulted in contact with the criminal justice system and subsequent diversion to hospital) need access to **secure inpatient services**. The service provided may include providing necessary advice and support to the Courts in appropriate disposal / sentencing. These services should only be for patients who present risks above the threshold for safe management in the community, who with the right preventative services in place will be very few in number. (See p39)
- 9.3** In line with NHS England guidance, other than when following diversion from the criminal justice system, admission should only take place following a **pre-admission Care and Treatment Review** (for planned admissions) or a 'Blue Light' meeting (for unplanned admissions). Admission should always be with a clear stated purpose and set of expected outcomes. (See p40)
- 9.4** Inpatient services should be **integrated into a broader care pathway**, working closely with community mental health and learning disability services. Generic inpatient mental health services should be used for people with a learning disability and / or autism who require non-secure inpatient care. Where people cannot be supported effectively or safely in generic inpatient mental health services, assessment and treatment services should be small and integrated with community services as part of a broader care pathway. (See p41)
- 9.5** Hospitals should not become de facto homes: **discharge planning** should start from the point of admission, and care should be regularly reviewed, in line with NHS England Care and Treatment Review guidance and Care Pathway Approach (CPA) requirements. (See p42)
- 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, and for both children and adults, provision of **single-sex accommodation** is essential. (See p42)

# Explanatory notes

These notes provide more detail to the previous section on what services should look like for people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges.

## 1 My care is planned, proactive and coordinated.

- 1.1** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges, and who at times might need extra support to remain in the community, should expect local health and care services to be using increasingly sophisticated risk stratification to anticipate and meet their needs. This should include an **'at risk of admission' register** to provide those most at risk of admission to hospital with proactive, preventative support.

**Rationale:** behaviour that challenges can often be predicted, and early intervention taken to prevent, manage or minimise that behaviour. Understanding the factors that increase the risk of people developing or displaying behaviours that challenge, and having a clear understanding of which individuals are most at risk, can enable services to work together to proactively put in place appropriate anticipatory support.

### Further notes:

- Commissioners should risk-stratify their local population of people with a learning disability and / or autism to enable them to put in place appropriate anticipatory support. The [NICE guideline on challenging behaviour and learning disabilities](#) contains useful guidance on understanding the risks of developing behaviour that challenges.
- At a minimum, each Clinical Commissioning Group (CCG) (or an organisation nominated by the CCG, for example a Commissioning Support Unit - CSU - or provider trust) will be required to develop a register of those 'at risk of admission'<sup>8</sup>. This should include all children and adults in their area with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges (including behaviours which may lead to contact with the criminal justice system) and who at times might need extra support to remain in the community (as opposed to experiencing a crisis and going into hospital). The register should be used to ensure that there is sufficient resource in each area to provide early interventions and personalised and coordinated support in the community.

<sup>8</sup> The 'at risk of admission' register may be an extension of the register required to be developed as part of the "[DH Winetrbourne View Review - Concordat: Programme of Action](#)" December 23012 which asked that "all primary care trusts develop registers of all people with learning disabilities or autism who have mental health conditions of behaviour that challenges in NHS-funded care as soon as possible and certainly no later than April 2013" and that CCGs should "maintain the local register from 1st April 2013".

- There will be a designated “data controller” for this register. The data controller will make sure that the data is stored securely with access controls and will ensure that the register is managed in line with the law and best practice as set out in the [HSCIC’s IG Toolkit](#) and elsewhere. The accuracy, security and appropriate availability of the information it contains will be maintained at all times. It must also link to other relevant registers such as the Special Educational Needs (SEN) register, and commissioners should work to identify and implement the most appropriate way of doing this in their local area.
- The register will include information that monitors whether the individual is effectively supported and reviewed in order that contingency plans can be put in place as necessary and will be subject to regular review with input from the multi-disciplinary teams across health and social care, and representation from other key providers of services.
- Creation and maintenance of the register will need to account for the obligations towards the patient under the Data Protection Act, the duty of confidentiality owed and the Human Rights Act. These can be incorporated into the processes supporting the patient and include ensuring the patient is informed about the register and their rights around inclusion. See the relevant guidance for more information.

- 1.2** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should have a **person centred care and support plan**, which they have been involved in drawing up and which they have a copy of. For children and young people up to the age of 25 with a special educational need and / or disability, this should take the form of an Education, Health and Care (EHC) plan.

**Rationale:** many people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges will require highly-individualised, long-term support from a wide range of organisations, including proactive and reactive strategies for managing challenging behaviour. Person-centred care and support plans can help achieve this. Currently, only some people with a learning disability and / or autism who have a mental health condition or behaviour that challenges have a care and support plan and / or a care coordinator to manage that plan. Yet while some have no plan, others who use multiple services have several.

**Further notes:**

- Section 24 of the Care Act 2014 outlines local authorities’ legal responsibility to prepare a care and support plan for an adult. It suggests that this should be done whenever it is required to meet the individual’s needs, or whenever the local authority decides to do so.  
Commissioners should ensure that all adults with a learning disability and / or autism who have a mental health condition or behaviour that challenges have a person centred support and care plan, not just those on CPA.
- There should be just one plan for each individual, which brings together all services and focuses on what is important to and for the person and their family. This should include plans resulting from Annual Health Checks for people with a learning disability (see p30).

- Plans should focus on the goals and outcomes that the individual wants to work towards and the care and support they need to do so. This will include support from health and social care services, education services, family and carers, voluntary and community services, peer networks, as well as actions which the individual can take for themselves to self-manage their health and wellbeing and maintain their independence.
- Plans should include advance crisis and contingency planning that has been developed and agreed with the individual, their family, providers and other professionals as applicable.
- There should also be clear processes for review including the ability to undertake an emergency review where this is needed.
- For children and young people (aged 0-25) with a special educational need and / or a disability, person-centred plans would take the form of an education, health and care (EHC) plan. Local authorities have a duty to develop an EHC plan for all children and young people (0-25) with complex special educational needs and disabilities. This should include an in-depth multi-agency assessment of the child or young person and family - their strengths, aspirations and desired outcomes for their child alongside the full range of factors impacting on their child's development, achievement, enjoyment and inclusion. The plan should then set out the core outcomes to be achieved and how a coordinated package of education, health and care will help achieve this. Families should receive support to actively engage with developing their child's care and support plan.
- Care and support planning can be led by a variety of different people or teams: health and social care professionals, such as those in the community learning disabilities team, or forensic mental health team, or specialist voluntary or community sector organisation. For children and young people it will be the SEN Department who lead on the development of EHC plans, with other agencies such as CAMHS inputting into this.
- No matter who leads it, the individual and their family and carers must be involved in the planning process. It is their plan.
- Services and support offers identified through the care planning may need to be commissioned either for the local population, or if the individual has a personal budget, at the individual level.
- Further guidance on personalised care and support planning for people with long-term conditions is available at [www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/lc-care/](http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/lc-care/).

**1.3** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should be offered a named **local care coordinator 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 child or adult and their family where appropriate.

**Rationale:** people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges will often require a complex range of services delivered by a number of different agencies. It can be difficult for the individual or their family to navigate these services, and poorly coordinated care can result in worse outcomes or crises occurring. Currently, some people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges (e.g. those on the Care Programme Approach) will have a local care coordinator, but others do not.

### Further notes:

- Commissioners should extend the offer of a named local (care) coordinator to all people with a learning disability and / or autism who have a mental health condition or behaviour that challenges.
- In this context, local (care) coordination means that a named person is allocated responsibility for coordinating and navigating the individual's care and support. This is distinct from the role of advocate - the local (care) coordinator will normally work for the local authority or health service, whereas advocates are independent. In children's services, the term 'key worker' is often used to mean the same thing.
- Named care coordinators could be a range of different people from different organisations / professional backgrounds. They do not have to be clinical but do need to have the right skills to be able to undertake an effective coordinating role for people with a learning disability and to be supported to continue to develop those skills.

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

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- 2.1** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should receive information about their care, in formats that they can understand and should receive appropriate support to help them communicate, in keeping with the new [Accessible Information Standard](#).

**Rationale:** health and social care organisations are required by law to follow an accessible information standard, published in June 2015, to ensure that people with a disability receive information in formats that they can understand, and that they receive appropriate support to help them to communicate.

- 2.2** Increasingly, people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care. 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.

**Rationale:** people should have choice and control over the care and support they receive. People with a learning disability and / or autism who have a mental health condition or display behaviour that challenges, and their families of children in this group, should have the same rights to choice and control as everyone else (though in some cases, for instance to due legal restrictions, there may need to be limits on the choice a person can exercise for their own safety or the protection of others).

But this is not simply about respecting their rights: giving people more choice and control also means they are more likely to benefit from the support they receive. [Formal evaluation](#) has shown that personal health budgets work best for those with higher levels of need, which is likely to be true for many people with a learning disability and / or autism who have a mental health condition or whose behaviour challenges.

### Further notes:

- Many people already have a right to personal budgets, including as direct payments in some cases. Direct payments should be offered to anyone eligible for a social care package and carers where they are assessed as having eligible needs which can be managed by the individual or their representative. Anyone who is eligible for NHS Continuing Health Care, including those with a learning disability, has a right to have a personal health budget. As part of the Education Health and Care (EHC) plan process, children with a special educational need should be offered a personal budget.
- In addition to these existing rights, the NHS planning guidance [Forward View into action: Planning for 2015/16](#) sets an expectation that CCGs will roll out [personal health budgets](#) to others who could benefit. This must include people with a learning disability. [Formal evaluation](#) has shown that personal health budgets work best for those with higher levels of need, and it is particularly recommended that commissioners consider routinely offering [personal budgets](#) to young disabled people who are moving towards adult life; people being discharged from long-term hospital care; and other people with learning disabilities or autism who have high support needs and are not well served by conventional service approaches.
- Personal Budgets and Personal Health Budgets must be linked to a person-centred care and support plan - which the individual (and their family) is involved in developing, focusing on the outcomes that are important to them.
- Commissioners should give an individual a clear indication about how much money is being provisionally allocated to them before the planning discussions start. They should also be transparent about how long a particular funding stream is likely to be available for.
- Commissioners should offer different means of managing the budget - either notionally, as a direct payment to an individual or their representative or through a third party arrangement.
- There should be as few restrictions as possible in how the budget can be spent (so pre-payment cards should not be the only way that people can spend their budget).
- Commissioners should ensure that they take a positive approach to risk, enabling people to try different approaches and not dismissing something just because it is not what is usually commissioned.
- People taking up personal budgets must have access to information, advice and brokerage to help them understand the choices available, exercise those choices and help them plan how to use and manage their budget.

- Personal budgets and personal health budgets are of no value without a range of options for people to choose from. Therefore there will need to be significant market and provider development in most areas. These options do not have to be NHS-provided nor should they be limited to things routinely commissioned by the NHS or local authorities. There will also need to be development of support functions for e.g. brokerage, local (care) navigation / co-ordination.
- Peer-to-peer support can be useful in helping people use personal budgets / personal health budgets and commissioners should consider how peer networks might be developed to assist with this.
- See further guidance on [personal health budgets](#) and [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk).

**2.3** At key points in their interaction with health and care services, people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges should have access to different types of **independent advocacy**. In addition to the legal right to advocacy, people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges 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. (See below).

**Rationale:** With regards to care and support processes, it can be difficult for people with a learning disability and / or autism or their families to understand the options available to them and to make their voices heard about the care and support provided to them, helping to shape or challenge what that care and support looks like. Advocacy not only helps them exercise their rights but should also lead to care and support being better tailored to individual need. It is likely to be particularly important at key decision points (such as during hospital discharge planning). It is similarly essential to recognise that for this group of people the need for advocacy support should not simply be a 'revolving door' service, only available at isolated points and / or during times of crises. Outside of care and support processes, individuals in this group are likely to require long-term advocacy support to develop essential life skills to maintain stability in their day-to-day lives, as well as when accessing meaningful activities in their community.

**Further notes:**

- There are several situations where local authorities already have a duty to provide advocacy. Anyone detained under the Mental Health Act should have access to an Independent Mental Health Advocate. Under the Mental Capacity Act, anyone who lacks capacity to make particular decisions for themselves, including serious medical treatment and a change of accommodation, should have access to an Independent Mental Capacity Advocate. Under the Care Act, anyone who may experience 'substantial difficulty' in being involved in care and support 'processes' and who does not have an 'appropriate adult' to support them should have access to an Independent Advocate. Under the Children and Families Act, advocates should be made available for children

and young people who have special educational needs and their families. When a young person becomes 18, there is a duty to ensure access to advocacy separate to the young person's parents or unpaid carers if that is what they want. Under the Care Act, if anyone is likely to be placed in hospital for 28 days or more and would have 'substantial difficulty' understanding the process, the local authority must provide independent advocacy if it is agreed that this would be in the person's best interest. This applies even if the person has an 'appropriate individual' available to support them. This applies equally to those people whose needs are being jointly assessed by the NHS and the local authority or support is being provided jointly.

- In addition to these situations where access to advocacy is a legal right, non-statutory advocacy services should be more widely available to people with a learning disability and / or autism who have a mental health condition or behaviour that challenges, and to their families. It is important that non-statutory advocacy is available for people and their families both over the long-term to empower them to take control of their day-to-day lives, as well as at key transitional points. For instance to support a young person with an EHC plan in year nine when transition planning for adulthood should begin or when a young person is leaving school (though advocacy is also available at any point during EHC planning). To enable this, commissioners should ensure a range of advocacy services are available including self, peer and group advocacy, as well as smaller voluntary or community sector organisations.
- In particular, statutory and non-statutory advocacy should be made available to all people with learning disabilities and / or autism who are leaving an inpatient setting after a period of time in specialist hospital.
- All people working with and supporting people with a learning disability and / or autism with a mental health conditions or behaviours that challenge need to understand the different types of advocacy (statutory and non-statutory) and proactively offer the most appropriate type as and when required. This means ensuring information is provided in ways that people can understand. The [Accessible Information Standard](#) should be used to support this. Staff supporting people with a learning disability and / or autism with a mental health conditions or behaviours that challenge should also include the advocates within discussions and care planning processes.
- All advocacy services should be independent and provided separately and distinctly from care and support providers.

### 3 I live in the community with support from and for my family and paid carers.

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- 3.1** All parents caring for children (of whatever age) who have a learning disability and / or autism and who are at risk of developing or are beginning to develop a mental health condition or behaviour that challenges should be offered practical and emotional support and **evidence-based parenting training**, in line with NICE guidance, which is targeted to their specific challenges and needs.



**Rationale:** family carers often play a huge role in providing day-to-day support to children and adults with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges. Supporting them to manage challenging behaviour effectively can improve outcomes for them and for their children, and reduce the likelihood of crises requiring more restrictive intervention by health and care services (such as hospitalisation).

**Further notes:**

- [NICE guidance](#) on appropriate parent-training programmes is available.

**3.2** All parents caring for children (of whatever age) with a learning disability and / or autism who have a mental health condition or display behaviour that challenges should have **access to short breaks** suitable for people whose behaviour challenges, and support to care for their child from specialist multidisciplinary teams.

**Rationale:** family carers often play a huge role in planning, managing or providing the support given to people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges. This is exceptionally demanding, and short breaks play a vital role in helping families and carers cope with the ongoing demands of looking after their child. Short breaks also provide an opportunity for the individual concerned to access specialist support, have new experiences and develop new skills. Additionally, they can be used in times of crisis or potential crisis as a place where people can go for a short period. Instead of going into an inpatient setting, having 'time out' in a safe environment can help to dissipate developing tensions and frustrations.

**Further notes:**

- There are different forms of breaks. Some involve having care workers available to live-in with a person with learning disabilities and / or autism whose behaviour challenges for a short time (e.g. weekend); in other cases, it may be preferable to offer accommodation in another environment with specialised support - though it is important that this should not be a hospital or a setting where other people receive permanent care and support.
- Commissioners should ensure that a range of short breaks is available for individuals and their families in each local area. As this cohort consists of people whose behaviour challenges, it is essential that short break provision takes account of this and suitable arrangements are made: this may mean commissioning specialist short break provision.
- Access to short breaks should be built into individuals' support plans, but should also be readily available in times of crisis.
- Commissioners should ensure that there are short breaks specifically for children and parents that offer family placement and relevant leisure and recreation. With the correct levels of support families can still be enabled to have the benefits of a short break whilst remaining together should they wish to. Alternatively families and siblings may benefit from some protected time apart. The Department for Education has issued guidance on short breaks for carers of disabled children.

**3.3 Alternative short term accommodation** (available for a few weeks), which open as and when is needed, can be used in times of crisis or potential crisis as a place where people can go for a short period, preventing an avoidable admission into an inpatient setting. They might also provide a setting for assessment from intensive multi-disciplinary health and care teams (see section 7 below) where that assessment cannot be carried out in the individual's home.

**Rationale:** Instead of going into an inpatient setting, having 'time out' in a safe environment can help to dissipate developing tensions and frustrations. They might also provide a setting for assessment from intensive multi-disciplinary health and care teams (see section 7 below) where that assessment cannot be carried out in the individual's home.

**3.4** Everyone who is getting a social care package who has a learning disability and / or autism and who has a mental health condition or behaviour that challenges should have access to **paid care staff trained and experienced in supporting people with behaviours that challenge, mental health conditions** and those who may have come into contact with or 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. Local authorities should use Market Position Statements and "strategic provider"/ "preferred provider" frameworks with specific service specifications including requirement for staff training in Positive Behaviour Support (PBS) to develop a market of providers with these skilled staff.

**Rationale:** paid care staff play a huge role in providing day-to-day support to many children and adults with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges. Supporting them to manage challenging behaviour effectively can improve outcomes for them and for individuals they support, and reduce the likelihood of crises requiring more restrictive intervention by health and care services (such as hospitalisation).

#### **Further notes:**

- Local authorities need to ensure that the social care provider market can meet the needs of these individuals. It is recommended that commissioners consider working with a smaller number of highly specialised providers that have staff who are trained and experienced in supporting people with behaviours that challenge, mental health conditions and offending behaviour.
- Care staff require training in proactive and reactive strategies including positive behavioural support which is not a single intervention or therapy but a multi-component framework for delivering a range of evidence based supports to increase quality of life and reduce the occurrence, severity or impact of behaviours that challenge. [Ensuring Quality Services](#) provides further guidance.
- Because the total number of people in this cohort is small, it may be necessary for local authorities to collaborate to develop strategic provider / preferred provider frameworks. Where this happens, it is essential that it does not lead to people being moved many miles away from home to access services: commissioning collaborations need to be as local as possible.

- To develop the local provider market, authorities should use Market Position Statements with an explicit focus on people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges (including offending behaviours).
- Individual budgets should reflect care hours being paid at the living wage at a minimum, and in many cases reflect the additional skill and experience needed to care for somebody with complex needs.
- Active involvement in the development of providers in the required skills and competencies should be the responsibility of commissioners.

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

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- 4.1** People with a learning disability and / or autism who have a mental health condition or whose behaviour challenges should be offered a **choice of housing, including small-scale supported living**. This choice may be circumscribed by the Ministry of Justice in some instances when 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).

**Rationale:** the right home, environment and people can improve independence and quality of life, and help individuals manage behaviours that challenge and reduce the risks to themselves and others.

### Further notes:

- People with a learning disability and / or autism who have a mental health condition or who display behaviour that challenges should be supported to live as independently as possible, rather than living in institutionalised settings (which, for instance, housing with occupancy of six or more can quickly become). This includes those people leaving specialist hospitals after long inpatient spells. This could mean 'mainstream' housing either provided by a housing association, private landlord, family or shared ownership scheme. It should not be assumed that individuals want to live with others, unless this is an active choice.
- Housing should meet people's needs in a person-centred way and be in accordance with the Valuing People principles of rights, independence, choice and inclusion. These principles are also articulated through the [REACH standards](#) for supported living.
- Existing property may need to be adapted to meet the individual's needs, for instance by installing safety equipment or assistive technology. Use of a Disabled Facilities Grant (DFG) might be needed to do this and the rules over DFG usage need to be interpreted with appropriate breadth and paying full attention to the guidance i.e. it is not just for adaptations to accommodate physical disability and the needs of the family should be considered also.
- For some people, there may be specific requirements that are designed to keep them and others safe (for example, the criminal justice system may place restrictions on where individuals live as a condition of discharge).

- Choice of housing should be offered early in planning processes. Housing is an area where the future needs of people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges (including offending behaviours) can, to a certain extent, be predicted. The transition planning process - for the transition into adulthood - is an ideal opportunity to gain an understanding of future housing needs. If conducted correctly and in a timely way, it can help ensure that the right mix of housing is available for the local population (including bespoke housing when needed, e.g. including sensory equipment). Additionally, this needs to be recognised during other transitions, e.g. ageing or changes in physical health needs
- CCGs could consider allowing people with a personal health budget to use some of their budget to pay for / 'top up' housing costs if this meets a health need and is agreed as part of the individual's care and support plan.

**4.2** Anyone with a learning disability and / or autism who has a mental health condition or behaviour that challenges should be offered **settled accommodation**. This should include exploring home ownership, or ensuring security of tenure.

**Rationale:** having settled accommodation gives an individual greater security, but also makes it easier for them to change their care arrangements if they are not working well, without losing their home. Should the individual need to go to hospital, having settled accommodation should also make it easier to avoid delays to their being discharged back into the community.

#### **Further notes:**

- People with a learning disability and / or autism who have a mental health condition or who display challenging behaviour should be supported to explore options for home ownership or shared home ownership.
- People with a learning disability and / or autism who have a mental health condition or who display challenging behaviour should also be offered a tenancy. The [NDTi 'Real Tenancy Test'](#) can be used to assess whether tenancy rights within supported living services are being respected in practice.
- For people with tenancies who need to go into an inpatient setting or leave their home for a short period, commissioners need to work with providers and housing associations to ensure their tenancies are protected. If the individual is not returning to their previous home, arrangements should be made for securing future accommodation and tenancy or ownership prior to relinquishing any previous arrangements.
- There can be issues and additional complexities whereby individuals breach their tenancy agreements and may risk eviction, compounded when a person lives with others who are also vulnerable. Resolving issues like these will require commissioners to oversee close collaboration and planning between support providers, housing associations and specialist health and social care teams.
- There is legislation that allows commissioners to work across boundaries and commission together. For bespoke and specialist services, commissioners that require this type of housing for small numbers of people should consider this approach.

- 4.3 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 the local housing strategies.

**Rationale:** To ensure that everyone has choice about their housing it is important that the needs of individuals are identified and brought together within local housing strategies.

**Further notes:**

- Local housing authorities need to plan for the future housing needs of these individuals. Commissioners need to work closely with service providers (specialist if needed), their local housing authorities and housing providers to ensure that a wide range of housing is locally available, including bespoke housing when needed.
- This should involve developing strategic housing plans with local providers in order to build appropriate housing for now and the future.
- Local authorities should follow section 106 of the Town and Country Planning Act 1990, enabling them to propose plans to landowners for the development of properties that meet people's needs.

## 5 I have a fulfilling and purposeful everyday life.

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- 5.1 Everyone with a learning disability and / or autism who has a mental health condition or behaviour that challenges should have **access to activities / services (such as early years services, education, employment, social, sports/leisure) that enable them to lead a fulfilling and purposeful everyday life**. They should have as much choice and control as possible over the activities in which they participate, facilitated through person-centred care and support plans / EHC plans and personal budgets / personal health budgets - any restrictions posed (MOJ / MAPPA) will need to be considered but should not adversely affect the individual experiencing, where possible and under appropriate supervision, a fulfilling and meaningful life.
- 5.2 People should have access to **education, training and employment which addresses their needs** and which they can access within their local area. To enable this, support providers and multi-disciplinary specialist health and social care teams should provide training to mainstream service staff and / or provide support to individuals that enables them to participate in mainstream services and to access education and training within local schools and colleges.

**Rationale:** people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges have rights to access a range of public services that enable people to lead fulfilling, purposeful lives (such as early years services, education, employment services, leisure services). Like other people, they should be able to engage in meaningful activities and have opportunities to learn, contribute, and build friendships and relationships. This will improve their quality of life and can reduce challenging behaviours.

### Further notes:

- Specialist health and social care services for people with a learning disability and / or autism (see section 7 below) should work with a range of mainstream services (such as early years, sports and leisure activities, schools, after-school clubs, employment services) to make them accessible for people with a learning disability and / or autism who have a mental health condition or whose behaviour challenges. This might entail providing training or guidance to staff working in mainstream services on how to include, rather than exclude, people whose behaviour challenges, or providing additional support for the individual when they access those services.
- Health and social care commissioners should work with those that commission and manage mainstream activities to find ways to make them accessible to people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges. This should include working with schools, training providers and employers to develop local education and employment opportunities that meet the specific needs of people with a learning disability and / or autism who have a mental health condition or whose behaviour challenges.
- Children, young people and adults should have as much choice and control as possible over the meaningful activities in which they participate. This can be supported through personal budgets and personal health budgets. There will, however, be instances where some individuals are not able to participate in particular activities - perhaps even on a short-term basis - for their safety or the safety of others, but this should not be used to prevent creative and ambitious planning to maximise participation opportunities.
- Children should be able to participate in social activities designed for their age group rather than for all children, or primarily designed for adults.
- Commissioners and public sector agencies (including Jobcentre Plus) should work together to ensure that people in this cohort are provided with the specialist support that will enable them to access existing publicly-funded employment and training services, wherever possible. This is in line with the [NHS commitment to support people with learning disabilities into employment](#), as well as evidence which shows the health benefits of paid work. In addition, local authorities should commission supported employment training services that meet the specific needs of this cohort. If required, individuals should continue to receive support even after they have secured employment, for as long as they need, to help them retain the job or acquire additional skills. This support should be built into the individual's person-centred plan.

## 6 I get good care from mainstream NHS services.

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- 6.1** Everyone with a learning disability over the age of 14 should have an **Annual Health Check**. This is particularly important for those with communication difficulties. This should result in a **Health Action Plan** integrated into a single person-centred care and support plan. Where appropriate it should include a **'Hospital Passport'** to help staff in mainstream NHS services make the reasonable adjustments for the individual (including to accommodate behaviour that challenges) that are required by law.

**Rationale:** mainstream NHS services are required by law to make reasonable adjustments to ensure they are accessible to people with a learning disability and / or autism. Doing so will also reduce instances of challenging behaviour: pain, discomfort and anxiety associated with untreated medical disorders, which people with communication difficulties struggle to articulate, can result in behaviour that challenges. Proactively checking the health of people with a learning disability, drawing up proactive health action plans, and ensuring NHS services know what adjustments to make for an individual, can all help mainstream NHS services provide better care and reduce instances of behaviour that is described as challenging and which services may struggle to respond to.

#### **Further notes:**

- Anyone with a learning disability over the age of 14 should be offered an Annual Health Check, resulting in a Health Action Plan (which should be integrated into the individual's single person-centred care and support plan). In the context of seeking to reduce causes of challenging behaviour, this is likely to be particularly useful for people with communication difficulties, who might not be able to communicate pain, discomfort and / or anxiety caused by an untreated medical problem and respond by behaving in a way that challenges services. See related 2015 Directions.
- Reasonable adjustments should be made proactively, in advance of seeing patients. To facilitate this, commissioners should seek ways to support information sharing between services. Commissioners should support and monitor the use of hospital passports for people with a learning disability and / or autism who have a mental health condition or display challenging behaviour. These passports provide hospital staff with valuable information about the individual, which can help with planning and managing their care and reduce the likelihood of encountering situations which could trigger behaviour that challenges. People with a learning disability and / or autism who have a mental health condition or behaviour that challenges could also be flagged in health providers' records (and if the provider is an NHS Foundation Trust then this is a quality indicator requiring quarterly board reporting to Monitor), so each individual service provider can anticipate reasonable adjustments they might need to make in advance of seeing patients. That could include contacting the individual's GP to find out what adjustments are made there, or approaching the relevant local (care) coordinator for their input.

**6.2** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should expect universal NHS services to employ clearly identified and readily accessible **'liaison' staff** who have specific skills in working with people with a learning disability and / or autism, and are able to advise those services on reasonable adjustments.

**Rationale:** as set out in the Equality Act 2010, all public services are required to make reasonable adjustments to ensure they are accessible to people with a disability. Employing liaison staff with expertise in how to do this can help NHS services meet their legal duties, reduce instances of challenging behaviour in NHS service settings, and ensure the mental and physical health needs of people with a learning disability and / or autism are effectively met in the community.

### Further notes:

- For people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges, priority should be given to making reasonable adjustments to primary care, acute hospitals and mental health services. The relevant adjustments will depend on the individual, but straightforward adjustments could include offering longer appointment times, ensuring the availability of an advocate and providing information in different ways.
- There should be clearly identified and readily accessible staff within universal services who have specific skills in working with children, young people and adults with a learning disability and / or autism. These staff can then be contacted as required to advise on potential adjustments.
- See detailed guidance on [reasonable adjustments for people with learning disabilities](#).

**6.3** Everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should expect **'quality checker'** schemes to be in place ensuring that mainstream services serve them appropriately.

**Rationale:** NHS services are required by law to make reasonable adjustments to ensure they are accessible to people with a disability. Independent Quality Checker schemes, which support people with a learning disability to check how well a service is meeting the needs of people with a learning disability, are a powerful way of ensuring NHS services meet these requirements effectively.

### Further notes:

- The [Quality Checkers initiative](#) seeks to establish a centralised system for NHS Quality Checking by people with learning disabilities. This entails using indicators of quality which people with learning disabilities themselves consider to be relevant and important and which may therefore differ from those which have historically been used. Quality checkers with learning disabilities will themselves carry out the evaluation, part of which will involve talking to service users with learning disabilities about their experiences and views of the service in question. Further information will be published on the NHS England website.

**6.4** In **mainstream mental health services**, everyone with a learning disability and / or autism who has a mental health condition or displays behaviour that challenges should be able to expect services to regularly audit how they serve people with a learning disability and make improvements as a result, using the Green Light Toolkit. They should be able to expect new initiatives and investment in mainstream mental health services (such as new investment in CAMHS, IAPT and the Crisis Concordat) to improve their access to those services.

**Rationale:** mental health conditions are significantly more common amongst people with a learning disability and / or autism than the general population, and these mental health conditions are often a factor behind behaviour that challenges. For many children and adults with a learning disability and / or autism, mainstream mental health services can and should meet their needs rather than relying on specialist services for people with a learning disability and / or autism.



### Further notes:

- To support improvement in mental health services, commissioners should ensure that the [Green Light Toolkit](#) audit is regularly completed in their area and resultant action plans implemented.
- The Learning Disabilities Observatory has published [a wide range of resources](#) on making reasonable adjustments for people with learning disabilities who need mental health services and support.
- Commissioners should ensure that their local action plan under the Mental Health Crisis Concordat identifies the support that should be provided to children, young people and adults with a learning disability and / or autism who have a mental health condition or display behaviour that challenges.
- Commissioners should ensure that the [IAPT Positive Practice guidance for people with learning disabilities](#) is being followed around psychological therapies.
- Local areas drawing up [transformation plans](#) for child and adolescent mental health services (CAMHS) should ensure their plans cover the full spectrum of need, including children with a learning disability and / or autism.

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

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- 7.1** Everyone with a learning disability and / or autism who has a mental health condition or behaviour that challenges should have access to **integrated specialist multidisciplinary health and care support for people with a learning disability and / or autism in their community** when required. This needs to include children, young people (particularly at the point of transition between childhood and adulthood) and adults, as well as those who may have come into contact with or are at risk of coming into contact with the criminal justice system, including people with lower level social care and / or health needs.
- 7.2** The support available should include: supporting people with a learning disability and / or autism who have a mental health condition or behaviour that challenges to access mainstream services (including wider health and social care services and services for people who may have come into contact with the criminal justice system) or enabling those services and families to support this cohort, and providing direct assessment and specialist clinical therapeutic support. The support might be provided by children's services, child and adult mental health services and specialist community learning disability teams working together through a 'Collaborative Care' model; or by combined teams (e.g. all age, learning disability and autism).

**Rationale:** though mainstream (health and social care) services can and should meet a large proportion of the everyday needs of people with a learning disability and / or autism who have a mental health condition or behaviour that challenges, there will remain a requirement for specialist support for people whose learning disability or autism makes meeting their health and social care needs particularly complex.

#### Further notes:

- This specialist support should be provided in collaboration with mainstream services, both health and social care, in most cases enabling them to continue to support the individual through expert support and advice. It is essential that mainstream services understand how and when they can access it.
- Local integrated multi-disciplinary teams will typically need to carry out five core functions:
  1. support positive access to mainstream services, to improve the patient experience and outcomes.
  2. enable others to provide effective person-centred support to this group, by working in partnership with individuals, families, support providers and mainstream services. This includes providing training.
  3. deliver direct specialist clinical therapeutic support such as assessment, intervention, Positive Behavioural Support and psychological and therapeutic support, where this has been identified as needed through the person-centred planning process.
  4. respond rapidly and effectively to crises, with the ability to provide 24x7 support.
  5. support commissioners in service development, the commissioning of individual support packages and quality monitoring.
- The work of these teams should be based around individual needs, and will vary over time. All support should be co-ordinated by a named co-ordinator (see section 1 on local care coordination). This is important for the individual and their family, as well as for mainstream services, which need to know how they can access support from a specialist multi-disciplinary team.
- Specialist support should be available for all children, young people and adults with a learning disability and / or autism who have a mental health condition or behaviour that challenges. For clarity, this includes: children as well as adults; people with autism whose behaviour challenges as well as people with a learning disability; and people with a learning disability and / or autism who have come into contact or are at risk of coming into contact with the criminal justice system.
- Specialist support might be provided by children's services, child and adult mental health services and specialist community learning disability teams working together through a 'Collaborative Care' model; or by combined teams (e.g. all age, learning disability and autism). Whatever structure is chosen, the key issue is to ensure that the five core functions set out above are available for people of all ages within this cohort.
- Local multi-disciplinary teams to support this cohort will typically need high levels of skills and experience including: person-centred approaches, autism, learning disabilities, offending, safeguarding, mental health (applicable to specific population), physical health (applicable to specific population), risk-taking and management, Positive Behavioural Support, functional assessment, and adapted psychological therapies and counselling.

- The types of professions that are likely to be needed include psychiatrists, psychologists, community nurses, speech and language therapists, behaviour analysts and social workers. However, this is not an exhaustive list, and there may be a need to expand capacity and employ additional specialists to meet local need.
- Teams should have developed networks across all health and social care services, housing, employment, education and the criminal justice system. They will need to provide an identified point of contact for mainstream services and perform a liaison role to: primary care, acute hospitals (particularly emergency departments), mental health services, liaison and diversion services, police, youth offending teams and probation.
- Teams should develop a range of care and support pathways in partnerships with individuals, families, support providers and commissioners. These should build on [NICE guidance in relation to people with learning disabilities and behaviour that challenges](#), as well as relevant NICE guidance on mental health conditions. They should reflect the resources and opportunities available within the community. Pathways need to incorporate the needs of very young children and be able to respond to early signs of the development of behaviours that challenge.
- Teams will contribute to the development and implementation of local workforce training strategies.
- Because the support is multi-disciplinary, it should be jointly commissioned by health and social care commissioners, and there needs to be a clear commitment from health and care services to work together and share information.

**7.3** Anyone with a learning disability and / or autism who at any one point requires additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and care support** at home or in short breaks services, to help prevent family or support package breakdown. This support should be provided by a highly-skilled and experienced multi-disciplinary team with specialist knowledge in managing behaviours that challenge. The 'step up' and 'step down' between specialist multidisciplinary support (above) and this intensive support needs to be seamless.

**Rationale:** there will be times when individuals with a learning disability and / or autism who have a mental health condition or display challenging behaviour need more intensive support in the community than that normally available through local multi-disciplinary specialist teams if they are to avoid or manage a crisis and stay in the community, or to settle back into the community after a spell in hospital or residential school.

#### Further notes:

- Intensive support should be available to help prevent family or care package breakdown, and help people with a learning disability and / or autism to remain in the community. This should include physical, psychological and behavioural assessment, treatment and support of the type delivered by multi-disciplinary teams described above, but at a greater intensity (24 hours a day, seven days a week) for short periods of time, and provided by highly-skilled and experienced support workers with specialist knowledge and expertise in managing behaviours that challenge (including behaviour that can lead to contact with the criminal justice system).

- Such intensive support should also be available to help those being discharged from inpatient services, or leaving residential schools, to transition safely and promptly back to the community.
- The team providing this intensive support should ensure all other options have been explored before an individual is referred to a specialist hospital (in line with upcoming NHS England guidance on admissions).
- This intensive support should be provided in the individual's home, or where that is not possible, in an alternative short term accommodation (see section 3.3).
- Existing intensive support services for people with learning disabilities often estimate that their caseload at any one time is likely to be 10-15% of their Community Learning Disability Team's caseload.
- This support should be provided by a highly-skilled and experienced multi-disciplinary team with specialist knowledge in managing behaviours that challenge, including offending behaviours. The 'step up' and 'step down' between specialist multidisciplinary support (above) and this intensive support needs to be seamless, which may mean the intensive support service being delivered by the same team but with a 'ring-fenced' caseload. The team will require specialist knowledge in how to support and work with the psychological stressors experienced by family members and paid carers.
- Useful guidance includes: [NICE guidelines on challenging behaviour and learning disabilities](#) and on relevant mental health conditions; the [Mansell report](#) on services for people with learning disabilities and challenging behaviour or mental health needs; the Royal College of Psychiatrists publication [Challenging Behaviour: A Unified Approach](#); NHS England and LGA guidance [Ensuring Quality Services](#); guidance by the Challenging Behaviour Foundation and Council for Disabled Children on [how to develop effective local services for children with learning disabilities whose behaviours challenge](#), and Department of Health guidance [Positive & Proactive: reducing the need for restrictive interventions](#).

## 8 I am supported to stay out of trouble.

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- 8.1** People with a learning disability and / or autism 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** as the rest of the population. Through collaboration with multi-disciplinary specialist health and social care services for people with a learning disability and / or autism (see above), 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 make reasonable adjustments such that they can effectively support people with a learning disability and / or autism, and to identify learning disabilities or autism amongst the people they support.

**Rationale:** some of those people with a learning disability who end up in hospitals following contact with the criminal justice system have mild-moderate learning disabilities, in addition to autism and additional mental health needs, as well as to have experienced difficult backgrounds (often from troubled families and / or victims of abuse or neglect themselves, frequently with a history of alcohol misuse)<sup>9</sup>. There is a need for more of a focus on reducing the likelihood of offending or reoffending from as early on as possible. This will secure better outcomes for them and those around them and will therefore require collaboration between services aimed at preventing or reducing anti-social or offending behaviour, community mental health and forensic services, and specialist learning disability or autism services to ensure they have appropriate access.

#### Further notes:

- Specialist multidisciplinary learning disability and / or autism services (see above) should provide advice and support to other services/agencies whose work is likely to reduce the risk of antisocial or offending behaviour to ensure they are able to cater effectively to people with learning disabilities and / or autism. This should include: community safety partnerships, youth offending teams, liaising and diversion schemes (see below), youth inclusion teams, street triage, drug and alcohol programmes, troubled family schemes, gangs services.
- Specialist multidisciplinary learning disability and / or autism services should also work with these services to improve screening and identification of learning disabilities, autism and mental health problems amongst children, young people and adults. As part of local assessment, referral and support arrangements, professionals should have clear referral routes for functional assessments and health and social care support from these specialist teams.

**8.2 Liaison and diversion schemes** should seek to support people through the criminal system 'pathway' enabling people to exercise their rights and / or where appropriate, diverting people to appropriate support from health and care services; clear pathways for diversion to health and social care services should be established through local multi-agency protocols.

**Rationale:** People with a learning disability and / or autism should be appropriately supported through the criminal system pathway, ensuring that their specific needs are recognised and met, and where appropriate, diverted to appropriate health and social care support and services.

#### Further notes:

- NHS England is currently [trialling Liaison and Diversion services](#), operating to a national service specification, in different parts of England. An evaluation is due to be published soon.

**8.3** When required, anyone with a learning disability and / or autism should have access to specialist health and care services that support people who have come into contact with **or are at risk of coming into contact with** the criminal justice system (i.e. offering a community 'forensic' function), including the expertise to manage risk posed to others in the community. The interventions offered by those services will depend on the needs of the individual and the level

<sup>9</sup> See literature review by the Tizard Centre commissioned for this service model.

of risk they pose, from circles of support to individual and group offence-specific interventions aimed at reducing offending. It is likely that some people will be best served by **mainstream forensic services** able to work with people with learning disabilities or autism (likely to include people with more mild-moderate learning disabilities); some by **multi-disciplinary specialist health and social care** services for people with a learning disability and / or autism (see above). In some areas, **specialist forensic learning disability teams** or hospital outreach teams work with small numbers of people with learning disabilities who pose a more significant risk to others, usually spanning several localities.

**Rationale:** there are a range of health and care services (sometimes adapted specifically for people with a learning disability) that can be provided in the community to support people who may have come into contact with the criminal justice system, including those who have offended and those at risk. Currently, many people with a learning disability or autism often find themselves excluded from mainstream mental health or forensic services because of their learning disability or autism, and excluded from learning disability services because they are considered too able or too risky.

#### Further notes:

- The local offer should include individual and group offence-specific interventions aimed at reducing offending - for example, work to prevent sexual offences, violent and aggressive offences and fire setting. It could include offering adapted Community Orders with mental health treatment to the courts, in partnership with police, probation and other relevant parties.
- It should involve establishing links with other services (such as the police, MAPPA, Liaison and Diversion, the courts, probation, youth offending teams, housing and employment) to facilitate pathways away from the criminal justice system.
- It should include a care co-ordination function for individuals with forensic behaviours (including to enable a safe, well-managed and speedy return to community for those being discharged from secure inpatient settings). See also section 1 on care coordination.
- It should include the provision of support, supervision and training to social care providers working with people with a learning disability and / or autism at risk of offending.
- It should provide specialist assessment and expertise in positive management of risks in the community. This should include advice on the appropriateness of the community options available to people on the criminal system 'pathway' and when diversion should be considered (e.g. advice to the courts), as well as on the reasonable adjustments required for someone going through the criminal justice system.
- It should provide support and facilitation to less restrictive settings for those people moving on from inpatient settings.
- How those interventions are provided will also depend on the individual's needs and the risks they pose: it is likely that some people will be best served by mainstream forensic services skilled-up so that they are able to work with people with mild-learning disabilities or autism; some by specialist services for people with learning disabilities and / or autism skilled-up so that they are able to work with lower-risk individuals. In some areas, specialist forensic learning disability teams or hospital outreach teams work with small numbers of people with learning disabilities who pose a more significant risk to others, usually spanning several localities.

- Staff will need training and processes to support appropriate information sharing and to enable informed decision making about when and what information to share. Patients will need to be appropriately informed about proposed flows of information and who is involved in helping deliver their care and support.

## 9 If I need assessment and treatment in a hospital 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.

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- 9.1** People with a learning disability and / or autism who present a severe and 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 intensive support and assessment is temporarily required that cannot be provided in the community. They should have access to assessment and treatment of mental health and behaviour disorders 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. With the right support at the right time in the community, use of these inpatient services should be very rare and for defined purposes: in the region of England where people with a learning disability are most likely to be supported in the community rather than hospital, at any one time approximately 20 beds per 10,000 people with a learning disability on GP registers will be occupied by people with a learning disability.
- 9.2** People with a learning disability and / or autism who need assessment and treatment for a mental disorder whilst preventing harm to the public (and whose behaviour has often resulted in contact with the Criminal Justice System and subsequent diversion to hospital) need access to **secure inpatient services**. The service provided may include providing necessary advice and support to the Courts in appropriate disposal / sentencing. These services should only be for patients who present risks above the threshold for safe management in the community, who with the right preventative services in place will be very few in number.

**Rationale:** a clear commitment has been made to reduce the number of people with learning disabilities and / or autism who have a mental health condition or display behaviour that challenges. No-one should live in a hospital. At the same time there remains a requirement for assessment and treatment of mental health and behaviour disorders in hospital for a minority of people where it is necessary for their immediate safety or for the protection of others.

### Further notes:

- Non-secure hospital care for people with learning disabilities and / or autism who have a mental health condition and behaviour that challenges should be available to people with a learning disability and / or autism just as it should be for people without and most of this provision

should be in general services (see above). It should provide a setting in which they can access a comprehensive, responsive and flexible range of support and services to assess and treat mental disorders when that assessment and treatment cannot be achieved safely in the community. All inpatient services should offer evidence based interventions (cf. NICE guidelines), that are reasonably adjusted as necessary, delivered by appropriately qualified staff who are actively engaged with peer support and quality networks.

- However, there is no disorder or diagnosis which, in itself, requires treatment in a hospital. Therefore non-secure hospital services should be for people who present a significant and immediate risk to those around them and / or to themselves. People should not receive treatment and support in hospital if the same treatment and support can be safely provided in a non-hospital setting or in the community.
- With the right support at the right time in the community, use of these inpatient services should be very rare: in the region of England where people with a learning disability are most likely to be supported in the community rather than hospital, at any one time approximately 20 beds per 10,000 people with a learning disability on GP registers will be occupied by people with a learning disability. Annex A illustrates how reliance on inpatient care varies across England.
- Some people with a learning disability and / or autism and a mental health condition or behaviour that challenges will need treatment for a mental disorder whilst preventing harm to the public, and will have been diverted to hospital from the criminal justice system. In addition to specialist assessment, support and advice prior to potential court appearance, such services may also provide advice and support to the Courts in appropriate disposal / sentencing. Secure services should only be for the small number of patients who present risks above the threshold for safe management in the community. Whilst for children this will always be determined by the courts (in accordance with section 25 of the Children's Act 1989), for adults this will only be in some cases. The goal should be to minimise the need for such services, through early intervention, community specialist and forensic support and prevention. Annex A also illustrates how demand for secure inpatient care varies across England.
- Secure services should offer evidence-based interventions that reflect NICE guidelines, delivered by appropriately qualified staff. These interventions may include specialist and evidence-based therapeutic interventions that are required for the management of offending behaviours (in particular sexual offending), aggression to others, psychological consequences of abuse and trauma (including post-traumatic stress disorder), therapies for personality disorders and approaches to supporting people with autism.
- In accordance with the Mental Health Act, treatment should be sought within the least restrictive option.

**9.3** In line with NHS England guidance, other than when following diversion from the criminal justice system, admission should only take place following a **pre-admission Care and Treatment Review** (for planned admissions) or a 'Blue Light' meeting (for unplanned admissions). Admission should always be with a clear stated purpose and set of expected outcomes.

**Rationale:** people should not receive treatment and support in hospital if the same treatment and support can be safely provided in a non-hospital setting or in the community.



### Further notes:

- Admission should be based on clearly agreed criteria and follow standard processes.
- Admission should be to a clear and stated end, and have specific patient outcomes in mind. For the majority of patients, these outcomes should include recovery and return to the community (or sometimes in the case of secure inpatient services, prison) at the earliest opportunity.
- In line with [upcoming] NHS England guidance, people with a learning disability and / or autism should only be admitted to hospital following a pre-admission Care and Treatment Review (for planned admissions) or a 'Blue Light' meeting (for unplanned admissions).

**9.4** Inpatient services should be **integrated into a broader care pathway**, working closely with community mental health and learning disability services. Generic inpatient mental health services should be used for people with a learning disability and / or autism requiring non-secure inpatient care. Where people cannot be supported effectively or safely in generic inpatient mental health services, assessment and treatment services should be small and integrated with community services as part of a broader care pathway.

**Rationale:** people admitted to hospital should be admitted for a clear and stated clinical goal, with their assessment and treatment undertaken with a good understanding of their personal history, their life contexts and with discharge planning starting from the day of admission. This makes close coordination with other services along the pathway essential. Hospitals are not homes so people should not be admitted as a backstop for placement or family breakdown or because there is nowhere else for them to go.

### Further notes:

- Partly to facilitate close coordination with local services, generic inpatient mental health services can and should be used acutely for individuals within this cohort who need non-secure hospital care. However, commissioners should ensure reasonable adjustments are made and that the services are appropriate environments for people who may be vulnerable. They should also make sure that individuals within this cohort can access specialist skills as necessary (such as those relating to people with autism or communication difficulties). These could be provided through existing liaison services.
- Where people requiring non-secure inpatient care cannot be supported effectively or safely in generic mental health services, assessment and treatment services should be small (typically five to six beds).
- Assessment and treatment in a hospital should be part of a care pathway. To that end, admissions should be to hospital services that are as local as possible, and inpatient services should coordinate closely with relevant community services and families / carers (particularly in the case of children) to prepare for discharge.
- Wherever appropriate, inpatient services should work closely and reflexively in partnership with families in the process of assessment, formulation, diagnosis and treatment. Contact and communication with families should be actively supported (unless particular circumstances dictate that this is inappropriate or inadvisable) and as much continuity with life prior to admission as possible. This may require financial support (for instance for travel costs).

**9.5** Hospitals should not become de facto homes: **discharge planning** should start from the point of admission, and care should be regularly reviewed, in line with NHS England Care and Treatment Review guidance and CPA requirements.

**Rationale:** hospitals are intended to provide assessment and treatment, not a home. For that reason and because discharging people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges can be a long and complex process, discharge planning should start from the point of admission.

**Further notes:**

- NHS England intends to publish further guidance on Care and Treatment Reviews shortly.

**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, and for both children and adults, provision of **single-sex accommodation** is essential.

**Rationale:** people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges can be vulnerable in inpatient settings. Inpatient environments should be suitable for their age and sex.

**Further notes:**

- Section 131A of the Mental Health Act creates a duty upon managers to accommodate children and young people who are admitted under the Act or under any other legal power in an environment suitable for their age, subject to their needs. This applies to children with learning disabilities. Children in inpatient settings must also have access to education.
- For children, secure settings need to reflect the [Children Act \(1989\)](#) section 25 arrangements and the [Home Office Guidance for Children under 13 years](#).
- Provision of single sex accommodation is essential, in particular given evidence of the vulnerability of women with learning disabilities in mixed sex environments and service focus on the needs of men who present behavioural challenges.

## 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, 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, it should be assessed to be in their best interests applying the Mental Capacity Act 2005 and its Code of Practice.

The above paragraph above applies to the 'at risk' register described above as it does to all recording and sharing of confidential personal information for the purposes set out in this document.

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. The information recorded or shared should be in proportion to the risk in each case.

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 need to be supported with adequate training and procedures to ensure they share information appropriately and are able to make informed judgements about disclosing information when required.

Despite the challenges posed, patients and their carers should always be aware of who may access their personal data and why (called fair processing).

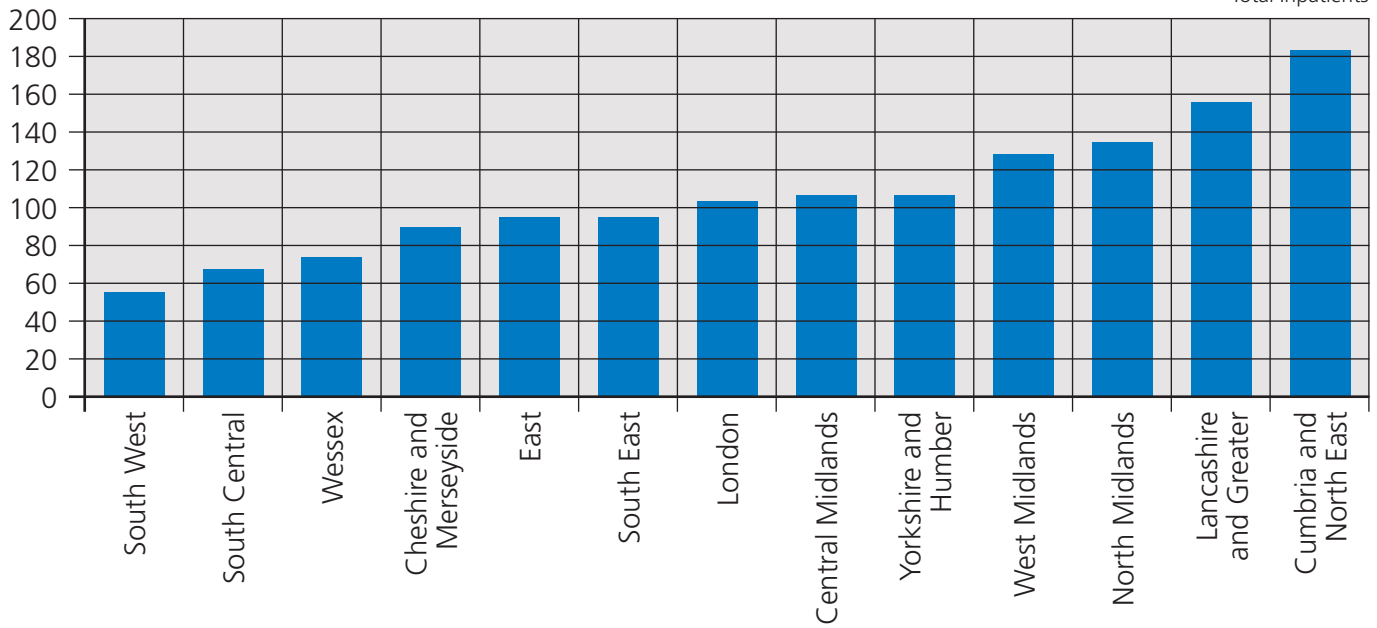
# Annex A - Geographical variation in demand for inpatient services

The charts below show the rates of inpatient care per learning disability registered population for a number of sub-regions. Each chart shows the number of inpatients (CCG and specialised commissioned) originating from each sub-region, divided by the total learning disability population for each sub-region. Please note the following, which explain the data sources used and any assumptions made in calculating these inpatient rates.

1. The total number of inpatients is taken from the Assuring Transformation (AT) data collection at the end of March 2015 - a snapshot position rather than an average over a period of time. AT is a commissioner-based data set submitted by all CCG and specialised commissioners. This data set is about people with a learning disability and / or autism who are in inpatient beds for mental and / or behavioural healthcare needs.
2. Assuring Transformation does not include a CCG of origin for specialised commissioned patients. In order to map such patients to their CCG of origin, data from the national specialised commissioning database was used. In this way 1,020 of the 1,300 specialised commissioned patients reported in Assuring Transformation were mapped to their CCG of residence. The remaining 280 were distributed in proportion to the 'known' patients. That is, if x% of the 1,020 specialised commissioned patients originated from sub-region A, then x% of the remaining 280 were also assumed to originate from sub-region A.
3. This proportionality was also applied to each security setting, so sub-region A was allocated x% of the 'unknown' general / non-secure patients, x% of the low secure patients, and so on.
4. Assuring Transformation data is published on a suppressed basis, in which numbers are rounded to the nearest 5 and numbers below 5 are replaced by an asterisk. The data shown in these charts has been calculated using unsuppressed data, with suppression rules applied to the final calculated values.
5. The denominator is the CCG learning disability population for 2013/14 taken from the QOF registers, as published by HSCIC in the [Indicator Portal](#) in March 2015. It is acknowledged that the published populations are for adults only, and no attempt has been made to estimate the under 18 learning disability populations.

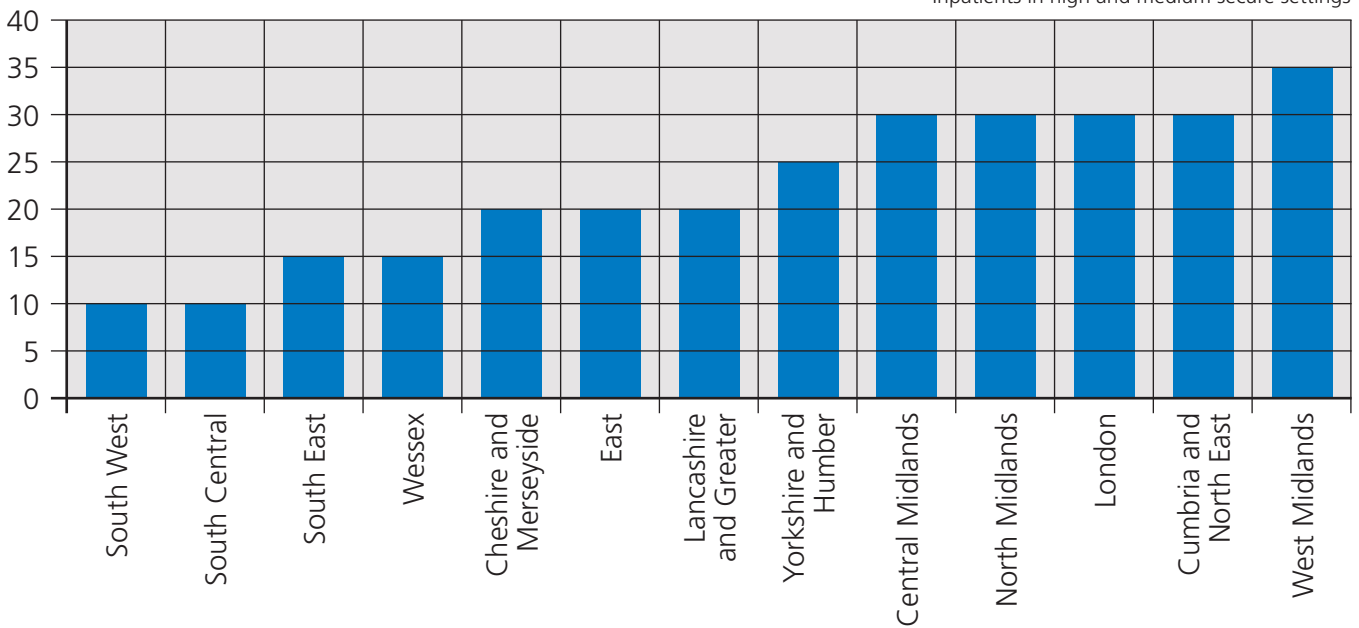
## Inpatients per 10,000 learning disability population (suppressed)

Figure 1  
Total Inpatients



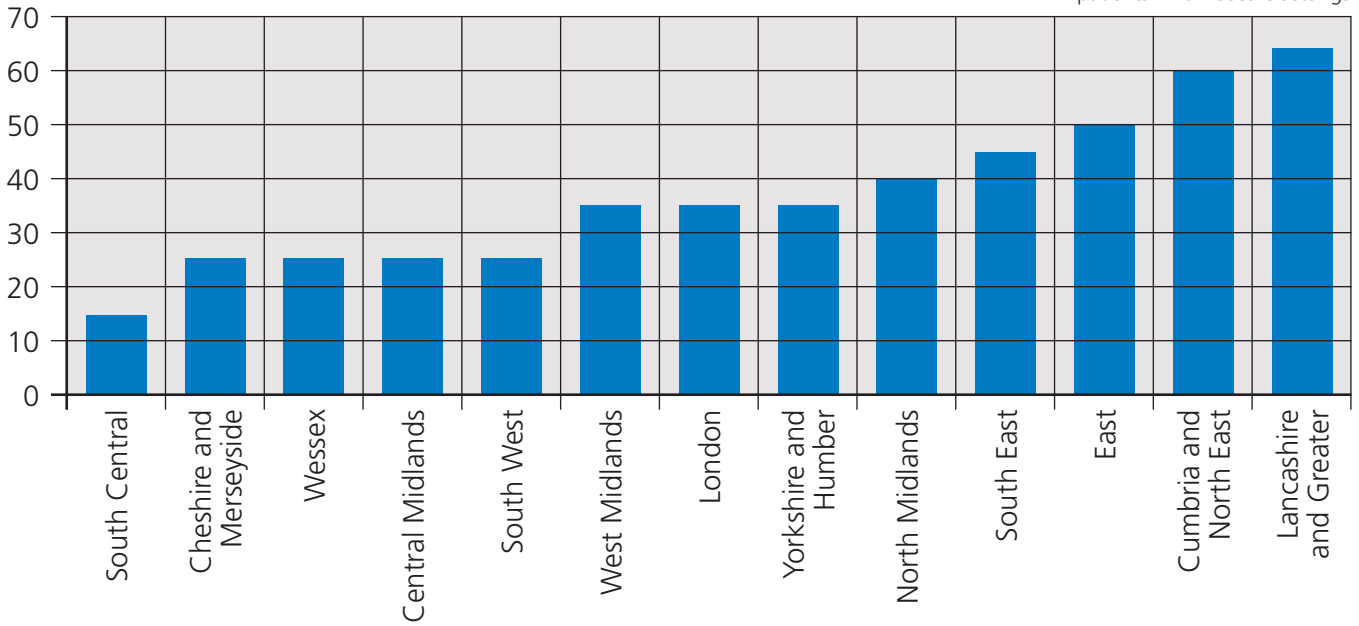
## Inpatients per 10,000 learning disability population (suppressed)

Figure 2  
Inpatients in high and medium secure settings



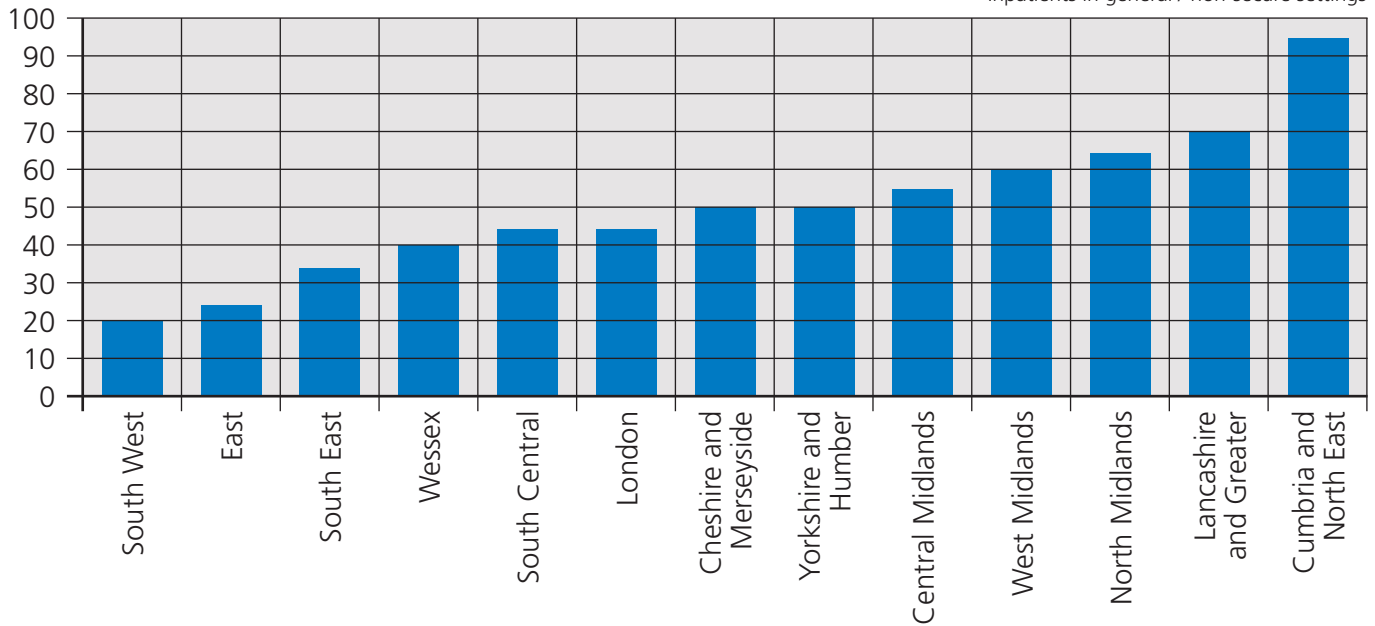
## Inpatients per 10,000 learning disability population (suppressed)

Figure 3  
Inpatients in low secure settings



## Inpatients per 10,000 learning disability population (suppressed)

Figure 4  
Inpatients in general / non-secure settings



# Annex B - Terminology

## Learning disability<sup>10</sup>

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

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- a reduced ability to cope independently (impaired social functioning), and:
- which is apparent in childhood as delayed developmental milestones and has a lasting effect on development.

Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability; however, learning disability is conventionally defined as an IQ score of below 70 together with the features described above.

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 disabilities are different from specific learning difficulties such as dyslexia or a mental health problem, which do not affect intellectual ability. A mental health problem can affect anyone at any time and can be treated.

## Autism<sup>11</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. 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)

<sup>10</sup> Adapted from *Valuing People*, Department of Health, 2001.

<sup>11</sup> Adapted from *Fulfilling and rewarding lives*, Department of Health, 2010.

- 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 independently lives, 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.

## “Challenging behaviour”

This term 'challenging behaviour' covers a wide range of different of behaviours, which include self-injury or physical aggression, severe agitation and extreme withdrawal, as well 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. All of these described behaviours may vary in intensity and severity. The simplest definition of the term is: behaviour that has a significant adverse effect on the quality of life of the individual and / or the health and safety of the individual or others.

A variety of factors are likely to contribute towards the development, maintenance and escalation of behaviour that challenges. These include (but are not limited to): biological and genetic factors, physical ill-health, impaired communication abilities, mental ill-health, neurological disorders, the impact of poverty and social disadvantage, quality of support, and exposure to adversities. Some people have a long and persistent history of challenging behaviour, 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 problem. 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.

Some individuals can be supported to understand and manage some of their own behaviours in some cases; services too can help reduce the circumstances in which episodes of challenging behaviour are likely to occur. However, it requires a skilled and informed response from health and social care services in partnership with the person and those who provide support - the person's family and service providers. Conversely, a lack of support can increase the likelihood of behaviour that challenges, as can major change and disruption.



# Annex C - 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.

## Organisations represented:

- Association of Directors of Adult Social Services (ADASS)
- Association of Directors of Children's Services (ADCS)
- Avenues Group
- Cambridge Intellectual and Developmental Disabilities Research Group
- Centre for Welfare Reform
- The Challenging Behaviour Foundation
- Darlington Borough Council
- Department for Education (DfE)
- Department of Health
- Devon CCG
- Health Education England
- Improving Health and Lives (IHAL)
- Local Government Association
- Surrey County Council
- London Borough of Camden
- Ministry of Justice (MOJ)
- The National Autistic Society
- National Development Team for Inclusion (NDTI)
- National Forum of People with Learning Disabilities
- National Valuing Families Forum
- NHS Confederation
- NHS England
- NICE
- Oxford Health, NHS Foundation Trust
- Partnership Trust
- People Hub
- Policy into practice
- Public Health England
- Royal Mencap Society
- Centre of Engagement
- Seeability
- Sheffield Health and Social Care NHS Foundation Trust
- University College London
- University of Kent
- University of Warwick
- West Park Hospital

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

DRAFT service model guidance for commissioners of health and social care services  
**July 2015**

Local Government Association (LGA)  
Association of Directors of Adult Social Services (ADASS)  
NHS England