

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



Service model for commissioners of health and social care services

Supplementary information for commissioners

October 2015



Supplementary information for commissioners

1 I have a good and meaningful everyday life.

- 1.1** Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition¹ should be included in **activities and services (such as early years services, education, employment, social and sports/leisure) that enable them to lead a good and meaningful everyday life.** They should have choice and control over the activities in which they participate, facilitated through person-centred care and support plans/ Education, Health and Care (EHC) plans and personal budgets/personal health budgets (see principles 2 and 3) – any restrictions imposed (Ministry of Justice/MAPPA) will need to be considered but should not adversely affect the individual experiencing, where possible and under appropriate supervision, a fulfilling and meaningful life.
- 1.2** Everyone should have access to **education, training and employment (including supported internships)** which they can access within their local area. To enable this, support providers and specialist multi-disciplinary health and social care teams (see principle 7) should provide training to mainstream service staff and/or provide support to individuals and their families/carers² that enables them to participate in mainstream services and to access education and training within local schools and colleges. Commissioners should also seek to ensure that supported employment/training services meet the needs of this group.
- 1.3** Everyone should have the opportunity to **develop and maintain good relationships** with people. Commissioners should be mindful of the importance of relationships to keep people safe and well, and should therefore seek to offer good support to families/carers, friends and others (see principle 4). This should form a key part of people's person-centred care and support plans (see principle 2).

¹ For simplicity, henceforth when we refer to 'everyone' or 'people' in this document, we are referring to this defined group of people (children, young people and adults) unless otherwise stated and when we refer to 'people with learning disabilities and/or autism', we are referring to people with learning disabilities and /or autism who display behaviour that challenges, including those with a mental health condition.

² In this document we use the term 'carer' to mean those people who provide unpaid support to someone. This is often a family member, but not always. We refer to people who provide paid support as 'paid support and care staff'.

Rationale: people with a learning disability and/or autism who display behaviour that challenges have the same rights as other people to access a range of public services that enables them to lead good and meaningful lives. Just like everyone else, 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 behaviour that challenges.

Further detail:

- Specialist multi-disciplinary health and social care services for people with a learning disability and/or autism (see principle 7) should work with mainstream services (such as early years, sports and leisure activities, schools, after-school clubs and employment services) to make them accessible for people with a learning disability and/or autism. This might entail providing training or guidance to staff working in mainstream services on how to include, rather than exclude, people whose behaviour can challenge, or providing additional support to 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. 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.
- People should have as much choice and control as possible over the activities in which they participate and be empowered to know about the choices available to them. This can be supported through personal budgets and personal health budgets (see principle 3). 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 those designed for all children, or primarily designed for adults.
- Commissioners and public sector agencies (including Jobcentre Plus) should work together to ensure that people 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 a learning disability into [employment](#), as well as evidence which shows the health benefits of paid work.
- Local authorities should commission supported employment training services that meet the specific needs of this group. 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 care and support plan (see principle 2).
- Under the Care Act local authorities must ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome. Under the Children and Families Act, preparation for entry into adulthood (including employment), should be considered early and form part of transition planning.

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

- 2.1** Local health and care services should develop a **dynamic register** based on sophisticated risk stratification of their local populations. This will enable local services to anticipate and meet the needs of those people with a learning disability and/or autism who display behaviour that challenges, or who are at risk of developing behaviour that challenges, ensuring local services plan appropriately and provide early interventions, including 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 detail:

- 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.
- Risk stratification should focus on prevention and early intervention with the aim of reducing the likelihood of behaviour that challenges by providing support at an early stage to proactively address these risk factors, including through early screening for children and young people suspected of having a learning disability and/or autism, and via the identification of additional risk factors for development of behaviour that challenges, such as those with additional mental health, physical health, sensory or communication needs; and those exposed to high rates of environmental adversity. It should be recognised that early detection of risk factors and systematic assessments of behaviour is the key to prevention of behavioural difficulties and the basis of early intervention. [The NICE guideline on challenging behaviour and learning disabilities](#) contains useful guidance on understanding the risks of developing behaviour that challenges.
- As a minimum, as part of this broader approach to risk stratification, each Clinical Commissioning Group (CCG) (or an organisation nominated by the CCG, for example a CSU or provider trust) will be required to develop a register of those 'at risk of admission'³ in line with [NHS England Care and Treatment Review policy and guidance](#). This register will include those

³ The 'at risk of admission' register may be an extension of the register required to be developed as part of the '[DH Winterbourne View Review - Concordat: Programme of Action](#)' December 2012 which asked that "all primary care trusts develop registers of all people with learning disabilities or autism who have mental health conditions or 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"

people whose community placement or tenancy is at risk of breakdown and those people who are at risk of an inpatient admission. 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 specialist multi-disciplinary teams across health and social care and representation from other key providers of services.

- 2.2** Everyone should have a single **person centred care and support plan**, incorporating a range of other plans including behaviour support plans where appropriate, as well as crisis and contingency plans, which they have been involved in drawing up and which they have a copy of. Plans should focus on what is important to the individual. For children and young people up to the age of 25 with a special educational need (SEN), this should take the form of an Education, Health and Care (EHC) plan.

Rationale: many people with a learning disability and/or autism will require highly individualised, long-term support from a wide range of organisations and services, including proactive and reactive strategies for managing behaviour that challenges. Person-centred care and support plans can help achieve this. Currently, only some people with a learning disability and/or autism 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 detail:

- The Care Act 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 that challenges have a person centred support and care plan, not just those on the Care Programme Approach (CPA).
- There should be just one plan for each individual, which brings together records from all previous services and relevant clinical information but which focuses on what is important to and for the person and their families or carers. This single plan can bring together a range of other plans including, but not restricted to, plans resulting from Annual Health Checks for people with a learning disability (see principle 6) and behavioural support plans focused on reducing behaviour that challenges. The [NICE guidance](#) on challenging behaviour and learning disabilities includes information about behaviour support plans.
- For some people, a Communication Passport should be included within their single plan. A communication passport is a person-centred approach to passing on key information about people with complex communication difficulties who cannot easily communicate for themselves. It can help ensure consistency in approach and planning across the different services and agencies working with the individual and enable an individual to own their story so far when moving between different services.

- 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, paid support and care staff, 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, and shared with external agencies (such as the police or duty teams) - in line with appropriate information governance.
- For children and young people (aged 0-25) with a special educational need, person-centred care and support plans would, in most instances, take the form of an education, health and care (EHC) plan. Local authorities have a duty under the Children and Families Act 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 their families/carers – 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/carers should receive support to actively engage with developing their child’s care and support plan. More information and resources about EHC plans and other aspects of the special educational needs and disability reforms are available from the [Preparing for Adulthood](#) programme.
- Where a child or young person is not eligible for an EHC plan, education, health and social care agencies should work together to develop a person centred care and support plan for that child or young person, as outlined above.
- 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 disability team, or community forensic teams, or specialist voluntary or community sector organisation. For children and young people it will be the Special Educational Needs (SEN) Department who lead on the development of EHC plans, with other agencies such as CAMHS and community health inputting into this.
- People’s person-centred care and support plans should be reviewed regularly, including in advance of transition to adulthood. There should also be clear processes and the ability to undertake an emergency review where this is needed.
- No matter who leads it, the individual and their family and carers must be involved in the planning process from the outset, starting at the point of assessment. The Children and Families Act states that the assessment should start with the needs and wishes of the child and their family. Under the Care Act, assessments for care and support for adults must focus on the impact of need on the individual’s wellbeing, and the outcomes they want to achieve. For some people with behaviour that challenges, further assessments that draw on skills from multi-disciplinary specialist services (see principle 7) may be needed, including a functional assessment to better understand the behaviour and those factors influencing it.

- Services and support offers identified through the care and support planning process 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](#) is available from NHS England, and [Think Local Act Personal \(TLAP\)](#).
- 2.3** Everyone should be offered a named **local care and support navigator or keyworker** to coordinate and ensure timely delivery of a wide range of services set out in the person-centred care and support plan, working closely with the person and their families/carers where appropriate and ensuring a consistent point of contact.

Rationale: people with a learning disability and/or autism will often require a complex range of services delivered by a number of different agencies. It can be difficult for the individual or their families or carers to navigate these services, and poorly coordinated care and support can result in worse outcomes for people, or crises occurring.

Further detail:

- Commissioners should offer a named local care and support navigator to all people with a learning disability and/or autism. This 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 an advocate – the local care and support navigator 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 'navigators' 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/or autism and to be supported to continue to develop those skills.

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

- 3.1** Everyone should receive information about their care and support in formats that they can understand and should receive appropriate support to help them communicate, in keeping with the new [Accessible Information Standard](#).

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.

Further detail:

- The Accessible Information Standard tells organisations how they should ensure that patients with a disability receive information in formats that they can understand, and that they receive appropriate support to help them to communicate. The Standard applies to all providers of NHS and publicly-funded adult social care.
- Commissioners should ensure that contracts, frameworks and performance-management arrangements with provider bodies enable and promote the Standard's requirements.

3.2 Individuals, and where appropriate, families/carers, should be integral partners in care and support planning discussions (see principle 2). Even where people lack capacity to make specific decisions, they should be involved in care and support planning discussions wherever possible and any decisions taken on their behalf should be made in their best interests. These discussions and the final plan should be person-centred and focused on what is important to the individual. Increasingly, people should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care and should have access to information advice and support to help them understand the choices available to them, exercise these choices and to help them plan how to use and manage their budget. Many will already have a right by law to personal budgets or personal health budgets, but commissioners should be rapidly and ambitiously extending this offer beyond rights guaranteed in law.

Rationale: people should have choice and control over the care and support they receive. People with a learning disability and/or autism, and families/carers of children in this group, should have the same rights to choice and control over different aspects of their lives as everyone else (though in some cases, for instance due to legal restrictions, there may need to be limits on the choice a person can exercise for their own safety or the protection of others). 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 (see link below) 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.

Further detail:

- 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 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) planning 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 a learning disability and/or autism who have high support needs and are not well served by conventional service approaches.
- The personal health budget '[right to have](#)' [guidance](#) does not explicitly limit a personal health budget to the living arrangements in which it can be received. People living in nursing or residential care may also benefit from receiving care and support via a personal health budget. However, when making this via a direct payment, a CCG must be certain that using a direct payment adds value to the person's overall care; where no additional choice or flexibility has been achieved by giving someone a personal health budget, then allocating a direct payment only adds an additional financial step and layer of bureaucracy into the commissioning of the care and support.
- Personal budgets and personal health budgets must be linked to a person-centred care and support plan (see principle 2), which the individual (and their family/carer) is involved in developing, focusing on the outcomes that are important to them. Commissioners will need to ensure that person-centred care and support planning sits at the heart of the offer of a personal health budget and that people have the right level of information and support to be able to take up the offer.
- 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 support 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, e.g. brokerage, local (care and support) 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.

3.3 At key points in their interaction with health, education and care services, people should have access to different types of **independent advocacy**. In addition to the legal right to advocacy, people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives. This will include in preparation for and on leaving a specialist hospital⁴. Both statutory and non-statutory advocacy should be delivered by services that are independent of the organisations providing the person's care and support.

Rationale: it can be difficult for people and/or their families/carers to understand the options available to them and to make their voices heard when care and support options are being offered to them, or to help to shape or challenge what that care and support should look like. Advocacy not only helps people to exercise their rights but should also lead to care and support being better tailored to meet 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 and benefit from long-term advocacy that can empower them, increase independence and can provide opportunities for connections and friendships with others.

Further detail:

- 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 decisions relating to serious medical treatment and/or 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 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 interests. This applies even if the person has an 'appropriate adult' 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.

⁴ 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients.

- In addition to these situations where access to advocacy is a legal right, non-statutory advocacy services should be more widely available to people and 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 9 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 non-statutory advocacy options are available, including self-advocacy (focused on investing in people to speak up for themselves), peer advocacy (where an individual with a shared experience advocates alongside or on behalf of the person) and family advocacy (where family members advocate alongside or on behalf of their family member). These more informal forms of advocacy have the potential to reach many people and, in addition to up-skilling people, can provide opportunities for meaningful connections with others. Commissioners should ensure that advocacy services are of a good quality.
- In particular, statutory and non-statutory advocacy should be made available to all people with a learning disability and/or autism who are leaving an inpatient setting after a period of time in a specialist hospital or leaving a residential educational placement.
- All people working with and supporting people with a learning disability and/or autism need to understand the different types of advocacy available (both 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 should also include their advocate(s) within discussions and care and support planning processes.
- All advocacy services should be independent and provided separately from care and support providers.

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

- 4.1** All families or carers who are providing care and support for people who display behaviour that challenges should be offered **practical and emotional support** and access to **early intervention programmes**, including evidence-based parent training programmes, and other skills training, in line with [NICE guidance](#) which is targeted to their specific strengths, challenges and needs.

Rationale: families/carers often play a huge role in providing day-to-day support to people with a learning disability and/or autism who display behaviour that challenges. Supporting them can improve outcomes – both for themselves and for the person they are providing care and support to, and can reduce the likelihood of crises requiring more restrictive intervention by health and care services (such as hospitalisation). The presence of high stress levels in family members and carers has a detrimental impact on the person they are supporting and can impact on behaviour that challenges.

Further detail:

- Support for families and carers is a key component of effective support for people. This support should be focused on the whole family's needs and should recognise the impact of living with and/or providing care and support to a person with behaviour that challenges.
 - Reviews of evidence-based parent training programmes have shown the effects to reduce behavioural problems among children. The [NICE guidelines on challenging behaviour and learning disabilities](#), includes information on appropriate parent-training programmes. Commissioners should ensure that parents or carers of people with a learning disability and/or autism (of whatever age) can participate in parenting programmes.
 - Families/carers should be provided with support that recognises the personal and emotional impact of supporting a person with behaviour that challenges. Commissioners should seek to identify and offer access to local peer support networks (offering peer-to-peer support), as well as access to formal support through disability-specific support groups for family members or carers.
 - Commissioners should seek to identify and offer families/carers access to skills training specific to the needs of the person they are supporting, including training that is offered to the wider workforce, to help them take part in and support interventions for the person.
 - Commissioners should explore options for involving families/carers in the design and delivery of local workforce training strategies.
- 4.2** All families or carers who are providing care and support for people who display behaviour that challenges should be offered information about **carer's assessments and advocacy support** in their own right, **access to short breaks/respice** suitable for people whose behaviour challenges and which meets their own needs, and support to care for the person from specialist multi-disciplinary health and social care teams (see principle 7).

Rationale: families and carers should be offered information about their own rights and options for support, including through carers' assessments. Short breaks/respite options can play a vital role in helping families and carers cope with the ongoing demands of providing care and support. 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 a hospital setting, having 'time out' in a safe environment can help to dissipate developing tensions and frustrations.

Further detail:

- Families/carers should be offered information about their rights and entitlements, including information about how to get a formal carer's assessment (or 'parent carers needs assessment' for those caring for a child) and how to access advocacy support. Any services or support to be provided for parent carers of disabled children can be included in a child's EHC plan.
- Commissioners should ensure that short break/respite services meet the needs of both the family/carer and the individual.
- There are different forms of breaks, and commissioners should be personalised, creative and flexible in their approach. Some may involve having care workers available to live-in with a person for a short time (e.g. weekend); others might include providing support to take someone out or away for the weekend. In some 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 find creative and innovative ways of providing breaks that meet individual and family/carer needs, working in partnership to provide a positive experience based on an understanding of what both individuals and families/carers want from a short break. They should not expect people to 'slot in' to models or forms of short breaks that will not meet their needs.
- Commissioners should ensure that a range of short break options are available for individuals and their families/carers in each local area. As this group 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' person-centred care and 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 (not only those siblings with caring responsibilities) may benefit from some protected time apart. The Department for Education has issued [guidance on short breaks](#) for carers of disabled children.

4.3 Alternative short term accommodation (available for a few weeks) should be available to people, as and when it is needed, to be used in times of crisis or potential crisis as a place where people can go for a short period, preventing an avoidable admission into a hospital setting. It might also provide a setting for assessment from teams providing intensive multi-disciplinary health and care support (see principle 7) where that assessment cannot be carried out in the individual's home.

Rationale: having 'time out' in a safe environment can help to dissipate developing tensions and frustrations. This might also provide a setting for assessment from intensive multi-disciplinary health and social care teams (see principle 7) where that assessment cannot be carried out in the individual's home.

4.4 Everyone who is getting a social care package should have access to **paid support and care staff trained and experienced in supporting people who display behaviour that challenges** and those who may have come into contact with or at risk of coming into contact with the criminal justice system. These staff should be able to deliver proactive and reactive strategies to reduce the risk of behaviour that challenges, in line with [NICE guidelines](#).

4.5 Local authorities should use **Market Position Statements** with an explicit focus on people with a learning disability and/or autism. **They should identify a group of preferred providers**, which can demonstrate minimum quality standards and competencies. These providers should be seen as genuine partners of specialist multi-disciplinary health and social care teams (see principles 7 and 8.3) as part of multi-agency working. Commissioners, along with the providers, should develop competency frameworks such as that provided by [Health Education England](#). These competency frameworks need to include requirements for staff training, for example person-centred approaches, communication and Positive Behaviour Support (PBS), in line with the [PBS competency framework](#).

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

Further detail:

- Local authorities need to ensure that the social care provider market can meet the needs of people who display behaviour that challenges. It is recommended that commissioners consider working with a smaller number of highly skilled providers that have staff who are trained and experienced in supporting people who display behaviour that challenges, including behaviours which may result in contact with the criminal justice system. Commissioners should ensure that within this group of providers, individuals are offered choice of support that meets their needs.

- There should be an expectation that no provider will give up on people they are supporting if their behaviour escalates. There should be an expectation that they will cooperate with other local providers and specialist teams to stabilise the situation pending further considered planning.
 - Care and support staff should be trained in proactive and reactive strategies, including Positive Behaviour Support (PBS), which is not a single intervention or therapy but a multi-component framework for delivering a range of evidence-based support to increase quality of life and reduce the occurrence, severity or impact of behaviours that challenge. [Ensuring Quality Services](#) provides further guidance on PBS. PBS training should be in line with the competency standards outlined in the PBS competency framework. [NICE guidance on challenging behaviour and learning disabilities](#) provides more detail on staff training and supervision.
 - While most people with a learning disability and/or autism will not come into contact with criminal justice services, providers should be appropriately trained and supported to know what their response should be – for example, this might involve staff acting as an Appropriate Adult, for which they should undertake training.
 - Training requirements should be built into contracts. Quality checking by experts by experience should be used to support the contract monitoring of services to support best outcomes for individuals. Commissioners should be assured that providers have given due regard to the personal and emotional strain which may be experienced by paid support and care staff.
 - Because the total number of people in this group is small, it may be necessary for local authorities to collaborate to develop social care 'strategic provider'/'preferred provider' frameworks for this group. There should be an expectation that larger or established providers would support smaller organisations (e.g. with training, help in emergency situations and staffing). 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 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. Market position statements should understand the needs of the requirements of investors on providers as part of creating strategic plans. In addition, there should be an expectation that good quality care delivers cost effective outcomes over time.
 - Individual budgets should reflect care hours being paid at the national living wage as a minimum, and in many cases reflect the additional skills and experience needed to provide care and support for somebody with complex needs.
 - Active involvement in the development of providers in the required skills and competencies should be the responsibility of commissioners.
-

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

- 5.1** People should be offered a **choice of housing, including small-scale supported living**. This choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the individual is on an offender pathway. Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person's person-centred care and support plan (see principle 2). Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning.

Rationale: the right home and environment can improve independence and quality of life, and can help reduce behaviours that challenge. People may often experience a lack of control over where they live, who they live with and their environment. These factors can have a major impact on an individual's wellbeing and their behaviour.

Further detail:

- People 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 could mean 'mainstream' housing either provided by a housing association, private landlord, family or ownership schemes such as HOLD (Home Ownership for people with Long-term Disabilities). Housing should not create new campus sites, hence commissioners should be cautious of contracting with providers keen to create schemes of multiple units within close proximity.
- It has been shown that people who present with behaviour that challenges can be effectively supported in ordinary housing in the community. Decisions should be based on what is right for each individual, but for most people, supporting them in a home near their families and friends, and enabling them to be part of their community will be the right decision. This is in accordance with the Valuing People principles of rights, independence, choice and inclusion.
- People should not be placed in voids in existing services or group living arrangements if it is not based on individual need and based on a person centred approach to planning. Where people live, the location, the community and the built environment need to be understood from the individual perspective at the outset of planning. Environments that are poorly organised or unable to respond to the needs of the person can increase the likelihood of behaviour that challenges.
- It should not be assumed that individuals want to live with others, nor should it be assumed that they want to live alone. It should be about what the person wants and needs. Where a person actively chooses to live with others, careful planning and consideration of compatibility, risk and sustainability needs to take place.

- Existing property or new builds may need to be adapted/developed to meet the individual's needs, for instance by installing safety equipment or assistive technology (such as sensors, call-bells, or environmental controls such as automatic water shut-off valves). Commissioners and providers need to work with individuals and families/carers to find creative solutions, acknowledging that very simple and affordable solutions can have a big impact.
- 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, whilst paying full attention to the guidance, i.e. these grants are not solely intended to pay for adaptations to accommodate physical disability; where appropriate the needs of the family should also be considered.
- 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 a learning disability and/or autism 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 individuals with a personal health budget to use some of their budget to contribute to housing costs if this meets a health need and is agreed as part of the individual's care and support plan.

5.2 Everyone 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 and support 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 detail:

- People should be supported to explore options for home ownership or shared home ownership.
- People 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 an 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 such as 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.

5.3 Commissioners need to work closely with housing strategy colleagues to ensure that the future needs of this group are understood, considered and planned for strategically, and form part of 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 detail:

- 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.

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

- 6.1** Everyone with a learning disability over the age of 14, should be offered an **Annual Health Check**. This is particularly important for those with communication difficulties. Everyone should have a **Health Action Plan**, which identifies how any physical and mental health needs will be met, and this should form an integral component of a person's person-centred care and support plan (see principle 2). Where appropriate it should include a **Hospital Passport** to help mainstream NHS services make the reasonable adjustments required by law (including meeting the needs of people who display behaviour that challenges) and ensure equity of health outcomes for people.

Rationale: people are entitled to expect the same health outcomes as everybody else. Mainstream NHS services have statutory duties under the Equality Act to make reasonable adjustments to ensure they are accessible to people with a learning disability and/or autism. Difficulties of communication or a lack of understanding about how and when to seek help may contribute to behaviour that challenges as a result of pain, discomfort, unrecognised or untreated physical and mental health conditions being left unmet. In other instances it may be due to the approach of healthcare practitioners and their lack of understanding and knowledge about how to work effectively and make the reasonable adjustments required, as well as the constraints of established ways of working that do not enable the flexibility of approach required. The provision of annual health checks and the use of health action plans and Hospital Passports are important examples of reasonable adjustments that have almost universal value. However other adjustments will be specific to individual people, their needs and service contexts.

Further detail:

- The starting point should be for mainstream primary and secondary NHS services to be able to identify people with a learning disability and/or autism within their systems, to ensure that care pathways and practices are routinely 'reasonably adapted' to meet individual needs and to closely monitor equity of outcomes experienced by them.
- Reasonable adjustments should be planned in advance of seeing individuals. To facilitate this, commissioners should seek ways to support information sharing between services. In some instances this can be achieved by introducing a 'flagging' system within healthcare providers' record system which highlights people who are entitled to reasonable adjustments (in the case of NHS Foundation Trusts, this is already a quality indicator requiring quarterly board reporting to Monitor). This will enable service providers to plan reasonable adjustments in advance of seeing patients. Appropriate responses might include contacting the individual's GP or other relevant lead professionals to find out what adjustments are made there, or approaching the relevant local support guide for their input.

- Everyone should have a Health Action Plan or equivalent (which should be integrated into the individual's single person-centred care and support plan or EHC plan, as appropriate). Where appropriate, the plan should include provision for regular medication reviews. In seeking to alleviate factors that may contribute to behaviour that challenges, this is particularly useful for people with communication difficulties, who may struggle to communicate pain, discomfort, distress etc. See the related [2015 Directions](#).
- Commissioners should support and monitor the use of Hospital Passports (which should include information on how to communicate with the person to best effect). This should include seeking to assure themselves that hospital services do in fact take due account of information enclosed in Hospital Passports when providing treatment, care and support. Hospital Passports should include a summary of the person's health needs and of the types of adaptation to usual pathways of care that will be needed to ensure equity of health outcomes should the person be required to attend hospital. Summary Care Records offer a further opportunity to enhance this when agreed information about an individual can be shared across health services online.
- The Equality Act also requires that users of healthcare services should be provided with relevant information in an accessible format, this is important in ensuring that people are supported to make sense of their needs, to make informed decisions, to understand their rights and entitlements and to raise concerns (see principle 3).

6.2 Everyone should expect universal NHS services to employ clearly identified and readily accessible primary and secondary healthcare **'liaison' workers** who have specialist knowledge and specific skills in working with people with a learning disability and/or autism which enable them to advise those services on how to make effective adjustments.

Rationale: as set out in the Equality Act, 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 behaviour that challenges 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 detail:

- Priority should be given to establishing sufficient Liaison Roles across primary care (including GP practices and Health Visiting), acute hospitals (including emergency departments), mental health services (including court liaison and diversion) and police custody and prison health services.
- People operating in these roles will provide support to mainstream healthcare staff, as well as acting as a point of contact for people using mainstream services and those who support them, before, during and following contact with services. They will also work strategically in liaison with senior managers to ensure that there is a functional, systems-based approach to ensuring better outcomes for individuals and to demonstrating that the organisation is meeting its Public Sector Equality Duty.

- Liaison workers should have strong links with local specialist learning disability and/or autism services. This should enable them to draw upon the specialist expertise of multidisciplinary health and social care teams (see principle 7), in a timely manner, where a collaboration between mainstream services and specialist practitioners is required to best meet a person's needs.
 - The nature of reasonable adjustments made should be individualised, but typical examples include offering longer appointment times, appointments at convenient times of day, ensuring the availability of an advocate and providing information in accessible ways.
 - People with a learning disability and/or autism, their families / carers and others who support them can play an important role in training mainstream staff.
- 6.3** Everyone should expect **'quality checker'** schemes to be in place ensuring that mainstream services serve them appropriately.

Rationale: quality checker services use experts by experience as 'auditors' of service quality. They use their own experiences of using services to make checks on the quality of care and support, and to give a view that is otherwise often missing from other forms of quality review. Their work helps to make sure services truly support people with a learning disability and/or autism to live full and healthy lives. Evaluations of quality checking schemes show them to be an effective and efficient use of resources and to be associated with increases in quality and improved outcomes.

Further detail:

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

6.4 Everyone should expect mainstream mental health services to regularly audit how effective they are at meeting the needs of people with a learning disability and/or autism. [The Green Light Toolkit](#) should be used to both **evaluate services and to agree local actions** to deliver real improvements. In many instances this will require investment in mainstream mental health services (such as Child and Adult Mental Health (CAMHS) Services, Improving Access to Psychological Therapies (IAPT) and services that are helping to deliver against the Crisis Care Concordat). In other instances there will be new initiatives to support mainstream mental health services to make reasonable adjustments to their pathways of care and support and to improve access to those services.

Rationale: mental health conditions are significantly more common amongst people with a learning disability and/or autism than the general population, and unmet mental health needs can be a powerful factor that can contribute to the development and maintenance of behaviour that challenges. For many children, young people 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 detail:

- 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 a learning disability 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 people in this group.
- Commissioners should ensure that the [IAPT Positive Practice guidance for people with a learning disability](#) is being followed around psychological therapies.
- Local areas drawing up [transformation plans](#) for CAMHS should ensure their plans cover the full spectrum of need, including children and young people with a learning disability and/or autism.
- Effective liaison roles will be key to supporting mainstream mental health services to understand how best to introduce reasonable adjustments so that assessment and treatment can be individualised around the needs of people with a learning disability and/or autism.
- Local NHS organisations should agree care pathways for how they will work together to meet the physical and mental health needs of this group that build on those for the rest of the population.

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

- 7.1** Everyone should have access to **integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community** that is readily accessible, when needed, by children, young people and adults with a learning disability and/or autism, including those who may have come into contact with or are at risk of coming into contact with the criminal justice system (see principle 8). Key functions of this specialist support should include: support to enable people to access mainstream health and social care services, work with mainstream services to develop their ability to deliver individualised reasonable adjustments, support to commissioners in service development and quality monitoring, and the delivery of direct assessment and therapeutic support.
- 7.2** Specialist support might be provided by a range of services, and often across services (e.g. children's services, Child and Adult Mental Health Services (CAMHS), learning disability CAMHS teams and specialist community learning disability teams). Support should be built around the needs of the individual through a **'Collaborative Care' model**, or by **combined teams** (e.g. all age, learning disability and autism). Individuals should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services. Access to and provision of support should be based on need.

Rationale: although mainstream (health and social care) services can and should meet a large proportion of people's everyday needs, there will remain a need for specialist support for some people where meeting health and care needs are particularly complex, and where there are an interplay of factors impacting on the achievement of equitable outcomes for people. It is essential that this specialist support is available to support people with the most complex of needs. Therefore in order to maintain the capacity of specialist teams, mainstream services should continue to support the majority of people with a learning disability and/or autism, albeit with the support of specialist services.

Further detail:

- Specialist support should typically be provided to mainstream services, both health and social care, as well as education, on a consultative basis; in most cases enabling them to continue to support the people with expert support and advice. It is essential that mainstream services understand how, where and when they can access support from colleagues in specialist services.
- 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, within a Positive Behavioural Support (PBS) framework, including psychological and therapeutic support, where this has been identified as needed through the person-centred care and support planning process (see further detail below);
 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 the intensity of specialist input will vary over time. It is important for the individual and their family/carer(s), as well as for mainstream services, to know how they can access this specialist multi-disciplinary support and what they can expect from this service.
 - There may be occasions where adjustments which would otherwise be required of mainstream services would far exceed what might be considered reasonable; or where even reasonably adjusted mainstream services still could not deliver the required equity of outcome alone. In these instances teams should be providing direct specialist clinical assessment and therapeutic support.
 - Local multi-disciplinary teams providing this support will typically need high levels of knowledge, skills and experience including with: person-centred approaches, autism, learning disability, forensic, safeguarding, mental health (applicable to specific population), physical health (applicable to specific population), positive risk-taking management, Positive Behavioural Support (PBS), 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, occupational therapists 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.
 - As 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.
 - Teams should have well established 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 collaborative ways of working (across different agencies) with clearly agreed pathways for people, ensuring that individuals experience continuity of care and support whilst accessing expertise from a range of agencies and services. These should build on [NICE guidance in relation to people with a learning disability and behaviour that challenges](#), as well as relevant NICE guidance on mental health conditions. Pathways need to incorporate the needs of very young children and be able to respond rapidly to early signs of the development of behaviours that challenge. This rapid response approach should be included within the local offer required under the Children and Families Act.
 - Teams should contribute to the development and implementation of local workforce training strategies.
 - In line with NICE guidance, specialist services should provide a detailed initial assessment to people who have been referred due to concerns about behaviours that challenge. The person and their family should be as fully involved in the assessment as possible, and it should start with the needs and wishes of the individual and their family. Screening for physical and health conditions is always essential but even more so where the person's behaviour has shown a recent or sudden change. The complexity and duration of assessment should be proportionate to the impact of the person's behaviour on their quality of life and wellbeing.
 - This assessment should inform the development of a behaviour support plan (see principle 2). In some cases, further assessment, including a functional assessment of behaviour, baseline assessment of quality of life and assessment of the impact of restrictive interventions should be undertaken.
 - In all instances, behaviour support plans should identify proactive strategies including changes to the environment (e.g. to remove exposure to known 'triggers') and promoting active engagement through personalised daily activities. Plans should also include adaptations of environment and routine to support the development of new skills, as well as providing guidance on the use of reactive strategies where behaviours of concern arise.
 - Behaviour support plans should take account of the knowledge and skills of those who will implement it and of their support needs. In some instances, specialist team members will role model, coach, or otherwise develop the abilities of others to sustainably implement behaviour support plans. Plans should also include measures to determine whether they are being accurately implemented and should be reviewed frequently.
- 7.3** Anyone who requires additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and social care support** at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be delivered by members of highly-skilled and experienced multi-disciplinary/agency teams with specialist knowledge in managing behaviours that challenge. The interface between specialist routine multidisciplinary support services (described above) and this type of intensive support service should be seamless.

Rationale: there will be times when individuals need more intensive support than that normally available through local specialist multi-disciplinary teams. Providing this support in the community allows greater opportunity to assess the person in their natural environment and can help to avoid or manage a crisis, and prevent potentially traumatic or inappropriate hospital admissions. This intensive support can also be provided to support the transition back into the community after a period of time in hospital or at residential school.

Further detail:

- Intensive support should be available for children, young people and adults to help prevent family or care and support package breakdown, and help people with a learning disability and/or autism to remain in the community. This should include the full range of assessments and support described above; however, delivered with a higher level of intensity and flexibility across 24 hours a day, seven days a week. This should allow effective behaviour support plans to be swiftly established in order that the situation can be stabilised.
- Intensive support will be for short periods of time, although the implementation of behaviour support plans may require ongoing involvement of intensive support staff. The assessment of risks and associated reactive strategies within the plan may require access to additional support, again on a 24/7 basis; if admissions are to be avoided commissioners may wish to consider option such as on-call intensive support staff or supplementing mental health crisis teams.
- The delivery of intensive support should be recognised as a challenging and occasionally traumatic area of work for staff whose effectiveness will be reliant on good access to support, training and ongoing supervision.
- Intensive support services should also be made available when people are discharged from inpatient services, or leaving residential schools. This will allow a responsive approach to assessment and support planning so that the likelihood of readmission is minimised.
- The team providing this intensive support should ensure all lesser restrictive options have been explored before an individual is referred to a specialist hospital (in line with NHS England guidance) and should provide in-reach support to those people who are in hospital settings to enable effective and timely discharge back to the community.
- Existing intensive support services for people with a learning disability often estimate that their caseload at any one time is likely to be 10-15% of their Community Learning Disability Team's caseload.
- 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 can be delivered by the same team but with a 'ring-fenced' caseload. The team members will require specialist knowledge in how to support and work with the psychological stressors experienced by family members and paid support and care staff.

- 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 a learning disability and behaviour that challenges 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 and Proactive: reducing the need for restrictive interventions](#).

8 If I need it, I get support to stay out of trouble.⁵

- 8.1** People who have come into contact with, or may be at risk of coming into contact with the criminal justice system, should have **access to the same services aimed at preventing or reducing anti-social or 'offending' behaviour⁶ as the rest of the population**. They should expect services (including those provided by youth offending teams, liaison and diversion schemes, as well as troubled family schemes and programmes such as those for drug and alcohol misuse) to identify people with a learning disability and/or autism amongst the people they support and to make reasonable adjustments so they can effectively support those people. This should be achieved through collaboration with specialist multi-disciplinary health and social care services for people with a learning disability and/or autism (see principle 7, and 8.3 below).

Rationale: some of those people with a learning disability and/or autism who end up in hospitals following contact with the criminal justice system may have experienced difficult backgrounds (often from troubled families and/or victims of abuse or neglect themselves, frequently with a history of alcohol misuse).⁷ They may not have been previously known to health and social care services prior to their contact with the criminal justice system and admission to hospital may be the first occasion when their learning disability and/or autism has been recognised. There is a need for more of a focus on reducing the likelihood of offending or reoffending from as early on as possible (see principle 4). This will secure better outcomes for people 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 (see 8.3 below), and specialist multi-disciplinary learning disability and/or autism services (see principle 7) to ensure they have appropriate access.

⁵ A small percentage of people with a learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting. They are included as a distinct group within this service model because their specific needs have not always been recognised; the model presents an opportunity to develop the support and services they may require.

⁶ The term 'offending' behaviour is used in this way to encompass those people whose behaviour has brought them into contact with the criminal justice system, even if they have not been convicted of an offence.

⁷ Tizard Centre, literature review commissioned for this service model, see: www.kent.ac.uk/tizard/resources/index

Further detail:

- Specialist multi-disciplinary learning disability and/or autism services should provide advice and support to other services/agencies whose work is likely to reduce the risk of anti-social or 'offending' behaviour to ensure they are able to cater effectively for people with a learning disability and/or autism. This should include: community safety partnerships, youth offending teams, liaison and diversion schemes (see below), youth inclusion teams, street triage, drug and alcohol programmes, troubled family schemes and gangs' services. More intensive input may come from an embedded team member (for example, situated within a youth offending team) who has the expertise and skills in working with people with a learning disability and/or autism and who knows how to draw down the additional support and expertise needed, including in relation to sexual health/sex education and speech and language/communication support. Some people will require basic social care support (for example, with housing and budgeting) in order to enable them to participate effectively in programmes.
 - Specialist multi-disciplinary learning disability and/or autism services should also work with these services to improve screening and identification of a learning disability and/or autism 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.
 - Health and social care systems, alongside youth and criminal justice system partners, should consider opportunities for pooling funding and increasing investment in early intervention services, which can prevent contact with the criminal justice system.
 - Under the Care Act local authorities must provide or arrange services, facilities or resources, or take other steps, which will contribute to preventing or delaying the development of care and support needs of adults in their area, regardless of whether they are eligible for social care. For example, this could be done through providing "lower level" local preventative support and enabling people be connected with peers and with other local community groups.
- 8.2 Liaison and diversion schemes** should seek to support people through the youth or criminal justice system 'pathway' enabling people to exercise their rights and/or where appropriate, diverting people to appropriate support from health and social care services. Clear pathways for diversion to health and social care services should be established through local multi-agency protocols.

Rationale: people 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 detail:

- Liaison and Diversion services aim to improve health outcomes, reduce re-offending and identify vulnerabilities earlier, thus reducing the likelihood that offenders will reach crisis-point.
- Specialist multi-disciplinary learning disability and/or autism services should work with Liaison and Diversion services to improve screening and identification of people who have a learning disability, autism and mental health conditions. There should be clarity in referral and support arrangements.
- Liaison and Diversion services should seek to identify people from their first engagement with criminal justice agencies in order to support them appropriately through the criminal justice pathway.
- NHS England is currently [trials Liaison and Diversion services](#), operating to a national service specification, in different parts of England.

8.3 When required, people should have access to **specialist multidisciplinary health and social care support for people who have come into contact with or may be at risk of coming into contact with the criminal justice system** (i.e. offering a community forensic function for people with a learning disability and/or autism) including the expertise to manage risks posed to others in the community. The interventions offered by these services will depend on the needs of the individual and the level of risk they pose, from individual and group offence-specific interventions, to specialist assessment and established links with other services aimed at facilitating appropriate pathways away from the criminal justice system. It is likely that some people will be best served by mainstream forensic services able to work with people with a learning disability and/or autism, and some by specialist multi-disciplinary health and social care services for people with a learning disability and/or autism. In some areas, specialist community forensic learning disability and autism teams or hospital outreach teams work with small numbers of people who pose a more significant risk to others, usually spanning several localities.

Rationale: there are a range of health and care services (sometimes adapted specifically for people with a learning disability and/or autism) 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 and/or autism often find themselves excluded from mainstream mental health or forensic services because of their learning disability and/or autism, and excluded from learning disability services because they are considered too able or too risky.⁸

⁸ Tizard Centre, literature review commissioned for this service model, see: www.kent.ac.uk/tizard/resources/index

Further detail:

- This specialist support can be organised in a range of ways, depending on local service arrangements, and the identified roles and responsibilities of those services. However, the key functions of this specialist support 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 adapted programmes or mental health treatment) to the courts, in partnership with police, probation and other relevant parties.
 - Establishing links and providing consultancy to other services/agencies (such as social care and mental health services, the police, MAPPA, Liaison and Diversion, the courts, probation, youth offending teams, housing, employment and education) to facilitate pathways away from the criminal justice system. This should include support to mainstream forensic services, which could be in a position to support some people (with expert support and advice) and other teams working with people with a learning disability and/or autism, including those working with children and young people (e.g. CAMHS) to ensure early intervention.
 - A care co-ordination function for individuals, including to enable a safe, well-managed and speedy return to the community for those being discharged from secure hospital settings; this may be through direct work with individuals or through advising other teams.
 - The provision of support, supervision and training to social care providers working with people with a learning disability and/or autism who may have come into contact with the criminal justice system, including those who have offended and those at risk, helping with the design of services and supports.
 - Specialist assessment and expertise in positive management of risks in the community and adapted treatment programmes (e.g. for substance misuse or sex offender treatment). 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. Advice to the courts should be provided in partnership with Liaison and Diversion services, and should inform pre-sentence reports by the National Probation Service.
- How those interventions are provided will also depend on the individual's needs and the level of risk they pose. It is likely that some people will be best served by mainstream forensic services able to work with people with a learning disability and/or autism, including through the development of liaison roles within community forensic teams, and with the support of specialist multi-disciplinary services for people with a learning disability and/or autism. Others will be served directly by specialist multi-disciplinary services for people with a learning disability and/or autism, skilled-up so that they are able to work with (often lower-risk) individuals. In some areas, specialist forensic learning disability and autism teams or hospital outreach teams work with small numbers of people who pose a more significant risk to others, usually spanning several localities.

- Teams delivering these functions of specialist support should develop collaborative ways of working (across different services and agencies) and agree clearly defined pathways for people, ensuring that individuals experience continuity of care and support and there is clarity in the roles and responsibilities of different teams.
- Staff will need training and processes to support appropriate information sharing and to enable informed decision making about when and what information to share. People 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 am admitted for assessment and treatment in a hospital setting⁹ 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** Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be **integrated into their broader care and support pathway**, with hospitals working closely with community mental health, learning disability/autism and other services, including those providing intensive community and/or forensic support (see principles 7 and 8).
- 9.2** When people are admitted for assessment and treatment in a hospital setting they should expect support to focus on **proactively encouraging independence and recovery**. Services should seek to minimise patients' length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment with measurable outcomes. Hospitals should not become de facto homes; discharge planning should start from the point of admission - or earlier for a planned admission. Care and treatment should be regularly reviewed, in line with [NHS England Care and Treatment Review guidance](#) and CPA requirements. Services should be as close to home as possible and provide care and treatment in the least restrictive setting.

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 – or beforehand, as part of a person's [Care and Treatment Review](#). This makes close coordination with other services along the pathway essential. Hospitals are not homes so people should never be admitted as a backstop for placement or family breakdown or because there is nowhere else for them to go.

⁹ 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients

Further detail:

- Assessment and treatment in a hospital should be part of a broader care and support pathway. 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 proactively 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). Support for families and carers must be part of any commissioning framework.

9.3 People who present an immediate risk to those around them and/or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment and/or treatment is temporarily required that cannot be provided safely and effectively in the community. They should have access to high quality assessment and treatment in **non-secure hospital services** with the clear goal of returning them to live in their home. Sometimes people will be detained under the Mental Health Act if the necessary conditions are met. People with a learning disability and/or autism should be assessed and treated in mainstream inpatient services where this is the most appropriate option. This is likely to be the case for people with a mild learning disability and/or autism who have a mental health problem of a type and severity that warrants inpatient care. Providers should make the reasonable adjustments to enable this (e.g. liaison nurses and collaborative working with learning disability and/or autism specialists). This might require providers to designate particular wards as suitable for this purpose. People whose learning disability and/or autism is more significant and who require an adapted environment and/or intensive specialist treatment and care should be admitted to a specialist unit if they require inpatient care. These specialist beds should be increasingly co-located within mainstream hospital settings as part of integrated specialist inpatient services, rather than in isolated stand-alone units. With the right support at the right time in the community, use of inpatient services should be rare and only for clearly defined purposes.

9.4 Admission to **secure inpatient services** should only occur where a patient is assessed as posing a significant risk to others. Often they will be detained under Part III of the Mental Health Act ('patients concerned in criminal proceedings or under sentence') and in contact with the criminal justice system, with or without restrictions from the Ministry of Justice. Some patients, however, may be detained in secure settings under Part II of the Mental Health Act where they pose an equivalent level of risk to others and this risk cannot be managed safely in less secure settings. For example, those who have been diverted away from the criminal justice system as a result of criminal justice agencies not taking the case through the courts, or discontinuing proceedings once it is seen that the person is already in hospital. In line with the Mental Health Code of Practice, only patients who require a combination of enhanced physical, procedural and relational security should be placed in secure services.

Rationale: a clear commitment has been made to reduce the number of people with a learning disability and/or autism who display behaviour that challenges in a hospital setting. 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, and in cases where there is diversion or direction from the criminal justice system.

Further detail:

- Where **non-secure** hospital care and support is provided within mainstream settings, these services should be actively identified, developed and supported to make the reasonable adjustments necessary to provide assessment and treatment for people with a learning disability and/or autism, including access to specialist skills as necessary (such as those relating to autism or communication difficulties). This also includes services that offer adapted environments for people who may be vulnerable.
- Where people cannot be supported effectively or safely in mainstream mental health settings, inpatient provision specifically for people with a learning disability and/or autism should be increasingly integrated within mainstream hospital sites and not in isolated settings, in order to ensure access to the full range of inpatient supports and safeguards and to allow for joint working and readily accessible liaison and facilitation resources. Examples of this include units attached to mainstream mental health services that enable access to both general and specialist mental health expertise, the up-skilling of mainstream mental health services and closer coordination with local services. The Green Light Toolkit should be used in the evaluation and development of actions for improvement of service provision (see principle 6).
- In line with the Mental Health Act Code of Practice, hospital provision for people should be as local as possible to enable people to maintain contact with families and communities, and to provide for better in-reach support and expertise, with the location of the placement, and considerations relevant to that decision, monitored and reviewed regularly. The relatively low numbers of people with a learning disability and/or autism requiring inpatient care (comparative to overall numbers of people with a learning disability and/or autism) and local variation in numbers, will necessitate local joint mental health and learning disability commissioning across CCG and local authority footprints to develop high quality, cost effective solutions.
- Non-secure hospital care and support should provide a setting in which people 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. Services should offer evidence-based interventions, in line with [NICE guidance](#), and/or published consensus on good and safe practice, that are reasonably adjusted as necessary, delivered by appropriately qualified staff who are actively engaged with peer support and quality networks.

- Some people will need treatment for a mental disorder whilst preventing harm to the public, including people who have been diverted or directed to hospital from the criminal justice system to secure settings. In addition to specialist assessment and support and advice prior to potential court appearance, such services may also provide advice and support to the courts in appropriate disposal/sentencing. 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. (See principle 8).
- Admission to inpatient settings should be authorised by an appropriate legal framework. This may include capacitous consent, Deprivation of Liberty safeguards or the Mental Health Act. All services will need to provide care and treatment in line with these legal frameworks.

9.5 Everyone, other than those following diversion or direction from the criminal justice system, should expect a **community (pre-admission) Care and Treatment Review (CTR)**. In urgent situations where there is not time to convene a CTR then there should be a 'Blue Light' meeting, in line with [NHS England policy and guidance](#). Admissions should always be with a clear stated purpose and set of expected outcomes. In the event of an urgent admission, where a CTR has not been carried out, then this should take place within 10 working days of their admission. After six months they should expect a mandatory CTR. Additionally, at any stage in hospital, should there be concerns about care and treatment, the person themselves, their family, advocate, commissioner or clinical team have a 'Right to Request' a CTR.

Rationale: people should not receive care and treatment in hospital if the same treatment and support can be safely provided in a non-hospital setting or in the community, and there should be robust processes in place to prevent people being admitted unnecessarily into inpatient settings. People and their families/carers should be empowered to have a say in their own care and treatment pathway and any admission to an inpatient setting should be supported by a clear rationale of planned assessment and treatment with measurable outcomes.

Further notes:

- The Care and Treatment Review (CTR) process is triggered at the point when a person is identified as "at risk" of being admitted to an inpatient setting. It facilitates a process of clarifying the nature of the presenting problems, identifying in detail the contributing factors, establishing clear aims and objectives for interventions and seeking alternatives to admission if possible. If there is not an alternative, the CTR ensures that there is a clear rationale for admission with clearly defined outcomes and initial plans for discharge in as short a time as possible.

- Admission to an inpatient setting 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 NHS England guidance, people with a learning disability and/or autism should only be admitted to hospital following a CTR or a 'Blue Light' meeting in urgent situations where there is insufficient time to convene a CTR.
- In the event of an urgent admission, the individual should have a full CTR within 10 working days of their admission.
- After six months there is a mandatory CTR. Additionally, at any stage in hospital should there be concern about care and treatment there is a 'Right to Request' a CTR, initially through contact with the individual's care coordinator. Anyone, including the individual, their family, advocate, clinical team and responsible commissioner can request a CTR.

9.6 For all inpatient provision (secure or not) children admitted to hospital should be placed in an **environment suitable for their age** and must have access to education. For adults, provision of **single-sex accommodation** is essential.

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:

- 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 a learning disability. Children in inpatient settings must also have access to education.
- For children, secure settings need to reflect the [Children's Act 1989 section 25](#) arrangements and the [Home Office Guidance for Children under 13 years](#).
- Provision of single sex accommodation for adults is essential, in particular given evidence of the vulnerability of women with a learning disability 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, their duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities. See further guidance for NHS commissioners on Equality and Health Inequalities legal duties.

Personal Information

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

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

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

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

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

Service model for commissioners of health and social care services

Supplementary information for commissioners
October 2015

Association of Directors of Adult Social Services (ADASS)

Local Government Association (LGA)

NHS England