



Department  
of Health

# Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

March 2015

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# Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

Prepared by the Department of Health

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## Ministerial foreword



The Autism Act 2009<sup>1</sup> remains the first and so far the only condition-specific legislation of its type in England. This demonstrates the importance Parliament has attached to ensuring that the needs of people with autism are met.

The original Adult Autism Strategy *Fulfilling and Rewarding Lives*<sup>2</sup> was published in 2010. In April 2014 this was updated by *Think Autism*.<sup>3</sup> This statutory guidance supports the strategy and its update, *Think Autism*, by giving guidance to local authorities and NHS bodies about the exercise, respectively, of their social care and health service functions (for the purpose of securing the implementation of the strategy and its update). The guidance builds on progress made over the last five years and sets out the expectations for local areas so they can continue to develop services and support in ways that reflect the assessed needs and priorities of their communities to secure implementation of the strategy.

Local Authorities and the NHS need to work in collaboration with local partners to take forward the key priorities in *Think Autism*. Crucially, at its core, people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care support criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the

local population, and informed by people with autism and their families.

The wider legislative changes since 2010 will also enable local services to support people with autism and their families better, and they are also outlined in this statutory guidance. The Children and Families Act 2014<sup>4</sup> will help to support young people in preparing for adulthood. The Care Act 2014<sup>5</sup> places a strong emphasis on preventing and delaying needs for care and support, making sure that there is appropriate information and advice for people, support for carers, and promoting integration between social care and health care services. It also places a duty on local authorities to promote a person's well-being when carrying out any of their care and support functions in respect of that person.

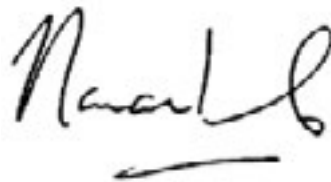
Autism should also not be seen as an add-on to services and with over half a million people on the autism spectrum in England, mainstream services will already be seeing or in contact with many people who have autism. By encouraging more innovation in the way services are delivered and through services making more reasonable adjustments, individuals can go to their local council office, GP or hospital feeling confident that those services are aware of their autism and knowing that adjustments can be made for them. Training and awareness of autism are key here.

Those who have followed the Adult Autism Strategy over the past five years will recognise that, as our approaches mature, our ambition has grown. *Think Autism* moved

the original vision of the strategy on, including an increased focus on areas such as criminal justice and employment. It is only right that the statutory guidance should do likewise.

Local authorities and the NHS have made a lot of progress in the ways that adults with autism are supported. The challenge is now to build on this progress, ensuring that this guidance is followed to make sure

that we improve the lives of hundreds of thousands of people with autism and their families. Also included is good practice and suggested actions that build on the statutory requirements. I know that you will join me in taking up this challenge, and this updated guidance will help local authorities and the NHS reach our shared vision for all adults with autism to live fulfilling and rewarding lives within a society that accepts and understands them.



**Norman Lamb**  
**Minister for Care and Support**

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- <sup>1</sup> Autism Act 2009 <http://www.legislation.gov.uk/ukpga/2009/15/contents>
  - <sup>2</sup> “Fulfilling and rewarding lives” The strategy for adults with autism in England (2010) [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)
  - <sup>3</sup> “Think Autism. Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update” (2014) <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
  - <sup>4</sup> Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
  - <sup>5</sup> Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

## Status of this guidance

1. This guidance is statutory guidance issued under section 2 of the Autism Act 2009 (the Act). It is issued to local authorities, NHS bodies and NHS Foundation Trusts and replaces the 2010 statutory guidance. It relates to England only.
2. An NHS body, under the Act and in this guidance, means the National Health Service Commissioning Board (referred to in the remainder of this guidance by its operational name, NHS England), a clinical commissioning group, an NHS Trust all or most of whose hospitals, establishments and facilities are in England and a Special Health Authority performing functions only or mainly in respect of England.
3. As set out in section 3 of the Act, it is to be treated as though it were guidance issued under section 7 of the Local Authority Social Services Act 1970<sup>6</sup> (LASS Act). This means that local authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course.”
4. Though the LASS Act does not directly apply to NHS bodies, section 3(2) of the Act makes it clear that for the purposes of this guidance “an NHS body is to be treated as if it were a local authority within the meaning of the LASS Act”. The Act also specifies that the functions of an NHS body concerned with the provision of relevant services (namely health services provided for the purposes of the health service) are to be treated as if they were social services functions within the meaning of the LASS Act.
5. Local authorities and NHS bodies must not only take account of this guidance, but also follow the relevant sections or provide a good reason why they are not doing so (one example might be because they can prove they are providing an equivalent or better alternative). If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or action by the Secretary of State.
6. The definition of NHS body in the Act does not include NHS Foundation Trusts. However, this guidance **does** include Foundation Trusts, and throughout, it is stated clearly what the responsibilities of local authorities, NHS bodies and NHS Foundation Trusts are. NHS Foundation Trusts will be expected to follow the guidance as it applies to them (unless there is good reason for not doing so), such as when planning and providing services for adults with autism, for example, in commissioning diagnostic services.
7. The guidance also includes good practice and suggested actions that build on the statutory requirements and existing guidance.

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<sup>6</sup> Local Authority Social Services Act 1970 <http://www.legislation.gov.uk/ukpga/1970/42/contents>

## About this guidance

1. The purpose of this guidance is to secure the implementation of the Adult Autism Strategy “*Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England*” 2010 as updated by *Think Autism* (2014) by giving guidance to Local Authorities, NHS Foundation Trusts and NHS bodies.

2. The guidance focuses on the areas which section 2 of the Autism Act 2009<sup>7</sup> requires to be addressed, in each case identifying what Local Authorities, Foundation Trusts and NHS bodies are already under a duty to do under legislation, what they are expected to do under other existing guidance, and what they should do under this guidance. Local Authorities, NHS bodies and Foundation Trusts should already be doing much of what

is expected of them in complying with this guidance as they should have followed the 2010 statutory guidance (which this guidance builds on and replaces).

### What has changed since 2010?

3. There have been major changes to many parts of the health and social care system, services and legislation since the Act and the 2010 Autism Strategy. These changes are summarised in Appendix A.

4. We have also, following our review of the 2010 Autism Strategy, refreshed it with *Think Autism* published in April 2014. This set out an updated programme of action to deliver the aims of the Act and is summarised in Appendix B. It places greater emphasis on involvement and awareness within the local community and on ways to look differently at support and engagement. *Think Autism* therefore builds on the 2010 Autism Strategy rather than replaces it, and the two should be read together.

5. In addition, we continue to expect local authorities, NHS bodies and Foundation Trusts in every local area to remain committed to the 2010 Autism Strategy.

6. Additionally, as well as reflecting the key legislation and health and social care reforms since 2010, the guidance puts greater emphasis on involvement and awareness within the local community and on ways to look to improve the way health and social care services identify the needs of adults with

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<sup>7</sup> Section 2 of the Autism Act requires that the guidance must, in particular, include guidance about- (a) the provision of relevant services (namely, as regards NHS bodies, health services provided for the purposes of the health service and, as regards local authority, services provided in exercise of their social services functions under the LASS Act) for the purpose of diagnosing autistic spectrum conditions in adults; (b) the identification of adults with such conditions; (c) the assessment of the needs of adults with such conditions for relevant services; (d) planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults; (e) other planning in relation to the provision of relevant services to adults with autistic spectrum conditions; (f) the training of staff who provide relevant services to adults with such conditions; and (g) local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.



autism. It also aim to ensure identified needs are met more effectively to improve the health and well-being of adults with autism.

7. These are both important points with regard to fulfilling the new challenges people with autism have set us in *Think Autism*. We remain committed to our future vision that:

*“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them, they can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”.*

### Terminology

8. Throughout the guidance, as in the strategy, we use the term “autism” as an umbrella term for all autistic spectrum conditions, including Asperger Syndrome. Many people with autism also have related hidden impairments such as attention deficit hyperactivity disorder, dyspraxia, dyslexia, dyscalculia and language impairments as well as associated mental health conditions and linked impairments that may not be obvious to other people.

# Monitoring Local Authorities, NHS Foundation Trusts and NHS bodies progress against the requirements in the guidance

## How will the Department of Health check progress of local communities'?

1. The Department of Health intends to continue to support Health and Wellbeing Boards through the local area autism self-evaluation exercise on an annual basis and to make the responses publicly available. The self-evaluation exercise will help demonstrate progress being made in implementing the Adult Autism Strategy, and highlight examples of good practice around the country.
2. There have been two self-assessment exercises undertaken by local authorities and their partners. A baseline assessment was carried out in 2011,<sup>8</sup> with a follow up assessment completed in 2013.<sup>9</sup>
3. A further self-assessment exercise is currently underway this year for 2014/15. This will enable adults with autism, their families and carers, and autism representative groups to hold services to account and assess whether changes are taking place. It will also allow the Department to compare progress across different areas identify areas where progress is still to be made and allow areas to compare performance with peers and neighbours.

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<sup>8</sup> Autism Self-Assessment 2011 – [https://www.improvinghealthandlives.org.uk/publications/1157/Autism\\_Self\\_Assessment\\_2011](https://www.improvinghealthandlives.org.uk/publications/1157/Autism_Self_Assessment_2011)

<sup>9</sup> Autism self-assessment framework 2013 – <http://www.improvinghealthandlives.org.uk/projects/autism2013>

# Understanding this guidance

Where the guidance says local authorities, NHS bodies and Foundation Trusts **“must”** it refers to legal duties imposed upon these bodies by the Autism Act 2009 or other Acts of Parliament e.g. the Care Act 2014, and the Children and Families Act 2014 (or secondary legislation made under such Acts).

Where the guidance says local authorities/ NHS bodies/Foundation Trusts **“should”** it refers to statements of policy or information with regard to the way in which Local Authorities (and in particular their Social Services Directors), NHS bodies and Foundation Trusts should exercise their functions with a view to securing the implementation of the autism strategy.

Local Authorities (and in particular their Social Services Directors), NHS bodies and Foundation Trusts may depart from this but only if they can demonstrate a good reason for doing so. Lack of sufficient resource would not necessarily constitute a good reason. These statements are intended to reflect current practice in many localities since the Autism Act 2009 and the first published Adult Autism statutory guidance (December 2010) or are drawn from evidence bases, for example, from the autism self-evaluation exercise, or available qualitative research and information gathered during review and refresh of the Autism Strategy in 2013/14.

## What the coloured boxes mean

To help navigate through the sections three different coloured boxes have been used to guide you about what your responsibilities are under the statutory guidance.



Local Authorities



NHS Bodies



Local Authorities and NHS Bodies and NHS Foundation Trusts

## Who must have regard to this guidance?

1. This guidance is for:
  - Local Authorities in relation to the exercise of their social services functions; and
  - The following bodies in relation to the exercise of their functions concerned with the provision of health services for the purpose of the health service in England: NHS Foundation Trusts, NHS Trusts all or most of whose hospitals establishments and facilities are in England, the NHS Commissioning Board (referred to in the remainder of this guidance by its operational name, NHS England), Clinical Commissioning Groups (CCGs) and Special Health Authorities performing functions only or mainly in respect of England.
2. The above bodies should ensure that this guidance is also followed by other organisations that deliver services under contract for them, such as those contracted to provide accommodation in a care home or day care on behalf of a local authority etc.
3. Independent sector providers (including both for profit and not for profit providers) who are providing services for the NHS via commissioning arrangements with the Board or CCGs or for local authorities (exercising their social services functions) via commissioning arrangements are required to follow the guidance if that requirement is included in those commissioning arrangements as it would be expected to be. So, on that basis, wherever guidance is included that refers to NHS bodies and/or local authority delivered services then independent sector providers should ensure that they follow this guidance.
4. We recommend that other providers of public services, such as providers of services to support people into employment, police, probation and the criminal justice system look to follow the guidance to help improve the delivery of the services they provide to adults with autism: for example ensuring that staff who provide services to adults with autism have received autism awareness training would clearly be of value across all public services. This should lead to better outcomes for people with autism and make best use of public resources.
5. It is also good practice for any provider who is delivering care which is self-funded, for example by the individual, their family or insurance, to follow the guidance.
6. The guidance may also be of interest to readers in Scotland, Wales and Northern Ireland (who have their own legislation and strategies).

# 1. Training of staff who provide services to adults with autism

1.1. Improving training around autism is at the heart of the autism strategy for all public service staff but particularly for those working in health and social care. This includes not only general autism awareness training, but also different levels of specialist training for staff in a range of roles, where this is needed to fulfil their responsibilities and for those who wish to develop their knowledge of autism.

1.2. When professionals do understand autism, the positive impact on the lives of adults with autism can be immense. Health and social care professionals must be able to communicate effectively with people with autism if they are to be able to manage their own care and exercise genuine choice and control. The 2010 statutory guidance for local authorities and the NHS made it clear that basic autism training should be available to all staff working in health and social care. This remains a key requirement of this updated statutory guidance.

1.3. From April 2015, the Care and Support (Assessment) Regulations 2014<sup>10</sup> will require local authorities to ensure that a person undertaking an assessment of an adult's care and support needs has suitable skills, knowledge and competence in the assessment they are undertaking, and is appropriately trained, and require local authorities, when carrying out an assessment, to consult a person who has expertise in relation to the condition or other

circumstances of the individual whose needs are being assessed where it considers the needs of that individual require it to do so.

1.4. In line with the 2010 statutory guidance, local authorities should be providing general autism awareness to all frontline staff in contact with adults with autism, so that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour and communication. In addition to this, local authorities are expected to have made good progress on developing and providing specialist training for those in roles that have a direct impact on and make decisions about the lives of adults with autism, including those conducting needs assessments. This expectation remains central to this updated statutory guidance.

<sup>10</sup> Care and Support (Assessment) Regulations 2014 [http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi\\_20142827\\_en.pdf](http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf)

**Local Authority, NHS bodies and NHS Foundation Trusts should:**

- Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care;
- Ensure that all autism awareness training enables staff to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics;
- Ensure that there is a comprehensive range of local autism training that meets National Institute for Health and Care Clinical Excellence (NICE) guidelines for those staff who are likely to have contact with adults with autism;
- Ensure those in posts whose career pathways are highly likely to include working with adults with autism (for example, personal assistants, occupational therapists, residential care workers, frontline health staff including all GPs and psychiatrists) have demonstrable knowledge and skills to:
  - Use appropriate communication skills when supporting a person with autism;
    - Support families and friends and make best use of their expert knowledge of the person;
    - Recognise when a person with autism is experiencing stress and anxiety and support them with this;
    - Recognise sensory needs and differences of a person with autism and support them with this;
    - Support the development of social interaction skills;
    - Provide support with transitions and significant life events;
    - Understand the issues which arise from co-occurrence of mental ill health and autism;
    - Support people with autism to gain and maintain employment (where appropriate);
- Ensure those in posts who have a direct impact on and make decisions about the lives of adults with autism (including, for example, psychiatrists, those conducting needs assessments) also have a demonstrable knowledge and skills in the areas listed above as well as a good understanding of:
  - How autism may present across lifespan and levels of ability, and are defined and diagnosed, and the relevant pathways and screening tools;
  - The common difficulties faced by individuals on the spectrum and their families/carers, including social and economic hardship;
  - Developmental trajectory of autism;
  - The impact of autism on personal, social, educational and occupational functioning, and interaction with the social and physical environment;

- Current good practice guidelines (e.g. NICE Quality Standard)<sup>11</sup> and local diagnostic and care pathways;
- Current good practice guidance with respect to an individual with autism's capacity to assess risk;
- Available guidance for good practice in post-diagnostic support and intervention.
- Ensure that both general awareness and specialist autism training is provided on an ongoing basis and that new staff or staff whose roles change are given the opportunity to update their autism training and knowledge;
- Recognise that women with autism may be missed and misdiagnosed as they may be better able to mask their social difficulties. There can also be a perception that autism is something that men have and this can impact on women being referred for diagnosis. Improved awareness and training should help overcome this;
- Involve adults with autism, their families and carers and autism representative groups when commissioning or planning training. This may be in terms of inviting them to comment on or contribute to training materials, or asking them to talk to staff about autism and how it affects them, or to provide or deliver the training, for example they could help put together a multi-agency plan with regard to autism training for staff.

Good practice for local authorities, NHS bodies and NHS Foundation Trusts would be to maintain adequate staffing levels and build on the skill set of staff who are suitably trained, to ensure continuity of service.

#### **NHS bodies and NHS Foundation Trusts should:**

- Ensure they are involved in the development of local workforce planning, and GPs and primary care practitioners are engaged in the training agenda in relation to autism.

#### **Local Authorities must:**

- Ensure that any person carrying out a needs assessment under the Care Act 2014 has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Where the assessor does not have experience in the condition, the local authority must ensure that a person with that expertise is consulted.

<sup>11</sup> NICE Quality Standard on autism (2014) <http://www.nice.org.uk/guidance/qs51>

## Additional information on good practice in delivering training effectively

1.5. As the 2010 strategy and guidance made clear, initial autism awareness training can be delivered as part of existing equality and diversity training or similar programmes. Local authorities, NHS bodies and NHS Foundation Trusts may also want to consider online training, DVDs etc. as well as using the DH-commissioned online resources and information about autism for those working in the health and social care sectors. To find out more go <https://www.gov.uk/government/news/autism-training-resources>

1.6. Skills for Care and Skills for Health with the National Autistic Society have developed resources to help enhance awareness of autism and improve skills among social care and health workers. To find out more go to <https://www.skillsforcare.org.uk/skills/Autism/Autism.aspx>

1.7. The Department of Health has commissioned the College of Social Work to develop a Continuing Professional Development curriculum guide on autism linked to the Professional Capability Framework and a set of learning materials for social workers. Both will be available later in 2015.

### What else can help?

- There is considerable scope to share resources with other organisations locally – for example, co-commissioning a training programme or course.
- The most effective training will help staff put what they are learning in context, by reflecting the situations they work in – for example, in terms of the kinds of reasonable adjustments that can be made to their working environment.
- When identifying who requires training within an organisation, it is important to consider all staff – not just those in frontline service delivery. For example, a practice manager may have a key role to play in making adjustments to the environment to make it accessible for adults with autism; the response of a receptionist can make a big difference to whether an adult with autism makes and keeps an appointment.
- As well as budgeting for core awareness training, it will be necessary to allocate funding for more specialist autism training for certain staff – including those practitioners who have identified an interest to specialise in autism. It is not expected that each local authority, NHS body or Foundation Trust develops its own specialist training programme, but rather that applications for specialist training are considered within the training budget.
- When involving people with autism in the planning and delivery of training, it is necessary to ensure that the whole autism spectrum is covered, by means of considering differences in reasonable adjustments that may be required, and discouraging reliance on preconceptions of autism. Training should encourage staff to make appropriate adjustments for each individual with autism. Local authorities, NHS bodies and Foundation Trusts should make sure that involvement in training is meaningful for both trainees and people with autism.



## 2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

2.1. Diagnosis can be particularly important for adults who did not have their condition or sensory issues recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult. They may also have been receiving learning disability or mental health services, where their autism was not recognised or supported.

2.2. While local authorities will lead commissioning for care and support services for people with autism, CCGs are expected to take the lead responsibility for commissioning of diagnostic services to identify people with autism, and work with local authorities to provide post-diagnostic support for people with autism (regardless of whether they have an accompanying learning disability, other hidden impairments or a co-occurring mental health problem).

2.3. A diagnosis represents the formal clinical confirmation of autism and the clear elimination of an alternative diagnostic explanation for an individual, based on all the available information – including patient experience, carer reports, direct observation and special interview schedules, to find out if characteristic behaviour was present during childhood and has continued to adulthood. A diagnosis of autism is therefore usually made by a specially trained health professional, working as part of a multi-disciplinary team. For adults, this is most commonly led by a psychiatrist, or by a clinical psychologist, or speech and language therapists who also has

had sufficient training and clinical experience in diagnosing a wide range of other mental and behavioural disorders frequently found in people with autism.

2.4. A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their whole family, as well as their participation in learning, employment or other activities. Some people with suspected autism may not need further support. However, this does not mean that they should not have access to a diagnosis. For some people, simply having a diagnosis of autism confirmed can be incredibly important, and can help them avoid needing more intensive support at a later stage for example, if they hit a crisis point.

2.5. We have taken a number of actions since 2010 to support local authorities and NHS bodies and Foundation Trusts in each local authority area to develop a clear pathway to diagnosis and post-diagnosis. In every local area, the NHS is expected to have a pathway to diagnosis, just as the local authority should have a clear framework for assessing the care and support needs of adults with autism. We will continue to ask local authorities, NHS bodies and Foundation Trusts to assess their progress on developing and maintaining a pathway to diagnosis through the autism local area self-evaluation exercise.

2.6. Each local authority area should have an easily accessible autism diagnostic service, but it is not expected that a specialist diagnostic team will be located in all areas.

Key professionals such as GPs and mental health practitioners should be aware of the pathway and of how to refer to that diagnostic service.

2.7. To enable these duties to be fulfilled, local authorities, NHS bodies, and Foundation Trusts should take the following steps.

**NHS bodies and NHS Foundation Trusts should:**

- Provide access to services that can diagnose autism, and it's frequently associated medical and mental health conditions.

**Clinical Commissioning Groups should:**

- Designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.

**Local Authorities informed by NHS bodies should:**

- Seek to work with CCGs to ensure there is a suitably trained lead health professional to develop diagnostic and assessment services for adults with autism in their area.

**Local Authorities and NHS bodies should jointly:**

- Ensure the provision of an autism diagnostic pathway for adults including those who do not have a learning disability and ensuring the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs. NICE guidance and NICE Quality Standard on autism represent best practice when developing diagnostic services and related services.

**Clinical Commissioning Groups and NHS England should:**

- Establish, maintain and promote autism diagnostic pathways, working with partners in local authorities. This includes giving appropriate post diagnostic advice and support;
- Promote NICE best practice (e.g. where people seeking an autism diagnosis have a first appointment within 3 months of their referral) as set out in the NICE Quality Standard on autism [QS51]. GPs have an important role to play in recognising autism and knowing where to refer locally for a diagnosis and other support.

**NHS England should:**

- Ensure that GPs, as the gatekeepers to diagnostic services, have adequate training specifically in autism beyond general awareness training (as outlined in Section 1) and a good understanding of the whole autistic spectrum and the diagnostic pathway that has been developed in their area. This will enable adults with autism to be supported more effectively from the start of their assessment process.

**Clinical Commissioning Groups and NHS England should:**

**NHS Bodies and NHS Foundation Trusts should:**

- Contact the adult with autism and any registered carers to inform them about their right to a needs assessment (for the adult) and a carer's assessment (for the carer) if they may have such needs;
- When an adult is diagnosed with autism, the NHS body or NHS Foundation Trust providing healthcare services to the adult informs, with the individual's consent, the relevant local authority adult social services department promptly to ensure that a care and support assessment can be carried out within a reasonable time period if the individual wants such an assessment.

**Local Authority, NHS bodies and NHS Foundation Trusts should:**

- Ensure the prompt sharing of information between diagnostic services and adult social care services about adults diagnosed;
- Ensure people have timely formal notification of their entitlement to an assessment of needs and, where relevant, a carer's assessment.

**Local Authorities should:**

- Ensure that people with autism are aware of the right to access a needs assessment (for the adult) and a carer's assessment (for the carer). The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.

## Local Authorities duties under the Care Act 2014 from April 2015

2.8. Local Authorities will also be subject to the following duties from April 2015 and must carry them out in relation to adults with autism as with all other adults:

- Section 1 of the Care Act<sup>12</sup> – duty, in exercising its care and support functions under Part 1 of the Care Act in the case of an individual, to promote that individual’s well-being;
- Section 3 of the Care Act – duty to exercise its functions with a view to ensuring the integration of care and support provision with health and health related provision where this would, in its area, promote well-being, help prevent or delay the development of care and support, or support, needs and improve the quality of such care and support;
- Section 4 of the Care Act – duty on local authorities to establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers and in particular on how to access the care and support that is available;
- Section 6 of the Care Act – duty of co-operation in general, in exercising functions relating to adults with care and support needs and carers with support needs, between local authorities and other relevant bodies, such as NHS bodies in its area, other local authorities, and specified persons responsible for exercising functions in relation to social security, employment and training, probation services, prisons and the police;
- Section 7 of the Care Act – duty to co-operate with the same relevant bodies in specific cases relating to individuals with needs for care and support;
- The Care and Support (Assessment) Regulations 2014 – duty to give information about the assessment process to the individual being assessed;
- Regulation 5 of the Care and Support (Assessment) Regulations 2014<sup>13</sup> which requires a local authority to ensure that a person carrying out an assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure that assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.

<sup>12</sup> Part 1 of the Care Act 2014 – Sections 1,3,4,6 and 7 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>13</sup> Regulation 5 of the Care and Support (Assessment) Regulations 2014 – [http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi\\_20142827\\_en.pdf](http://www.legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf)

**Local Authorities must:**

- Under section 47(1) of the National Health Service and Community Care Act 1990,<sup>14</sup> local authorities have a duty to assess a person who may be in need of community care services. Section 9 of the Care Act 2014<sup>15</sup> will replace the duty in section 47(1) from April 2015 (as to which see below). This assessment may be triggered either by the individual requesting it or if the local authority believes community care services may be necessary. This duty applies to people with autism and is not dependent on them having been formally diagnosed as having autism. Such an assessment should be carried out by trained practitioners, and where there are potential signs of autism, the assessment should take account of the communication needs of adults with autism. Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ.

This is particularly important for some people with autism, including those with Asperger syndrome, who may face very significant challenges in their everyday lives, despite having average or above average IQ.

The Care Act requires local authorities to conduct a needs assessment where it appears to the authority that the adult may have needs for care and support. It is vital that local authorities fulfil their duties under statute by ensuring that adults diagnosed with autism who may have care and support needs are offered an assessment.

**Under the Care Act (from April 2015), local authorities must:**

- Carry out a supported self-assessment of the care and support needs of an adult with autism if that is what the adult wishes (providing they have capacity to consent);
- Involve individuals (including those with autism and their carers) when carrying out certain care and support functions in respect of them, such as when conducting needs or carers assessments, preparing care and support, or support, plans (and when revising such plans);
- Where required provide access to an independent advocate to enable the individuals engagement in determining their support;
- Arrange access to an independent advocate for individuals with autism for the purpose of facilitating their involvement in the above mentioned matters. In particular where a person with Autism would have difficulty in understanding the process of assessment including retaining that information, and or would not be able to meaningfully contribute their views, wishes or feelings and there is no appropriate person who knows them to support them in fully engaging in the process;
- Identify the outcomes individuals (including those with autism) wish to achieve for their day to day lives in their needs assessments and carer's assessment.

<sup>14</sup> Section 47(1) of the National Health Service and Community Care Act 1990 – <http://www.legislation.gov.uk/ukpga/1990/19/section/47>

<sup>15</sup> Section 9 of the Care Act 2014 – <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

**NHS bodies and NHS Foundation Trusts should:**

- Look at people's experiences of the autism diagnostic process locally and assure themselves that this is acceptable, for example, involving NHS England local audit teams.

## Additional information on good practice in delivering training effectively

### NICE guidelines

2.9. To help standardise and improve the care and management of autism, and to enable health and social services to support people with autism more effectively, NICE has published three clinical guidelines on autism and a quality standard.

2.10. NICE has also produced:

- An Implementation Pack:<sup>16</sup> developing a multi-agency local autism team, to support local areas;
- A series of costing tools;<sup>17</sup>
- Support for Commissioning<sup>18</sup> which outlines the key actions that commissioners should take to deliver the quality improvements outlined in the NICE quality standard;
- A Quality Standard on Autism;

A Quality Standard on Autism describes the high-priority areas for quality improvements in the defined care area of autism support. Each standard consists of a prioritised set of specific, concise, underpinning, comprehensive recommendations, designed to support the measurement of improvement in diagnosis. These importantly include specific reference to people with possible autism needing a diagnostic assessment by an autism service (locally defined) having the assessment start within 3 months of a referral, in which people identified as potentially having co-existing physical or mental health conditions should in addition receive an assessment of such needs. These therefore contribute to improvements in the holistic health and social care outcomes defined in national outcomes frameworks, and enable commissioners to address service provision gaps, and address best practice evidence-based care.

<sup>16</sup> Developing a multi-agency local autism team implementation pack – <https://www.nice.org.uk/guidance/cg128/resources/autism-developing-a-multiagency-local-autism-team-implementation-pack>

<sup>17</sup> NICE guidelines [CG142]: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum – costing tools and templates <https://www.nice.org.uk/guidance/cg142/costing>

<sup>18</sup> QS51 Autism: support for commissioning – <http://www.nice.org.uk/guidance/qs51/resources/qs51-autism-support-for-commissioning2>

## Guidance for Commissioners of Diagnostic Services for Adults with Autism

2.11. The Joint Commissioning Panel for Mental Health (JCP-MH) will publish soon a guide to support CCGs (with their local authority partners) to commission effective diagnostic and post diagnostic services in ways that achieve better health outcomes for adults with autism.

2.12. The JCP-MH guide will show how CCGs can specify the core components of the agreed NICE compliant diagnostic assessment process and referral protocols to be used by healthcare professionals with expertise in supporting people with autism and co-existing mental or physical health problems, following initial screening by primary care and non-autism specialist community teams.

## Good practice for diagnostic services

Good practice for diagnostic services should include:

- Appropriately trained health professionals;
- Access where necessary to multi-disciplinary team-based support that enables individual approaches based on a range of multi-professional expertise and relevant skills;
- Making use of a structured developmental history (using if necessary a valid autism-specific information-gathering tool e.g. Diagnostic Interview for Social and Communication Disorders (DISCO));
- Assessments by interaction with, and observations of, the person with autism (using if necessary a valid structured tool e.g. Autism Diagnostic Observation Schedule (ADOS));
- Physical examinations according to relevant clinical judgement and symptoms;
- Systematic assessments of co-existing conditions;

- Any other assessments required to create a full profile of the individual's strengths, skills, impairments and support needs – that can then be used to create a needs based positive person centred support and management plan that takes account of the context of the individual's life;
- Active involvement of people with autism, family members or carers, and the use of documentary evidence or records of early development and past/current behaviours (especially experiences of home life, education and social care);
- Communication of assessment findings and recommendations, using accessible information and approaches.

2.13. In line with NICE guidelines, it is now understood that it is not only specialist professionals trained in autism who can participate in the autism diagnosis process. However where a person presents with evident complex health and care and support needs, access should be commissioned, and be available, to more comprehensive assessment by local dedicated specialist autism professionals or multi-disciplinary diagnostic teams, resulting in further 'higher level' specific support recommendations and/or access to specialist autism case coordination and interventions.

### 3. Planning in relation to the provision of services for people with autism as they move from being children to adults

**3.1.** Transition to adulthood is a crucial stage in the lives of all young people, and a time when those with autism may face particular challenges. Good transition support for children and young people with autism can have a profound impact on their ability to reach their potential, through access to further learning or training, employment and independent living. Co-operation between the relevant authorities is crucial if the person is to fulfil their potential. Local authority children's and adult services, children's health services and social care all need to play a part.

**3.2.** The Children and Families Act 2014 provides for a new special educational needs and disability (SEND) support system, covering education, health and social care. Under the provisions of that Act, a young person (someone over compulsory school age and under 25) can ask the local authority to assess their Education, Health and Care (EHC) needs. Others, including schools and colleges, can also make such a request. This is with a view to an EHC plan being drawn up for the young person that sets out the special EHC provision required. The young person can further expect, when an EHC plan is being drawn up, to be able (subject to certain limited criteria being met) to choose which school or further education (FE) college they are to attend. They will also be given the opportunity of a Personal Budget to control some of the provision set out in an EHC plan.

**3.3.** However, local authorities, NHS bodies and Foundation Trusts need to recognise that not all young people with autism will have EHC plans. Receiving support in making

the transition to adulthood, and accessing appropriate services as an adult should not be dependent having an EHC plan. Indeed the Care and Support statutory guidance, issued under the Care Act, sets out that local authorities should consider how they can identify young people who are not receiving children's services who are likely to have care and support needs as an adult. The guidance identifies young people with autism whose needs have been largely met by their educational institution as an example.<sup>19</sup> Not everyone with autism will have an EHC plan, but this should not prevent planning for supporting the transition from children's, to adult, services.

**3.4.** NHS bodies and Foundation Trusts should seek to ensure that there are arrangements in place for routine support for any young person with a complex care need including those with autism in receipt of children and adolescent mental health services, in making the transition to adulthood, and adult services,

**3.5.** Where individuals do not fulfil referral criteria for adult services, there should be clear signposting to other sources of support and information; however, commissioners should also be vigilant to spot discontinuities between provision for young people and adults.

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<sup>19</sup> Care and Support Statutory Guidance – issued under the Care Act 2014 (Page 306): [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/366104/43380\\_23902777\\_Care\\_Act\\_Book.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf)



3.6. Young people with autism, whether they have an EHC plans or not, can expect to be helped with their transition from school or college to adulthood. Local authorities have duties under the Children and Families Act 2014 at the annual reviews of a child's EHC plan from Year 9 (age 13 to 14) onwards to consider what provision is required to help the child or young person in preparation for adulthood and independent living. Indeed, the expectation is that consideration of preparation for adulthood should begin right from the earliest point that special educational needs are identified.

#### **Local Authorities must:**

Under the Children and Families Act 2014 carry out the following duties, including duties which are relevant to children and young people with autism and their families:

- have regard to the *Special educational needs and disability code of practice: 0 to 25 years*<sup>20</sup>, including the chapter on Preparing for adulthood from the earliest years;
- take account of the views, wishes and feelings of children, young people and parents when carrying out their functions under Part 3 of the Act in relation to children and young people with SEND;
- keep the educational and care provision for these children and young people under review, consulting young people directly;
- make advice and information available to children, parents and young people, including advice and information which will help young people make the transition from school;
- review EHC plans annually. From at least Year 9, the annual review must include a consideration of the preparation for adulthood, including employment/higher education, independent living and participation in society. Transition planning must be built into the plan;
- focus on progress towards the achievement of outcomes in an EHC plan; and for those over 18 assess whether the educational and training outcomes have been achieved;
- make arrangements for ensuring co-operation between officers of the local authority who exercise functions which relate to helping the young person achieve a successful transition;
- publish a "Local Offer" of educational, health, care and training provision available to these children and young people from their areas and consult children, young people and parents in drawing up and reviewing the Local Offer. The Local Offer must include information about preparation for adulthood and independent living, and the arrangements for supporting young people moving from receiving social care services for children to receiving services for adults; and
- put in place – in co-operation with local partners – arrangements relating to the right of the parents of children and of young persons with an EHC plan to request a Personal Budget.

<sup>20</sup> <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>  
*Special educational needs and disability code of practice: 0 to 25 years*

### **Under the Care Act 2014:**

- carry out a child's needs assessment (also known as a transition assessment) where it appears to them that the person under 18 (referred to as a "child" in this Act but referred to as a "young person" in this guidance) is likely to have care and support needs after turning 18 and they are satisfied that it would be of significant benefit to that young person to do so. Young people with autism are identified by the Care and Support statutory guidance as a group whose members may not have received support as a child but who may have care and support needs in adulthood.<sup>20</sup>
- The assessment must look at whether that young person is likely to have such needs after turning 18 and, if they do, assess what those needs are likely to be and which are likely to be eligible needs. This duty applies to all young people with autism, not just those with an EHC plan. Local authorities must also continue to provide any children's care and support services the young person has been receiving under children's legislation until a conclusion is reached about whether or not the young person has needs for adult care and support and, if so, until those needs which are going to be met are beginning to be so met.

### **Clinical Commissioning Groups must:**

- work with children and young people with special educational needs or disability and their families, and local authority partners, to carry out EHC assessments and draw up EHC plans, including transitional support for young adults.
- jointly commission with local authorities provision for children and young people with SEND including the development of a Local Offer of services.
- secure the health provision set out in an EHC plan.
- have regard to the *Special education needs and disability code of practice: 0 to 25 years*.

<sup>21</sup> Care and Support Statutory Guidance - issued under the Care Act 2014 (Page 306):  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/366104/43380\\_23902777\\_Care\\_Act\\_Book.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf)

### **NHS bodies and NHS Foundation Trusts must, under the Children and Families Act 2014:**

- have regard to the *Special education needs and disability code of practice: 0 to 25 years*;
- co-operate with local authorities, for example, when EHC assessments are being carried out, when local authorities secure the special educational provision set out in EHC plans, when transition to adulthood is being discussed for children with EHC plans and in the production of the Local Offer;
- jointly commission services for disabled children and young people and those with SEN; and
- arrange the health provision set out in an EHC plan.

### Additional information on good practice on providing services for children and young people with autism as they move to being adults

3.7. The starting point for all those supporting a child or young person with autism through transition should be to aim high. With high aspirations, and the right support, the vast majority of children and young people with autism can go on to achieve successful long-term outcomes in adult life. Local authorities should work together with education providers and their partners to help children and young people realise their ambitions in relation to:

- higher education and/or employment – including exploring different employment options, such as support for becoming self-employed and help from supported employment agencies;
- independent living – enabling people to have choice and control over their lives and the support they receive, their accommodation and living arrangements, including supported living;

- participating in society – including having friends and supportive relationships, and participating in, and contributing to, the local community; and
- being as healthy as possible in adult life.

3.8. Research by the University of York,<sup>22</sup> commissioned by the Department of Health to inform the implementation of Fulfilling and Rewarding Lives, identified the services most valued by young people with autism in preparing for adulthood, particularly those with Asperger Syndrome and high functioning autism. These include:

- Help with facing and planning for adult life;
- Specialist, and on-going employment support;
- Peer support and opportunities to spend time with other with the same diagnosis;

<sup>22</sup> Beresford, B., Moran, N., Sloper, P., Cusworth, L., Mitchell, W., Spiers, G., Weston, K. and Beecham, J. (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions*, Working Paper, no: DH 2525, Social Policy Research Unit, University of York, York. <http://php.york.ac.uk/inst/spru/research/summs/transitionsASC.php>

- Voluntary work placements in settings where autism was understood and accommodated.

3.9. The research emphasised the importance of autism specific services, delivered by autism trained professionals throughout the transition process.

### Transition from school: need for a person-centred approach

3.10. It is crucial to listen to the views of children, parents and young people as arrangements are made for transitions from school, using a person-centred approach. The process should allow the person with SEND to express what they would like to happen in the future and get them actively involved. Where the person has an EHC plan, they will need to be involved before, during and after review meetings. The approach should be all about listening to the person and what they want for their life and the future, with family, friends, supporters and professionals working together with them to make this happen. Children and young people should be provided with any appropriate support to help them express their views on the transition to adult life.

### Transition planning

3.11. Planning for transition should start early, and for children with EHC plans, must start in Year 9.

3.12. Agencies across education, health and care should work together, perhaps setting up a transition pathway, to support good transitions to adulthood. Transition planning should cover all relevant areas of service provision, including housing and employment support.

3.13. The local authority should co-operate with health services to ensure that young people's EHC plans and health care plans are aligned.

3.14. Local authorities should consider effective planning for the transition to adult health and care services and, where a young person with autism is nearing the end of formal education, consider good exit planning when carrying out transition planning.

3.15. Local authorities should work with schools, colleges and other post-16 providers, as well as other agencies, to support young people to participate in education or training and to identify those in need of targeted support to help them make positive and well-informed choices.

### Information for children, young persons and parents

3.16. Children, parents and young people should be provided with information about the provision that is available on transitions to adult life, for example, through the Local Offer.

3.17. Voluntary organisations, such as the National Autistic Society and Ambitious about Autism, can give advice to individuals who are making the transition between school and adult provision/life.

### Information, advice and guidance on career choice

3.18. A key element of successful transition is the provision of excellent careers information, advice and guidance. Schools and colleges must secure independent careers guidance – for schools this applies to pupils in Years 8-13, and colleges all students up to the age of 18 and 19-25 year olds with a Learning Difficulty Assessment (LDA) in place or with an EHC plan. Schools and colleges should seek to raise the career aspirations of their SEND students and broaden their employment horizons. They should use a wide range of imaginative approaches, such as taster opportunities, work experience, mentoring, exploring entrepreneurial options, role models and inspiring speakers.

## Local Offer

3.19. Local authorities should seek input from Autism Partnership Boards from the outset of developing and then reviewing Local Offers. By bringing together several organisations to deal specifically with improving services for people with autism, the boards provide a useful forum to gain feedback and expertise on proposals.

## Study programmes

3.20. Post-16 providers (including school sixth forms) are expected to offer all students a study programme which is coherent, appropriately challenging, and supports the progression of the individual. Study programmes are programmes of learning for 16-19 year olds, or 16-25 year olds where the student has an EHC plan (or a statement or LDA issued under the previous SEND regime). They are based on a young person's prior attainment and designed to meet clear educational and career aspirations.

3.21. Each learner should have a study programme which is personalised to meet their own individual needs, and which offers them the best opportunities to progress successfully to life beyond school or college. It is good practice to provide opportunities which go beyond the classroom – for example, work placements with employers or voluntary placements with community organisations.

3.22. Colleges that offer courses which are designed to provide pathways to employment should have a clear focus on preparing students with SEND for work. This includes identifying the skills that employers value, and helping young people to develop them. Further information is contained in this

[factsheet](#)<sup>23</sup> on study programmes for young people with SEND.

## Employment

3.23. Achieving paid employment not only brings young people financial independence, but it can be key to building confidence and self-esteem, increasing health and well-being, and to gaining friendships and a social life. There are also benefits for the economy, employers, families, the local community and wider society.

3.24. Two study programmes with a specific vocational focus to support young people into employment are supported internships and traineeships.

- **Supported internships**<sup>24</sup> are a structured study programme based primarily at an employer. They enable young people aged 16-24 with a statement or LDA or EHC plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace. Supported internships are unpaid, and last for a minimum of six months. Wherever possible, they support the young person to move into paid employment at the end of the programme. Alongside their time at the employer, young people complete a personalised study programme which includes the chance to study for relevant substantial qualifications, if appropriate, and English and maths.

<sup>23</sup> Study programmes factsheet – <http://www.preparingforadulthood.org.uk/resources/pfa-resources/factsheet-study-programmes-for-students-with-learning-difficulties-and-or-disabilities>

<sup>24</sup> What are supported internships? – <http://www.preparingforadulthood.org.uk/what-we-do/supported-internships/dfc-information-for-employers>

- **Traineeships**<sup>25</sup> are designed to help young people who want to get an Apprenticeship or job but don't yet have appropriate skills or experience. They are a mainstream education and training programme with work experience that is focused on giving young people the skills and experience that employers value. At the core of a traineeship is work preparation training, English and maths for those that need it and a high quality work experience placement.

3.25. In addition to this, **Apprenticeships** allow young people or adult learners to earn while they learn in a real job, whilst also gaining a qualification. The Government is committed to making Apprenticeships **inclusive and accessible**<sup>26</sup> to all.

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<sup>25</sup> Find a traineeship – <https://www.gov.uk/find-traineeship>

<sup>26</sup> Employer toolkit for inclusive and accessible apprenticeships – <https://www.gov.uk/government/collections/apprenticeships-equality-and-diversity>

## 4. Local planning and leadership in relation to the provision of services for adults with autism

4.1. In line with the 2010 statutory guidance, *Think Autism* highlights the role local authorities and NHS bodies should have in planning services for adults with autism. In particular, local authorities and NHS bodies should develop commissioning plans for services for adults with autism and review them annually. Local authorities should also allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism.

4.2. In addition, local commissioning plans should set out how local authorities will ensure that adults with autism are able to access direct payments (where appropriate) and benefit from the personalisation of health and social care. Local partners should already have a local autism partnership board in place, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for improved services. Autism partnership boards have proved to be a highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance. It is therefore essential for their partnership arrangements to be established in areas where they are not currently.

4.3. Services should support an individual to achieve the outcomes identified across the spectrum of needs aligned with the local offer and market position statements. These describe what local resources are available for people in the local community to access.

4.4. It is important that parents, young people and adults with autism can access information that is relevant to them to help them make choices about the type of support they can receive.

4.5. Health and social care services need to recognise the impact that autism has on an individual's life and consider this alongside any additional needs such as a learning disability or mental health condition ensuring that there is a personalised approach with targeted support. In addition, Health and Wellbeing Boards should work with NHS bodies and Foundation Trusts to raise awareness and make reasonable adjustments to enable people to access appropriate services in their local community.

### Health and Wellbeing Boards

4.6. Health and Wellbeing Boards have a crucial role to play in overseeing implementation of the Adult Autism Strategy. As a local health and wellbeing system leader, bringing together partners from NHS England, CCGs, HealthWatch and Local Authorities, the Health and Wellbeing Board is central to ensuring the needs of people with autism are addressed locally. Health and Wellbeing Boards across the country have been developing their Health and Wellbeing strategies based on local evidence contained in their Joint Strategic Needs Assessments (JSNA) to improve the life outcomes for local people.

4.7. Achieving better outcomes for adults with autism requires local partners to work together, and Health and Wellbeing Boards are well placed to lead this joint working. With the support, guidance and leadership of Health and Wellbeing Boards the aspirations, vision and priorities of *Think Autism* can be embedded and owned locally to meet the needs of the whole community including people with autism. Planning and resource allocation systems should be designed to

reflect the full range of needs, including those for people with real complex needs.

4.8. Health and Social care services should recognise how autism affects an individual's life including any additional needs arising from for example, a learning disability or mental health issue. Health and Wellbeing Boards should therefore promote people's access in their local communities working through raising awareness and accessibility through reasonable adjustments.

**Local Authorities should:**

- Ensure that there is a meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders locally, including the CCG, and people with autism, and sets a clear direction for improved services;
- Allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism in the area, known as the autism lead. This lead should be appointed by the Director for Adult Social Services;
- Bring partners together, for example through Health and Wellbeing Boards, to ensure information sharing protocols are in place and that all necessary information for service planning is available;
- Ensure that there are appropriate arrangements in place to ensure senior level sign off for responses to the national autism self assessment exercises and other appropriate developments around the delivery of the local autism strategy.



**Local Authorities must:****Under the Care Act, from April 2015**

- Exercise their care and support functions with a view to ensuring the integration of care and support provision with health provision and the provision of other services that may have an effect on health (such as housing accommodation) where they consider this would, for adults in their area, promote well-being, improve the quality of care and support, or help prevent or delay the development of needs. This will apply in relation to adults with autism, as with all other adults. An example of this would be that a local authority when planning the way in which the care and support needs of an adult with autism are to be met, should consider local housing strategies and plans, and how those strategies and plans deal with adults with autism;
- Co-operate with relevant partners generally in exercise of their care and support functions, and in the case of individuals with care and support needs when requested to do so by a relevant partner, including in relation to adults with autism or their carers. These relevant partners include other local authorities, NHS bodies in the area, the police and probation service. Officers of each local authority responsible for care and support functions must also co-operate with other officers within the local authority responsible for housing, children's services and public health.

**Local Authorities, NHS bodies with commissioning responsibility should jointly:**

- Consider and include the number of people with autism in their area as part of the JSNA. Local partners will want to determine how they carry out responsibility locally, for example it could include such factors as identifying the age profile and range of support needs of people living with autism so as to predict how need and numbers will change over time;
- Develop and update local joint commissioning plans for services for adults with autism based on effective joint strategic needs assessment, and review them annually, for example with the local Health and Wellbeing Board;
- In developing such plans, it will typically be necessary (as a minimum) to gather information locally about:
  - The number of adults known to have autism;
  - The range of need for support to live independently;
  - The age profile of people with autism in the area – to enable local partners to predict how need and numbers will change over time (including children and young people, over 65s as well as working age).

4.9. To achieve the most accurate local information about the numbers of adults with autism and their needs, good practice suggests including the number of people with autism:

- from Black Asian Minority Ethnic (BAME) communities;
- by gender (men, women or other) including trans gender;
- in employment;
- likely to need employment support to gain or stay in work;
- placed in the area (and funded) by other local authorities;
- placed out of area by local authorities and/or NHS bodies;
- in hospital or living in other NHS-funded accommodation;
- resettled from long-stay beds or NHS residential campuses to community provision;
- living at home on their own, or with family members, or with older family carers and not receiving health or social care services.

4.10. Key professionals to engage in this evidence gathering are:

- Social care professionals;
- GPs (could identify numbers of people on their practice list who have an autism diagnosis and could also follow up with diagnostic services to find out if their patients have been given an autism diagnosis if this information has not come back after referral);
- Job centre managers;
- Employment support providers;
- Local autism groups and branches of national autism organisations.

## Supporting older adults with autism

4.11. Older adults with autism are a neglected group and have received less attention through policy, research and service provision. In part, this is because autism was only identified in the 1940s and the first generation of adults to be diagnosed are only now moving into older age. It is clear that approaches to older people with autism will need to change and develop.

4.12. The key message for local authorities and NHS bodies is that they need to plan appropriate services for older people with autism who live in the area, and ensure that mainstream services used by older people are appropriate for people with autism. Data collection is integral to the success of local planning, as will be incorporating this data in to local autism strategies and commissioning plans.

4.13. Local areas should have a diagnostic pathway in place for autism. They must ensure this works for older people, who report problems in being identified, not being able to provide a developmental history and additional health problems as obstacles to receiving a diagnosis.

4.14. Older adults with autism frequently rely solely on their families and friends for support. Preventative services will be particularly important for older adults with autism who are not eligible for social care support. Furthermore, special consideration is needed when planning for the transition into older age and the increased likelihood of other health issues, particularly when family may not be around to support adults with autism.

4.15. Further information on supporting older adults with autism is available through the NAS: [www.autism.org.uk](http://www.autism.org.uk).

## Supporting people with autism from BAME communities

4.16. People with autism from BAME communities report the same issues accessing diagnoses and support, but these issues can be compounded if their local authorities find those communities harder to reach. Therefore, it is crucial that local authorities, NHS bodies and Foundation Trusts must take extra steps to identify the needs of their BAME population and ensure that services are designed that support people from BAME communities effectively.

4.17. In planning services, the collection of data will be vital, to make sure that local authorities have an accurate picture of their population and needs. Furthermore, local authorities, NHS bodies and Foundation Trusts should be reaching out to BAME communities, for example through champions in faith and other community networks to raise awareness of autism. The provision of

information and consultation with families are key in this situation and should be provided in an accessible format. Local authorities, NHS bodies and Foundation Trusts should therefore particularly ensure that information on autism and support services are provided in additional languages, as appropriate, as well as translation and advocacy. Services should also be available in appropriate locations and at appropriate times.

4.18. Throughout this, however, it is paramount that local authorities and NHS bodies recognise that different communities will have their own specific needs.

## Promoting the rights of people with autism

4.19. People with autism have the same rights as others to have their needs recognised, assessed and, where appropriate, met. Expectations should be high and services should strive to meet these expectations.

### Local Authorities should:

- Using a variety of methods,<sup>27</sup> listen carefully to the views, wishes, feelings and beliefs of people including those with autism and their carers; this could be accomplished in part by autism partnership boards through consultation events or through online feedback forms for adults with autism who are unable to attend autism partnership boards.

<sup>27</sup> The National Autistic Society 'it involves us' guide sets out good practice on involvement of people with autism in partnership boards. – <http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx>

## Additional information on good practice in planning and commissioning effectively

4.20. In order to plan and commission services effectively, local authorities and their Health and Wellbeing Boards, CCGs and other partners need to have access to as comprehensive data on local numbers and needs as is possible. But gathering data on the numbers and needs of people with autism at a local level can be challenging. Health and adult social care services are currently likely to know of only a small number of all local people with autism. There are many reasons for this, including:

- Many people with autism are likely to be undiagnosed or misdiagnosed;
- Not all people with autism will come into contact with social care services and so local authorities are unlikely to have information on them or their needs;
- Many people, especially older adults and people from certain communities, are unknown to local authority and NHS services. This may be because they are not eligible for services provided by local authorities and NHS bodies or because they do not know what help is available, or because they rely heavily on methods to 'manage' their autism and/or family and friends;
- The way local services are organised. People with autism sit across a broad spectrum and consideration of aligned/ or comorbid conditions is needed such as learning disability or mental health services. Historically, people with autism may have approached services, but where they do not have a co-occurring learning disability or mental health problem, they are sent between teams and end up falling in between services.

- Historically, services have also not collected comprehensive data about this population. However, from April 2014 under the Adult Social Care Outcome Framework,<sup>28</sup> local authorities must now record information about a person's primary reason for support and whether the person has reported certain other health conditions, such as autism or other hidden impairments. This will initially include autism generally and detail Asperger syndrome if that information is known. It is essential that local authority systems record this information to ensure that over time there is a better understanding of the local population of adults with autism.

4.21. There is other action that local authorities, NHS bodies and Foundation Trusts in each area can take to gather effective data at a local level to plan and deliver the right services for local needs, including on those people with low level needs who are not eligible for care and support. Local estimates of prevalence can be calculated from national data. This can be useful as it allows local authorities to estimate unmet need. To do this, local authorities can use PANSI<sup>29</sup> (Projecting Adult Needs and Service Information), a database that uses national data to make projections on the possible impact of demography and certain conditions on local populations. In order to collect data on the older population, local authorities could also use the Projecting Older People Population Information System

<sup>28</sup> Adult Social Care Outcome Framework 2014 to 2015 – <https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-2014-to-2015>

<sup>29</sup> PANSI (Projecting Adult Needs and Service Information) – <http://www.pansi.org.uk/>

(POPPI),<sup>30</sup> which includes projections of prevalence of autism among older people.

4.22. Local authorities can also work with local groups such as those that provide advocacy services and befriending services to gather information about the number of people they help.

4.23. Housing can play a vital role in supporting people with autism to maintain good health, independence and improve quality of life. From April 2015, section 2 of the Care Act will place a duty on local authorities to provide or arrange services, facilities or resources, or take other steps, to contribute towards preventing, delaying and reducing the needs for care and support of adults in their areas. Sections 6 and 7 of the Care Act will require local authorities to ensure the co-operation of their officers who exercise care and support functions with their officers who exercise housing functions both generally and in specific cases, and provide for local authorities to co-operate with other relevant partners or persons, such as private registered providers of social housing. Further, local authorities will be required to exercise their functions, under section 3 of the Care Act, with a view to ensuring integration between the provision of care and support, health services, and health related services such as the provision of housing, where they consider that doing so would promote the wellbeing of adults in their area with care and support needs, contribute to the prevention or delay of the development of such needs or improve the quality of care and support for adults.

4.24. To be meaningful, Autism Partnership Boards should comprise sufficiently senior representatives from local authorities and have NHS representation. These members should also consistently attend meetings. People with autism, their families and carers should also be fully included. In order to involve people with autism, local authorities should consider what reasonable adjustments need to be made.

4.25. Guidance involving people with autism has been created by the National Autistic Society which looks at partnership boards and wider engagement in local autism plans and can be downloaded via the following link: <http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx>

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<sup>30</sup> Projecting Older People Population Information System (POPPI) – <http://www.poppi.org.uk/>

## 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015

5.1. Preventative support is important for people with autism. When people with autism do not have the right preventative support, the result can be that they can spiral into mental health crises with parents/carers left to pick up the pieces or, if they are not available, expensive and inappropriate inpatient admissions or even contact with the criminal justice system may result.

5.2. Furthermore, changes such as bereavement, moving home, getting married or divorced, having children or becoming unemployed can have a particularly significant effect on someone with autism. Everyday life may also create stresses that affect someone with autism, for example relationships in the workplace. Preventative support can help people with autism to manage such events and day-to-day life better.

5.3. From April 2015, section 2 of the Care Act will place a duty on local authorities to provide or arrange preventative services for people within their communities. In discharging their duties on prevention, local authorities should, in particular, ensure they are considering the needs of their local adult population who have autism, including those who do not meet the eligibility threshold for care and support.

5.4. The term “prevention” or “preventative” measures can cover many different types of support, services, facilities or other resources. There is no one definition for what constitutes preventative activity and this can range from wide-scale whole-population measures aimed at promoting health, to

more targeted, individual interventions aimed at improving skills or functioning for one person or a particular group or lessening the impact of caring on a carer’s health and wellbeing. In considering how to give effect to their responsibilities, local authorities should consider the range of options available, and how those different approaches could support the needs of people with autism.

5.5. “Prevention” is often broken down into three general approaches – primary, secondary and tertiary prevention as described in more detail in the Care and Support Statutory Guidance<sup>31</sup> issued under the Care Act 2014.

5.6. Preventative support can be provided in many different ways. Many adults with autism find it difficult to make friends. User-led and voluntary support groups help adults with autism build relationships with peers, friends, partners and colleagues and also support independent living and being part of the community. These are all part of preventative support systems, although they are only one part. Such support should form part of a comprehensive range of preventative support and be accessible and provide choice, for example, by ensuring there are a number of support options across a geographical area. Local authorities, NHS bodies and Foundation Trusts may find NICE shared learning examples useful.

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<sup>31</sup> Care and Support Statutory Guidance issued under the Care Act 2014 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/315993/Care-Act-Guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf)

5.7. It is important that all people with autism, whatever their level of need, can easily access information in their local area about what support from peers, charities or other community groups is available. The establishment and maintenance of a service for providing people in their area with information relating to care and support for adults is a duty which will be imposed on local authorities from April 2015 (under section 4 of the Care Act 2014).<sup>32</sup>

5.8. It is critical to the vision in the Care Act that the care and support system works to actively promote wellbeing and independence, and does not just wait to respond when people reach a crisis point. It will be vital that the care and support system intervenes early to support individuals, helps people retain or regain their skills and confidence, and prevents care and support needs developing or delays deterioration in such needs wherever possible.

5.9. There are many ways in which a local authority can achieve these aims whilst promoting wellbeing and independence and reducing dependency. This guidance sets out how local authorities should go about fulfilling their responsibilities, both individually and in partnership with other local organisations, communities, and people themselves.

5.10. The local authority's responsibilities for contributing towards the prevention or delay of care and support, or support, needs apply to all adults with autism in their area, including:

- people who do not have any current needs for care and support;
- adults with needs for care and support, whether their needs are eligible and/ or met by the local authority or not;
- carers, including those who may be about to take on a caring role or who do not currently have any needs for support, and those with needs for support which may not be being met by the local authority or another organisation.

#### **Under the Care Act Local Authorities must:**

- Provide or arrange services, facilities or resources, or take other steps, which they consider will contribute to preventing or delaying the development of care and support needs of adults in their area and support needs of carers, including the care and support needs of adults with autism and the support needs of their carers, 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 with autism to be connected with peers and with other local community groups;
- Have regard to the importance of identifying existing services, facilities and resources already available which could assist with carrying out the duty above, as well as the importance of identifying adults in its area (including those with autism) with care and support needs which are not being met. To do this effectively they should consult with adults with autism and their carers, in order to establish what support already exists and what needs are not being met, to help determine what preventative services etc. are needed.

<sup>32</sup> Part 1 of the Care Act 2014 – Section 4 – <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

**Local Authorities should:**

- Ensure that they include in local autism plans or strategies how people can access local autism advice and information easily in a way that is appropriate and identifiable for people with autism.

**NHS Bodies and NHS Foundation Trusts should:**

- Ensure that health and care staff who are highly likely to support people with autism, such as GPs, psychiatrists, counsellors and psychiatric nurses are appropriately trained beyond general basic awareness about autism;
- Ensure that people with autism have equal access to local psychological therapy services, such as Improving Access to Psychological Therapies (IAPT).<sup>28</sup> If an IAPT service can't help a person with autism or Asperger syndrome directly, arrangements should be made so that other appropriate local services can provide support.

### Additional information on good practice in delivering preventative support and advice effectively

- Services based around low-level interpersonal support, such as buddying schemes, have enabled many adults with autism to participate in different social and leisure activities, and promoted social inclusion and wellbeing. Access to these networks and to advice and information is vital to help people access the communities in which they live. It can also help to prevent people going into crisis situations, which can have a very detrimental impact on individuals and can be very costly for local authorities and NHS bodies.
- People with autism and their families have also told us that it can be hard sometimes to know where to go for advice and information locally as they do not fit into locally-used “boxes” or categories such as learning disability or mental health. Autism strategies developed by local authorities should ensure that they include how people with autism but without additional learning disabilities or mental health issues can access such advice and information easily in a way that is appropriate for them. One such example could be a one-stop shop that provides a safe and friendly place to speak confidentially to someone who understands autism, access, guidance and information about services, one to one sessions, workshops, training days and group activities for families, children and professionals; these have successfully been implemented in some parts of the UK and have received positive feedback from adults with autism.
- A revised Mental Health Act 1983 Code of Practice<sup>34</sup> was published on 16 January 2015 and will come into force on 1 April

<sup>33</sup> See the National Institute for Clinical Excellence (NICE) recommendations – <http://www.nice.org.uk/>

<sup>34</sup> The Mental Health Act 1983 Code of Practice <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>



2015. It has been prepared in accordance with section 118 of the Mental Health Act 1983. Chapter 20 of the Code addresses the particular key issues from the Act and Mental Capacity Act which are relevant to people with autistic spectrum conditions for professionals to ensure independence, dignity and respect to those they treat and assess.

- Many people with autism who have been detained under specific sections of the Mental Health Act will require, and be entitled to aftercare. Discharge planning for people with autism should begin when the person is admitted and involve health and local authorities to work together in the interests of an individual to ensure appropriate community-based support is in place before discharge. This will require assessment by a practitioner with expertise in autism.

## Mental Health

5.11. People with autism are more likely to have mental health needs than the wider population, but may have problems using mental health services because of the way they are organised and run. Preventative mental health services can prevent people with autism going into a crisis.

5.12. Practical materials designed to help improve the quality of mental health services for adults with learning disabilities and adults with autism have been developed by the National Development Team for Inclusion (NDTi). Reasonably Adjusted? – published in 2012, sets out the reasonable adjustments mental health services have put in place for people with learning disabilities and people with autism. In addition, the NDTi have produced materials to help services review their own quality and share and replicate good practice known as the Green

Light Toolkit (2013) it consists of an audit framework and guidance for making service improvements to mental health services and provides material designed to help improve the quality of mental health services for adults with learning disabilities and adults with autism. Full details of both reports can be downloaded from the NDTi website,<sup>35</sup> along with summaries aimed at different audiences such as Health and Wellbeing Boards.

5.13. Reasonably Adjusted?<sup>36</sup> is a database on the Improving Health and Lives Learning Disabilities Observatory (IHAL) website with downloadable examples of types of reasonable adjustments for people with learning disabilities and people with autism who need mental health services and support.

## Mental Health Crisis Care Concordat

5.14. The Mental Health Crisis Care Concordat<sup>37</sup> is a national agreement between local services and agencies involved in the care and support of people in mental health crisis. It sets out how organisations can work together better to make sure people get the help they need when they need it. The document sets out the principles and good practice that should be followed by health staff, police officers and approved mental health professionals when working together to help people in a mental health crisis.

<sup>35</sup> Reasonably Adjusted (2012) & Green Light Toolkit (2013) <http://www.ndti.org.uk.uk/news/national-news/green-light-toolkit/>

<sup>36</sup> Reasonably Adjusted? [www.ihal.org.uk/mhra/](http://www.ihal.org.uk/mhra/)

<sup>37</sup> Mental Health Crisis Care Concordat <https://www.gov.uk/government/publications/mental-health-crisis-care-agreement>

## Helping people with autism to keep safe

**5.15.** Local authorities and others must work together to help and protect people with care and support needs, who may be at risk of abuse or neglect as a result of those needs. But this should not prevent such people from making their own choices and having control over their lives wherever possible. Everyone in the community should understand the importance of safeguarding and helping to keep people safe.

**5.16.** The local authority must make information and advice available on how to raise concerns about the safety or wellbeing of an adult who is at risk of abuse or neglect because of their needs for care and support and should support public knowledge and awareness of different types of abuse and neglect and how to keep or support people with care and support needs to be physically, sexually, financially and emotionally safe. This information and advice should also cover who to tell when there are concerns about abuse or neglect and what will happen when such concerns are raised, including information on how the local Safeguarding Board works.

**5.17.** The Care Act makes the local authority's adult safeguarding duties statutory, in recognition of the need to proactively help and protect people with care and support needs, including people with autism, to keep safe from the risks of abuse or neglect. It places the establishment of Safeguarding Adults Boards on a statutory footing, so as to ensure local authorities, CCGs and chief police officers work together to develop and implement adult safeguarding strategies. This will better prepare local agencies who have relevant care and support functions both to prevent abuse or neglect and to respond to it when it occurs.

**5.18.** Further information on Safeguarding can be found in Chapter 14 of the Care and Support Statutory Guidance<sup>38</sup> issued under the Care Act 2014.

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<sup>38</sup> Safeguarding Chapter 14 of the Care and Support Statutory Guidance issued under the Care Act 2014 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/315993/Care-Act-Guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf)

**Local Authorities must:**

- Establish a Safeguarding Adults Board<sup>34</sup> for its area (under section 43 of the Care Act);
- Make enquiries (or arrange for most appropriate person to carry out enquiries), where they have reasonable cause to suspect an adult in their area who has needs for care and support is experiencing or at risk of abuse or neglect and as a result of their needs is unable to protect themselves against the risk of abuse or neglect; this must consider what, if any, action should be taken in the adult's case, and who should take such action (under section 42 of the Care Act),<sup>35</sup>
- Ensure that, where actions required to protect an adult with autism are identified through a safeguarding enquiry, they or the appropriate person takes the appropriate action to do so.

**Local Authorities, NHS bodies and NHS Foundation Trusts should:**

- Support wherever possible and appropriate when working with individuals and families to understand, recognise and prevent risk. Including knowing how to raise concerns and report problems. Examples include young people with autism transitioning into adulthood from children's services. Those who may not be eligible for care and support but should be able to access universal and primary care services such as GPs and others who can advise them as part of their transition plan.

<sup>39</sup> Safeguarding Adults Board <http://www.legislation.gov.uk/ukpga/2014/23/section/43/enacted>

<sup>40</sup> Part 1 of the Care Act 2014 – Section 42 – <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

## 6. Reasonable Adjustments and Equality

6.1. For many people with autism, mainstream public services can be hard to access. This can be due to a lack of understanding of autism among staff in those services but there are other contributory factors.

6.2. People with autism can have a number of sensory differences affecting all five senses that can impact on their lives in a number of ways including communication, socialising and living independently: for example they can be hypersensitive to light, smell, touch and noise; they can have significant difficulties with communication and can struggle with verbal or written language, for example instructions in forms or standard letters.

6.3. Under the Equality Act 2010,<sup>41</sup> all public sector organisations, including employers and providers of services, are required to make reasonable adjustments to services with the aim of ensuring they are accessible to disabled people, including people with autism. People with autism have a right to access mainstream services just like anyone else. There are other relevant duties that local authorities, NHS bodies and Foundation Trusts are under, as set out below, which should have a positive impact on the access which people with autism have to health and social care services. This is, at its core, about equal rights.

6.4. Without reasonable adjustments many services can be inaccessible for adults with autism. Putting in place reasonable adjustments can ensure that adults with autism are able to benefit fully from mainstream public services to live independently and healthily. For clarification, the reasonableness or otherwise of an adjustment depends on the consideration of how effective the change will be in assisting disabled people in general or a particular service user, whether it can actually be done, its cost, and the organisation's resources and size. Further explanation is provided by the Equality and Human Rights Commission (EHRC)<sup>42</sup> on what is meant by 'reasonable':

<sup>41</sup> Equality Act 2010 – <http://www.legislation.gov.uk/ukpga/2010/15/contents>

<sup>42</sup> Equality and Human Rights Commission <http://www.equalityhumanrights.com/your-rights/service-users/adjustments-disabled-people/what-meant-%E2%80%98reasonable%E2%80%99>

**Local Authority, NHS bodies and NHS Foundation Trusts must:**

- Comply with all the duties which apply to them under the Equality Act 2010, including:-
  - the duty to make reasonable adjustments to their services (whether they provide these services directly or outsource them) for disabled persons (such as those with autism); and;
  - the Public Sector Equality Duty<sup>38</sup> (the Equality Duty) created by the Equality Act 2010. This requires public authorities to have due regard to the need to, in exercising their functions, eliminate discrimination, harassment, victimisation and any other unlawful conduct under the Equality Act, advance equality of opportunity between persons e.g. who are disabled and those who are not, and foster good relations between e.g. persons who are disabled and those who are not.

6.5. From 1st April 2015, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014<sup>44</sup> provide that service users must be treated with dignity and respect and in particular a registered person must have due regard to any relevant protected characteristic (such as disability) of the

service user. They also provide that care or treatment for a service user must not be provided in a way that includes discrimination against a service user on grounds of any protected characteristic, such as the disability of that service user.

**NHS England and CCGs must:**

- Under the National Health Service Act 2006,<sup>40</sup> have regard to the need to reduce inequalities between patients with respect to their abilities to access health services and reduce inequalities between patients with respect to the outcomes achieved for them by health services being provided. This should positively affect the way that these bodies exercise their functions in respect of people with autism.

<sup>43</sup> Public Sector Equality Duty <http://www.equalityhumanrights.com/about-us/about-commission/equality-and-diversity/public-sector-equality-duty>

<sup>44</sup> Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/274719/Regs\\_draft.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/274719/Regs_draft.pdf)

<sup>45</sup> Sections 13G and 14T of the National Health Service Act 2006 – <http://www.legislation.gov.uk/ukpga/2012/7/section/23/enacted>

**NHS Foundation Trusts should:**

- As stated in the Risk Management Assessment Framework (2009) (Monitor's risk assessment framework 3),<sup>41</sup> have ways of identifying and flagging up people with autism, including those who have learning disabilities, and have protocols that ensure pathways of care are reasonably adjusted to meet needs, along with accessible information about treatment options, complaints procedures and appointments.

## Further information on good practice in delivering reasonable adjustments effectively

6.6. Each adult with autism is different and will have different needs that require reasonable adjustments to be made. Local authorities, NHS bodies and Foundation Trusts should work with each individual with autism to identify what reasonable adjustments should be made, which can include changes to:

- premises – taking account of hypersensitivities and providing quiet or lower-light areas;
- processes – scheduling appointments at less busy times, ensuring that the appointment is on time, allocating extra time to adults with autism and being flexible about communication methods, for example, less reliance on telephone-based services, appointments should run on time, with the flexibility to swap appointments around to ensure timekeeping;
- face-to-face communications – some people with autism would rather communicate non-verbally even in face-

to-face consultations; avoiding ambiguous questions, asking follow-up questions where further information is needed, being aware of sensitivity to touch, providing written information in advance of meetings are all helpful;

- written communications – ensuring essential documents and forms are available in accessible formats, in particular, easy read versions and formats that take account of sensory issues in their choice of colours, as set out in the statutory information standard at:– <http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2> written information could also be used to reinforce what was said in a face-to-face consultation, to enable adults with autism to process it.
- planning and preparation – offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect: for example visiting a council building in advance of a social care assessment, visiting a court prior to giving evidence or an optician's prior to an eye test.
- As part of *Think Autism*, the Department of Health's update to the Adult Autism Strategy, the National Autistic Society produced a guide to help local authorities better involve people with autism in their local planning and implementation. The guide is called *it involves us: Enabling meaningful inclusion of adults with autism in the development of local autism*

<sup>46</sup> Monitor's risk assessment framework 3 – [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299929/RAF\\_Update\\_AppC\\_1April14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299929/RAF_Update_AppC_1April14.pdf)

*plans*<sup>47</sup> it provides local authorities and other partners guidance on involving and engaging people with autism, both through Autism Partnership Boards and through wider consultation.

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<sup>47</sup> *It involves us: Enabling meaningful inclusion of adults with autism in the development of local autism plans* <http://www.autism.org.uk/news-and-events/news-from-the-nas/it-involves-us.aspx>

## 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity

7.1. People with autism or learning disabilities, who also have mental health conditions or behaviours viewed as challenging are entitled to get good quality safe care, whether at home, living in the community or in hospital. This section provides guidance on how to effectively support individuals with the most complex needs wherever they are receiving care and treatment. A number of studies and investigations have found that too many people with autism, including those who may have behaviour that others find challenging, or who have complex needs, continue to be placed in hospitals for assessment and treatment, in some cases, for many years, often far from where they wish to be placed and often received poor quality care.<sup>48</sup>

7.2. People with autism should be assessed, treated and cared for in the community wherever possible, and when they need to go into inpatient care it should be for the minimum time necessary and in a facility close to their home. Having complex needs does not mean people should go into long-term inpatient, residential care or assessment and treatment centres inappropriately or indefinitely.

7.3. People should live in their own homes with support to live independently if that is the right model of care for them. Behaviour others may find challenging lessens with the right support and individuals benefit from personalised care and living in the community. Specialist hospital settings should only be offered as a last resort, when essential and only for assessment and treatment. Discharge planning for people with autism should begin when the person is admitted and involve local authorities, NHS bodies and Foundation Trusts in working together in the interests of an individual to ensure appropriate community-based support is in place before discharge. Services that can meet the needs of people with complex needs are essential to minimising the use of secure health settings.

7.4. It is important that those who support people with complex needs, whose behaviour may challenge or who may lack capacity should have a good understanding of supported decision-making; understand the principle that people should not be treated as lacking capacity simply because they make an unwise decision; should consider their wishes and feelings; and all health and social care organisations need to understand the principle of least restrictive care – which means identifying a range of interventions and seeking the least restrictive ones for people with autism.

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<sup>48</sup> The Learning Disability Census 2014 showed that on 30 September 2014, there were 308 people with a diagnosis of autism and 908 people with a diagnosis of learning disability and autism in a mental health hospital – <http://www.hscic.gov.uk/catalogue/PUB16760>



**The Transforming Care Programme<sup>49</sup> sets out suggested ways for improving the quality of care for people with learning disabilities and or autism. These include Local Authorities, NHS bodies and NHS Foundation Trusts:**

- Putting in place arrangements to review all current inpatient placements and support everyone found to be inappropriately placed in a hospital setting to move to community-based support;
- Working together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour. This would include appropriate housing in the community underpinned by joined up commissioning and funding arrangements across local authorities and NHS commissioners and as appropriate self-funding arrangements;
- Working in partnership so there is a substantial reduction in reliance on inpatient care for people with autism. This requires personalised care planning, discharge planning, the provision of alternative community-based settings for treatment and care and support provision and crisis intervention and support.

7.5. This is not just about those people currently within inpatient settings but also about ensuring support for those who may be at risk of going into them in future. Care staff both in local authority teams such as those assessing adults' care and support needs and NHS funded providers needing to have a good understanding of the Mental Capacity Act 2005<sup>50</sup> (MCA) in order to help people with autism.

## Mental capacity

7.6. Professionals working with those with autism must be aware of and act within the MCA. Recent reports – including from the House of Lords Select Committee – have demonstrated that awareness of the MCA among health and care professionals is too low and as a result, service users are not benefitting from the rights afforded to them under the law.

7.7. The MCA is clear that professionals must assume an individual has capacity unless it is shown they lack capacity. Capacity is time and decision specific and must be reassessed as appropriate. The Act states that professionals should support those who might lack capacity to make the decision themselves. Where this proves not to be possible, professionals must consult with the individual's carers and those interested in the individual's welfare (e.g. family) in reaching a "best interests decision".

<sup>49</sup> Transforming Care: A national response to Winterbourne View Hospital – Department of Health Review Final Report (2012) – [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)

<sup>50</sup> Mental Capacity Act 2005 – <http://www.legislation.gov.uk/ukpga/2005/9/contents>

7.8. Professionals must have an understanding of what restrictions may be imposed through a person's care and the need to minimise restrictions and maximise individual freedoms. In accordance with the MCA's guiding principles, that professionals who provide care to an individual who lacks capacity must consider whether the care is

being provided in the least restrictive way possible to achieve the intended outcome. Where restrictions on an individual are of a degree that may amount to a deprivation of liberty, this must be authorised under the Deprivation of Liberty Safeguards or by an order of the Court of Protection under the MCA.

**Local Authorities, NHS bodies and NHS Foundation Trusts must:**

- Consider how to promote the article 8 right to family life<sup>47</sup> for people with autism, including opportunities for friendships and family contact, to a life in the community where possible, and the opportunity to develop and maintain relationships;
- Under section 67 of the Care Act,<sup>48</sup> local authorities must arrange for an independent advocate to be available to represent and support a person with autism for the purpose of facilitating their involvement in their needs assessment and the preparation and review of their care and support plan where they would otherwise experience a substantial difficulty in understanding relevant information, retaining that information, using or weighing that information or communicating their views, wishes or feelings (and there is nobody appropriate to support them for this purpose). This will require knowing in advance where such services can be commissioned.
- Ensure individuals are deprived of their liberty only with appropriate legal safeguards, e.g. under the Mental Health Act 1983 or MCA.

<sup>51</sup> Human Rights Act 1998: Article 8 – <http://www.legislation.gov.uk/ukpga/1998/42/schedule/1/part/I/chapter/7>

<sup>52</sup> Care Act 2014: Section 67 – <http://www.legislation.gov.uk/en/ukpga/2014/23/section/67/enacted?view=interweave>

### Local Authorities, NHS bodies and NHS Foundation Trusts should:

- Understand and take steps to implement least restrictive care options for people with autism, carefully considering how to provide appropriate care in a way that is least restrictive of the person's rights and freedom of action;<sup>49</sup>
- Ensure that health and care providers have clear policies on the use of restrictive interventions, and on reducing their use, and are training staff appropriately;<sup>50</sup>
- Ensure that services have a clear process to follow in the event of the use of restrictive interventions, including restraint, and that they are recording and reporting such instances appropriately;<sup>51</sup>
- Ensure staff exercising functions under the MCA have regard to the Mental Capacity Act 2005; Code of Practice 2007, and in particular, how it relates to people with autism;
- Ensure that professionals and staff performing functions under the Mental Health Act 1983 have regard to the revised Code of Practice (2015), particularly, but not limited to, the requirements that relate specifically to autism.<sup>52</sup>

## Additional information on good practice for supporting people with complex needs, whose behaviour may challenge or who may lack capacity

7.9. Good practice guidance on supporting people with learning disabilities, autism and those with behaviour which challenge

includes the 1993 Mansell report,<sup>57</sup> updated and revised in 2007. Both emphasise:

- the responsibility of commissioners to ensure that services meet the needs of
- individuals, their families and carers;

<sup>53</sup> Advice for staff on the use of restrictive interventions for patients with difficult behaviour <https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions>

<sup>54</sup> Guidance on commissioning or delivering workforce development for adult health and social care workers in England who may need to carry out restrictive practices or interventions as part of positive support for people with health and social care needs who can display or are at risk of displaying behaviour that challenges or are resisting essential care. <http://www.skillsforhealth.org.uk/images/images/news/A%20positive%20and%20proactive%20workforce.pdf>

<sup>55</sup> Positive and Proactive Care: reducing the need for restrictive interventions [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/300293/JRA\\_DoH\\_Guidance\\_on\\_RP\\_web\\_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf)

<sup>56</sup> Code of practice: Mental Health Act 1983 – the Code is statutory guidance to the groups listed in s.118 MHA. The legal status of the Code means that these groups must have regard to the Code. The guidance in the Code should be followed unless there are cogent reasons for departing from it.– <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

<sup>57</sup> Services for people with learning disability and challenging behaviour or mental health needs [Mansell report – revised edition 2007]– [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_080129](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_080129)

- a focus on personalisation and prevention in social care;
- that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
- that services/support should be provided locally where possible.

7.10. The Department of Health have published guidance *Positive and Proactive Care: reducing the need for restrictive interventions*<sup>58</sup> for all those working in health and social care settings for commissioners of services, executive directors, frontline staff and all those who care for and support people.

7.11. The Department of Health, Skills for Health and Skills for Care have developed a guide *a positive and proactive workforce*<sup>59</sup> for adult health and social care workers in England who may need to carry out restrictive practices or interventions as part of positive support for people with health and social care needs who can display or are at risk of displaying behaviour that challenges or are resisting essential care.

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<sup>58</sup> Positive and Proactive Care: reducing the need for restrictive interventions – [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/300293/JRA\\_DoH\\_Guidance\\_on\\_RP\\_web\\_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf)

<sup>59</sup> A positive and proactive workforce – <http://www.skillsforhealth.org.uk/images/images/news/A%20positive%20and%20proactive%20workforce.pdf>

## 8. Employment for adults with autism

8.1. Evidence shows that being in work and staying in work is beneficial for people's health and wellbeing. People with autism, like anyone else, want to work and have a variety of skills and talents that would be valued in a range of different workplaces.

8.2. Some people with autism will require support to get or keep a job. Yet adults with autism are currently significantly under-represented in the labour market, which has a detrimental impact on their financial circumstances and social inclusion, as well as being a waste of skills and abilities. The Autism 2010 strategy and *Think Autism* included commitments aimed at increasing the number of adults with autism in work through the provision of guidance and training to employers and employment support services and ensuring adults with autism benefit from employment initiatives. The Department for Work and Pensions has since introduced the Work Programme which provides personalised back to work support for unemployed people, including disabled people. It has also established Work Choice and Access to Work,<sup>60</sup> both of which help disabled people, including people with autism, find employment and stay in work.

8.3. Local authorities can also play a key role in supporting adults with autism in their area to gain employment by making sure that participation in employment is a matter considered in needs assessments, and in the exercise of their other care and support functions in respect of an individual, and that the care planning process takes account of existing or future work opportunities.

8.4. Local authorities also have a role to play in the provision or arrangement of preventative services and facilities; and in effective transition planning to ensure successful transition of young people with autism from education into employment. In their role as an employer, local authorities could set an example to other employers by becoming an autism-friendly place to work; and by actively recruiting and employing more people with autism through apprenticeships, traineeships or supported internships as mentioned in Section 3 under good practice.

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<sup>60</sup> Work Choice – <https://www.gov.uk/work-choice> and Access to Work <https://www.gov.uk/access-to-work>

**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, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become 'work ready';
- when carrying out a needs assessment, consider whether matters other than the provision of care and support could contribute to the achievement of the outcomes an adult with autism wishes to achieve in day-to-day life, and whether the adult would benefit from the provision of anything under section 2 or 4 of the Care Act (preventative services or information and advice services) ,or anything that may be available in the community, including signposting, as appropriate, to Access to Work for interview support, and to other appropriate benefits and agencies that can help people with autism to find and keep a job.
- Ensure that employment is promoted as a positive outcome for the majority of children and young people with autism who have EHC plans and that routes to employment are fully explored during the reviews of those plans from Year 9 (age 13-14) onwards and included in plans where appropriate. Information on preparing for and finding employment must be included in the local authority's Local Offer under the Children and Families Act 2014.

**It would be good practice for local authorities to work with local partners:**

- To include the employment support needs of the local population of adults with autism, including those who are not eligible for care and support, in local autism plans as part of supporting their health and wellbeing, and commission relevant services;
- To consult people with autism and their representatives, whether or not they are eligible for care and support, about barriers to employment and examples of local good practice;
- To have representatives from Jobcentre Plus and local employers join the local Autism Partnership Board and encourage them to attend and play a meaningful role in setting a clear steer for improving services. Developing employment support services will help a local authority meet its prevention duties under the Care Act 2014;
- So that employment services provided under the duty to prevent, reduce or delay needs address the needs of those leaving children's services who are not eligible for adult care and support, regardless of whether they had an EHC plan;
- So that young people understand what employment is (e.g. how it will impact on their daily routine and their expectations), even if this is just basic awareness given at transition stage;
- So that the work of the local authority itself in relation to promoting employment effectively addresses the issues and needs of people with autism. Local authorities could lead by example and consider where their employment practices could be adjusted and promoted for adults with autism; and
- To play an active part in developing and promoting local autism Apprenticeship schemes by proactively engaging employers and recruiting potential apprentices with autism.

**NHS bodies and NHS Foundation Trusts should:**

- Seek to ensure that occupational health providers from which they commission services have sufficient understanding and knowledge (of which Section 1 of this guidance relates) of the needs of people with autism in relation to accessing occupational health matters related to gaining and maintaining employment.

## Additional information on good practice supporting employment effectively

### Supporting people with hidden impairments

8.5. The Hidden Impairment Toolkit offers hints and tips on how employers can better support people with associated hidden impairments such as:

- Autistic Spectrum conditions including Asperger Syndrome;
- Attention Deficit Hyperactivity Disorder;
- Dyslexia;
- Dyspraxia;
- Dyscalculia;
- speech and language impairments.

### Work and supporting disabled people

8.6. The following website will be helpful to sign-post people to and may be of help to staff to be aware of <https://www.gov.uk/browse/disabilities/work>

### Employing disabled people and people with health conditions

8.7. This guidance provides links to websites to help employers become more confident when attracting, recruiting and retaining disabled people. This guidance also provides further resources.

<https://www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions>

### Advice on helping young disabled people make the transition to work

8.8. This guidance provides links to websites that help young disabled people find and stay in work. It is aimed at young disabled people, their parents and the professionals who work with them.

<https://www.gov.uk/government/publications/help-and-support-for-young-disabled-people-to-find-and-stay-in-work/help-and-support-for-young-disabled-people-to-find-and-stay-in-work>.

### The National Autistic Society

8.9. The National Autistic Society website has a range of employment information.

<http://www.autism.org.uk/working-with/employment-services.aspx>



## 9. Working with the criminal justice system

9.1. People with autism need access to support whether they are a victim, or witness, or are suspected of committing a crime. Local authorities, NHS bodies and Foundation Trusts can play a key role in supporting adults with autism who come into contact with the criminal justice system.

9.2. When people with autism come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. In some cases, it can positively change the way that police or courts view a situation. Police, probation services, courts and prisons should be supported so that they are aware of the communication challenges experienced by people with autism. NHS bodies, Foundation Trusts and local authorities should work with the criminal justice system to achieve this.

### The role of Local Authorities

9.3. Wherever possible, local authority based Community Safety Partnerships (CSPs) should be used as a vehicle for bringing agencies together to develop plans to support the Autism Strategy. CSPs are an important feature of the network of partnerships that help to tackle crime, and usually work at district or unitary authority level. Five 'responsible authorities' have statutory membership. These are the local authority; police; probation; CCGs; and the fire and rescue authority.

9.4. The responsible authorities are under a statutory duty<sup>61</sup> to work together to:

- reduce reoffending;
- tackle crime and disorder;
- tackle anti-social behaviour;
- tackle alcohol and substance misuse; and
- tackle any other behaviour which has a negative effect on the local environment.

9.5. In addition, CSPs are free to work with any other local partners they want to. Many include representatives from the business, or the voluntary, community and social-enterprise sectors.

### The role of NHS bodies and NHS Foundation Trusts

9.6. There is a need for the criminal justice system to refer people with autism for appropriate health and care support to divert them from offending, where appropriate, and prevent re-offending.

9.7. The new liaison and diversion standard service specification requires providers to identify a validated screening tool for autism acceptable to NHS England Area Team Health & Justice Commissioners. Information gained from assessments will (with the informed consent of the individual) be shared with relevant key decision makers within youth and criminal justice agencies (as appropriate), to enable them to make more informed decisions concerning the individual.

<sup>61</sup> Section 108, Policing and Crime Act 2009 – <http://www.legislation.gov.uk/ukpga/2009/26/section/108>

9.8. This information will also assist criminal justice agencies to consider whether reasonable adjustments are required to enable individuals to effectively engage in the youth and criminal justice systems. The ability of some people with autism to make decisions and predict consequences may need to be considered when looking at informed consent.

9.9. Liaison and Diversion is an assessment and referral service. Referrals will be made to appropriate support and treatment services within the community, across a range of commissioners, depending upon the types of need identified. Some people with autism who access Liaison and Diversion services will not be eligible to have their care and support needs met by the local authority. However, these individuals may benefit from preventative, or information and advice, services that local authorities have in place.

9.10. Information about the person with autism should go with them throughout the justice process, so that if they end up in prison or under probation supervision, the prison or probation provider should be made aware of that person's needs.

9.11. In addition, victims of crime with autism, as well as those accused of offences, need to be considered in the context of the criminal justice system. The duty on local authorities, under the Care Act, to carry out an assessment of an adult's needs for care and support where it appears to them that an adult may have such needs, may, for example, be triggered by their awareness of an adult having been the victim of a crime.

### Access to support in prison or other forms of detention

9.12. Local authorities have responsibilities, under the Care Act from April 2015, to assess the care and support needs of adults (including those with autism) who may have such needs in prison or other forms of detention in their areas (and to meet those needs which are eligible). NHS England is responsible for arranging the provision of health services for such prisoners and detainees. For people with autism this will include offering access to the local diagnosis pathway and access to assessment of care and support needs in advance of release from prison.

#### Local Authorities must:

- Under the Care Act, from April 2015, assess the care and support needs of adults (including those with autism) who may have such needs in prisons or other forms of detention in their local area, and meet those needs which are eligible;
- Work with prisons and other local authorities to ensure that individuals in custody with care and support needs have continuity of care when moving to another custodial setting or where they are being released from prison and back into the community.

#### It would be good practice for local authorities, in partnership with NHS bodies and NHS Foundation Trusts:

- As the Liaison and Diversion approach is rolled out, to connect with the local authority autism lead, relevant community care assessment team(s), and local preventative services with local Liaison and Diversion services.

**NHS bodies and NHS Foundation Trusts should:**

- Ensure that Liaison and Diversion services have in place a clear process to communicate the needs of an offender with autism to the relevant prison or probation provider;
- Ensure that in commissioning health services for persons in prison and other forms of detention
  - prisoners are able to access autism diagnosis in a timely way and;
  - healthcare, including mental health support, that takes account of the needs of people with autism.

**Local Authorities, NHS bodies and NHS Foundation Trusts should:**

- Seek to engage with local police forces, criminal justice agencies and prisons to the training on autism that is available in the local area;
- Consider undertaking some joint training with police forces and criminal justice services working with people with autism.

## Additional information on good practice to deliver effective criminal justice services

9.13. The website of the Autism and the CJS public engagement project funded by the British Psychological Society can be found at (<http://www.autismandcjs.org.uk/>). It is still in the development process, and has links and lay summary literature aimed at CJS professionals.

9.14. The guidance for CJS professionals on autism (published by the National Autistic Society (NAS) and endorsed by the Association of Chief Police Officers) is available to download at <http://www.autism.org.uk/%20working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx>

9.15. There is also a lot of information on the NAS website on autism and the CJS <http://www.autism.org.uk/working-with/criminal-justice/criminal-justice-system-and-asds.aspx>

9.16. The Care not Custody briefing paper: <http://www.prisonreformtrust.org.uk/Portals/0/Documents/care%20not%20custody%20coalitionlo.pdf> is useful resource.

9.17. This paper outlines how the government is ensuring that people with mental health problems, learning disabilities and other support needs caught up in the criminal justice system are identified and diverted into appropriate healthcare and support services.

# Appendix A: Key changes to relevant legislation and health and social care reforms since 2010

1. Since the 2010 statutory guidance there have been many changes in health and social care. Local NHS commissioning is now led by CCGs, supported nationally by NHS England. Local authorities have taken on important public health responsibilities for their local communities. The Care Act will make transformations to local care and support. There is a much stronger focus on personalised care and choice throughout health and social care with the individual more in control of their own lives. At a local level the NHS and local government now come together through Health and Wellbeing Boards to understand local health and care needs and discuss together the priorities for their local communities. For young people, there are new provisions in the Children and Families Act for special educational needs and disability support.

## Health and Social Care Act 2012 and what it means for adult autism

### Clinical Commissioning Groups

2. CCGs were created following amendments to the NHS legislation introduced by the Health and Social Care Act in 2012 and have become a vital part of the health service in England. When the NHS was restructured, CCGs took over certain functions from the primary care trusts, which were abolished under the new

system. CCGs' functions involve, in particular, the commissioning of most NHS hospital health care, NHS community health care, NHS ambulance services, and NHS mental health services. Between them, CCGs and the newly formed NHS England commission NHS services. Sometimes CCGs share responsibilities for commissioning health services with local authorities.

### NHS England

3. NHS England is the operating name of the NHS Commissioning Board, established in April 2013 as a statutory body corporate by section 1H of the National Health Service Act 2006, as amended by the Health and Social Care Act 2012. Before that, a predecessor special health authority, the NHS Commissioning Board Authority, established in October 2011, carried out certain functions in anticipation of the 2012 Act, subject to Parliament's passing that Act. NHS England oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England as set out in the Health and Social Care Act 2012, and co-commissioning with CCGs, and commissions certain services itself, such as prescribed specialised services and prison health services.

## Health and Wellbeing Boards

4. Health and Wellbeing Boards were required to be established in every upper tier and unitary Local Authority in England by the Health and Social Care Act (2012) and the requirement applied from 1 April 2013. They were introduced to provide a forum for local Government, NHS commissioners and providers, Healthwatch, local communities and wider partners, to share leadership for the local health and wellbeing system. Their main purpose is to improve the strategic co-ordination of commissioning services across the NHS, social care, public health and children's service and drive improvement in the health and wellbeing of local populations and reduce health inequalities, including for people with autism, through the JSNAs; and a strategy to address these in Joint Health and Wellbeing Strategies (JHWSs). Section 116A of the Local Government and Public Involvement in Health Act 2007 requires the Local Authority and partner CCG to prepare a "joint health and wellbeing strategy" where there is a JSNA.

## Joint Strategic Needs Assessments

5. The Health and Social Care Act established that JSNA functions are to be exercised by Health and Well-being Boards. Under section 194 of the 2012 Act, a Local Authority must establish a Health and Wellbeing Board, a committee of the local authorities, which should consist of a councillor, various officers for the local authority and representatives of other stakeholders. Section 116 of the Local Government and Public Involvement in Health Act 2007 as amended by the 2012 Act, provides that it is for the responsible local authority and each of its partner CCGs to

prepare any joint strategic needs assessment in relation to the authority's area. By section 196 of the 2012 Act, the functions of a local authorities and its partner CCG under section 116 are to be exercised by the Health and Wellbeing Board as established by local authorities.

## The Care Act 2014 and what it means for adult autism

6. The Care Act 2014 represents the most comprehensive reform of social care legislation in over 60 years, creating for the first time a single, modern statute for adult care and support. The Act puts in place requirements for local authorities to meet a person's eligible care and support needs, and to help and protect people with care and support needs, who may be at risk of abuse or neglect as a result of those needs. The provisions will take effect from April 2015. The areas of the Care Act which will be most relevant to local authorities' approach to autism are prevention, integration and co-operation (in terms of health and social care provision), information and advice, duty and powers to meet needs, safeguarding adults at risk of abuse or neglect, transition for children, and advocacy.

7. The Care Act is built around people, it:

- Creates a 'well-being principle' to underpin the care and support system. This means that people's well-being, and the outcomes which matter to them, will be at the heart of every decision that is made;
- Is a historic step for carers, putting their rights on the same footing as the people they care for, for the first time;
- Creates freedom and flexibility to encourage innovation and integration, to ensure that services are based around

people's outcomes, not structures and systems;

- Provides new focus on preventing and delaying needs for care and support, rather than only intervening at crisis point. This means services for the broader community, not just those with assessed care and support needs;
- Puts personal budgets on a legislative footing for the first time, which will be central to people planning their own care and support, and exercising control over how it is provided. This will include choice over how money available to meet their care and support needs will be managed (e.g. by direct payments);
- Will require local authorities to provide people with information and advice about the care and support system, and to promote the diversity and quality of the local care market, shaping care and support around what people want;
- Puts adult safeguarding on a statutory footing for the first time;
- Introduces a duty on local authorities to provide certain people with independent advocacy to enable them to participate actively in the assessment, care planning, review and safeguarding processes.

## The Children and Families Act 2014 and what it means for adult autism

8. Part 3 of the Act (Children and Young People in England with Special Educational Needs or Disabilities) commenced on 1 September 2014. There are opportunities for improved transition which are being brought about by the Act and should be made to work for children and young people with autism.

9. The Act requires local authorities when carrying out their special educational needs and disability functions have regard to the views wishes and feelings of children, parents and young people (i.e. those over compulsory school age but below 25), including young people with autism. The Act also gives new rights to young people, including young people with autism, for example, to make SEN appeals or disability discrimination claims to the First-tier Tribunal (SEN and Disability).

10. The Act provides for greater co-ordination between, in particular, local authorities and health bodies when making provision for children and young people with special educational needs or disabilities by:

- promoting integration of educational and training provision with health and social care provision where this will promote the well-being of these children and young people;
- requiring joint commissioning between local authorities and health commissioners of provision; and
- requiring co-operation between local authorities and its partners including health bodies.

11. The Children and Families Act requires local authorities to publish details of the education, health, care and training provision available for disabled children and young people and those with SEN from their areas. The Act sets out that parents, children and young people must be consulted about the preparation and review of this Local Offer. Under the associated Regulations when preparing and reviewing the "local offer" the local authority must also consult the NHS Commissioning Board, any relevant CCGs, NHS Trust or NHS foundation Trust, local Health Board and Health and Wellbeing

Board i.e. they must consult relevant NHS bodies.

12. Local authorities have duties to, where necessary, to carry out Education, Health and Care (EHC) assessments of children and young people and draw up Education, Health and Care plans setting out the provision for those children and young people. Local authorities have a duty to arrange the special educational provision set out in the plan and the responsible health commissioning body to arrange the health provision.

13. For children and young people with SEN but without EHC plans the new Special Educational Needs and Disability Code of Practice: 0–25 years gives improved guidance on identification of needs. The Code gives advice on four broad areas of need – communication and interaction; cognition and learning; social, emotional and mental health difficulties; and sensory and/or physical needs. The Code makes clear that a child or young person with an autistic spectrum disorder could have needs across all these four areas and that a detailed assessment should ensure that the full range of a child's needs are identified. The Code sets out a graduated approach to meeting children's difficulties beginning with the provision of high-quality teaching targeted at a child's area of weakness. If this is unsuccessful then there should be a process of SEN support where needs are assessed, interventions planned, implemented and reviewed with successive rounds of this process if necessary.

14. The Act and the Code make clear that there needs to be planning to achieve long-term outcomes for all children and young people with SEN, including employment outcomes. The Code includes a new chapter on Preparing for Adulthood which encourages professionals to aim high for children and young people with SEND and reminds schools and colleges of

their duties and responsibilities to provide careers advice to children and young people and advises them that they should raise the career aspirations of their students with SEN and broaden their employment horizons. The Code includes guidance on effective pathways to employment for these young people including apprenticeships, traineeships and supported internships.

## Appendix B: *Think Autism*: an update to the strategy for adults with autism in England

1. On 2nd April 2014, in line with duties under the Autism Act 2009, and following the 2013 review led by the Department of Health into progress on the 2010 Adult Autism Strategy *Fulfilling and Rewarding Lives*, the Government published *Think Autism*, an update to the 2010 strategy.

The update was published for three reasons:

- (i) To reflect what people told us during the Review of the 2010 strategy that was undertaken in 2013/14 in line with requirements under the Autism Act;
- (ii) To reflect progress that has been made since 2010 and commitments that have been delivered;
- (iii) To take account of changes in public services and new organisations.

2. *Think Autism* sets out fifteen priority challenges for action (see below) by people with autism, carers, professionals and others who work with people with autism. It also has a more focus on building communities that are more aware of and accessible to the needs of people with autism, on promoting innovative local ideas, services or projects that can help people in their communities and on how advice and information on services can be joined up better for people.

### An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.

- 2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
- 3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support.
- 4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
- 5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
- 6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

### The right support at the right time during my lifetime

- 7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
- 8. I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, is available for people with autism.



9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

### **Developing my skills and independence and working to the best of my ability**

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.



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