

Draft revised statutory guidance to implement the strategy for adults with autism in England

Consultation on new statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy for England

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Ministerial foreword



It has been four years since we published the Adult Autism Strategy Fulfilling and Rewarding Lives and the statutory guidance that supported it in

2010.¹ On 2nd April 2014, the Government published *Think Autism*,² which refreshed that strategy and set out a clear programme to improve the lives of people with autism, supporting local authorities, the NHS, other public services and their partners in local implementation.

A lot of good progress has been made since 2010. In line with the strategy, local authorities have appointed local leads to plan services for people with autism; people with autism have been increasingly involved in planning and designing services. We now have clear national guidelines on the care, management and diagnosis of autism.

Autism should not however be seen as an add-on to services or work programmes. With over 500,000 people on the autism spectrum in England, services will already be in contact with many people with autism. To deliver better outcomes all services need to engage more effectively with people with autism, continue to improve reasonable adjustments or adaptations and, most importantly, involve people in the design and

delivery of services by using and building their capabilities.

Local authorities and the NHS need to work in collaboration with local partners to take forward the key priorities in *Think Autism*. Local services need to work together in partnership so everybody has a shared understanding about how to deliver the support that people need.

Wider legislative changes will also enable local services to support people with autism and their families better. The Children and Families Act³ will help to support young people in preparing for adulthood. The Care Act⁴ places a strong emphasis on preventing and delaying needs for care and support, making sure that there's appropriate information and advice for people, support for carers, and promoting integration between social care and health care services.

Through services making reasonable adjustments, individuals can go to their local GP or hospital feeling confident that they are aware of their autism – and knowing what this means for communication or other aspects of their appointment. They need to be able to access their local communities and feel safe doing so. 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. Commissioning decisions need to be based on knowledge and awareness of autism, and informed by people with autism and their families.

This revised draft statutory guidance sets a clear direction for how health and social care can continue to implement the autism strategy and to further improve mainstream services to accelerate progress towards our vision of fulfilled and rewarding lives for people with autism.

I invite you to take part in the consultation around this draft guidance.

Norman Lamb

Minister for Care and Support

[&]quot;Fulfilling and rewarding lives" The strategy for adults with autism in England (2010) http://webarchive.nationalarchives.gov. uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf

² 'Think Autism': an update to the government adult autism strategy (2014) https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

Children and Families Act 2014 http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted

Care Act 2014 http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

About this consultation

This draft guidance is for Local Authorities (LAs), Foundation Trusts (FTs) and NHS bodies to support the implementation of the Adult Autism Strategy 2010 as updated by *Think Autism* (2014). It is currently provided as a draft for consultation, and will not be finalised until after the consultation, which is due to be completed in December this year.

The guidance focuses on the areas required by section 2 of the Autism Act 2009,⁵ in each case identifying what LAs, FTs and NHS bodies are already expected to do, and then setting out any additional elements introduced by *Think Autism* and key changes to key legislation and health and social care reforms since 2010.

The additional elements are focused on achieving the following outcomes:

- improving the way health and social care services identify the needs of adults with autism; and
- ensuring identified needs are met more effectively to improve the health and wellbeing of adults with autism.

These are both important steps towards 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".

We are, in particular, seeking views from:

- adults with autism, their families and carers;
- health and social care bodies responsible for the planning, commissioning and provision of services for adults with autism and their families and carers;
- representative local and national organisations;
- health and social care professionals; and
- any other party with an interest in improving the health and social care provided to adults with autism and to their families and carers.

Terminology

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.

⁵ Autism Act 2009 http://www.legislation.gov.uk/ukpga/2009/15/contents

What we want you to do

Local Authorities and Health bodies, including Foundation Trusts were mentioned are asked to consider the draft guidance and questions in each section.

To help navigate through the sections 3 different shared coloured boxes have been used to guide you.



For each section of the draft guidance we would like you to consider the questions being asked.

These questions will be set out in the accompanying answer booklet. Please fill in your answers in the booklet either online or in writing.

Full details of the consultation process are set out on page 49.

Status of this guidance

This guidance replaces the 2010 Statutory Guidance.

This statutory guidance is issued under section 2 of the Autism Act 2009 and is intended to provide local authorities with information, about the exercise of their social service functions, and "NHS bodies" (as defined under section 4 of the Autism Act 2009) and NHS Foundation Trusts ("FTs") about the exercise of their health functions, with the information they need for the purpose of securing implementation of the autism strategy. Local authorities, FTs and NHS bodies are required to act under the guidance, which means that they should follow it, unless they can demonstrate good reasons for not doing so.

The guidance is required by law, it is known as "statutory" guidance. It is to be treated as if it were guidance issued under section 7 of the Local Authority Social Services Act 1970⁶ (LASS Act) which means that local authorities and NHS bodies should follow this guidance or provide a good reason why they are not doing so. If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or default action by the Secretary of State.

Section 2(1) of the Autism Act 2009 requires that:

"For the purpose of securing the implementation of the autism strategy, the Secretary of State must issue guidance:

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

- (a) to local authorities about the exercise of their social services functions within the meaning of the Local Authority Social Services Act 1970 (c. 42) (see section 1A of that Act), and;
- (b) to NHS bodies and NHS foundation trusts about the exercise of their functions concerned with the provision of relevant services."

Though the LASS Act does not directly apply to NHS bodies, section 3(2) of the Autism Act 2009 makes it clear that 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 are to be treated as if they were social services functions within the meaning of that Act. These provisions do not apply to NHS Foundation Trusts but Foundation Trusts are expected to take the guidance into account, for example with commissioning diagnostic services.

What has changed since 2010?

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

We have also, following our 2013 review of the 2010 Autism Strategy, refreshed it with *Think Autism* published in April this year. This set out an updated programme of action to deliver the aims of the Autism Act 2009 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. In addition, we continue to expect every local area to remain committed to the 2010 Autism Strategy key themes as set out in **Appendix A**.

Understanding this guidance

Where the guidance says local authorities/health bodies "must" it refers to legal duties linked directly to parts of the Autism Act 2009 which must be complied with or other Acts of Parliament e.g. the Care Act 2014, and the Children and Families Act 2014.

Where the guidance says local authorities/health bodies "should" it refers to statements of policy or information on how Local Authorities, Social Service Directors and NHS bodies should seek to implement the Autism Act. Local Authorities, Social Service Directors and NHS bodies may depart from this but would be expected to offer a reasoned explanation for doing so. These statements are intended to reflect current practice in many localities since the Autism Act and the first published Adult Autism statutory guidance (December 2010) or where there is an evidence base, for example, from the Autism self-evaluation exercise⁷, or available qualitative research and information gathered during review and refresh of Autism strategy in 2013/148.

- The Autism Self-Assessment Exercise 2013
 http://www.improvinghealthandlives.org.uk/projects/autism2013
- A report on the listening phase of the review of the 2010 Adult Autism Strategy to assist in developing recommendations for the re-fresh of the strategy Autism Programme Board 3rd February 2014 meeting paper APB(14)27 https://www.gov.uk/government/groups/aapb

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

We intend to continue to support Health and Wellbeing Boards through the local area Autism self-evaluation exercise on an annual basis and to make public the responses. The self-evaluation exercise will help demonstrate progress being made in implementing the Adult Autism Strategy, and highlight examples of good practice area around the country.

There have been two self-assessment exercises undertaken by local authorities and their partners. A baseline assessment was carried out in 2011, with a follow up assessment completed in 2013.

A further self-assessment exercise will take place later this year (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 and identify areas where progress is still to be made and allow areas to compare performance with peers and neighbours.

Who must have regard to this guidance?

This draft guidance is for Local Authorities about the exercise of their social services functions, and NHS Foundation Trusts, NHS trusts all or most of whose hospitals establishments and facilities are in England, the NHS Commissioning Board (NHS England), CCGs and Special Health Authorities performing functions only or mainly in respect of England about the exercise of their health functions, for the purpose of securing implementation of the autism strategy.

The above organisations and bodies are asked to ensure that this guidance is also followed by other organisations that deliver services under contract for them, such as those contracted to provide residential or day care on behalf of a local authority etc.

Other providers of public services, those providing other public services such as employment services, police, probation and the criminal justice system are not legally required to have regard to this guidance. However, by following the guidance, those bodies could help improve the delivery of the services they provide: 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 bodies' resources.

The guidance may also be of interest to readers in Scotland, Wales and Northern Ireland (who have their own legislation and strategies).

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

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 roles and for those who wish to develop their knowledge of autism.

Where 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 the updated statutory guidance.

The Care and Support (Assessment) Regulations 2014 require those undertaking an assessment of care and support needs to have suitable skills knowledge and competence in the assessment they are undertaking, and where the assessor does not have experience in the condition, the local authority must consult someone with the relevant experience.

In line with the 2010 statutory guidance local authorities should by now 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 access to services for adults with autism, including those conducting community care assessments. This expectation remains central to the updated statutory guidance.

To implement the Autism Act Local authorities and NHS bodies should look to:

- Make autism awareness training available to all staff working in health and social care. In line with the principles set out in *Fulfilling and Rewarding Lives*, as a minimum, autism awareness training should be included within general equality and diversity training programmes;
- Ensure, as the core aims of autism awareness training, that staff are able 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 NICE guidelines for those staff who are most likely to have contact with adults with autism;
- Ensure those in key posts that have a direct impact or decision making role in relation to access to services for adults with autism such as GPs, Psychiatrists, Approved Mental Health Professionals or community care assessors and those whose career pathways are highly likely to include working with adults with autism, such as personal assistants, occupational therapists or residential care workers, have adequate training specifically in autism. The end goal of this should be that, within each area, there are key staff available who have clear expertise and specific knowledge in autism that goes beyond just having general autism awareness and making reasonable adjustments;
- Maintain adequate levels of staff who are suitably trained, to ensure continuity of service;
- 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;
- 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;
- Have a multi-agency autism training plan specific training for staff that carry out statutory assessments on adults with autism, including social workers working with children, on how to make adjustments to their approach and communication;
- Clinical Commissioning Groups (CCGs) and Foundation Trusts to be involved in the development of local workforce planning, and GPs and primary care practitioners should be engaged in the training agenda in relation to autism.

Additional information on good practice in delivering training effectively

- As the 2010 strategy made clear, initial autism awareness training can be delivered as part of existing equality and diversity training or similar programmes. Local areas 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
- Skills for Care with 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 http://www.skillsforcare.org.uk/Skills/Autism/Autism.aspx

It should also be borne in mind that:

 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.
- 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 or, NHS body develops its own specialist training programme, but rather that applications for specialist training are considered within the training budget.

Questions for consultation

We would like your views about the proposed guidance around training for NHS and local authority staff. Please write your answers in the answer booklet.

- 1.1 Do you think that this guidance explains the responsibilities that local authorities and NHS bodies have around training for their staff, and that it is sufficiently clear about what they should be doing?
- 1.2 Is the guidance on these responsibilities reasonable?
- 1.3 Do we need to highlight further the role that adults with autism and their families or carers should be playing in training programmes? If so, how?
- 1.4 What else do we need to include to ensure specific specialist autism training is provided to staff who carry out statutory assessments?
- 1.5 Would a description in the guidance setting out outcomes to be met at a particular level of autism training be helpful?
- 1.6 Is there sufficient information on how bodies should commission training?
- 1.7 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 1.8 Have you any other comments on this section?

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

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. 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.

We have taken a number of steps since 2010 to support local areas to develop a clear

pathway to diagnosis and post-diagnosis. In every local area, health services are now expected to have a pathway to diagnosis, just as the local authority will have a clear framework for assessing the care and support needs of adults with autism. We will continue to ask local areas to assess their progress on developing and maintaining a pathway to diagnosis through the local area self-evaluation exercise.

It is not expected that a specialist diagnostic team or service will be located in all areas. However, each area should have an easily accessible, local autism diagnostic service and key professionals such as GPs and mental health practitioners should be aware of the pathway and of how to refer.

Local authorities should seek to:

- Work with CCGs to ensure there is a lead health professional to develop diagnostic and assessment services for adults with autism in their area;
- Conduct assessments of needs jointly with another person/body if that person/body is carrying out an assessment or about to do so;
- Ensure the prompt sharing of information between diagnostic services and adult 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 must:

Under section 47(1) of the National Health Service and Community Care Act 1990,⁹ Local Authorities must assess a person who may be in need of community care services. This assessment may be triggered either by the individual requesting it or if the local authority believes community care services may be necessary. Assessment of eligibility for care services cannot be denied on the gro2unds 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.

It is vital that local authorities fulfil their duties under the 1990 Act by ensuring that adults diagnosed with autism who may have community care needs are offered an assessment. This is not a new requirement.

Section 9 of the 2014 Care Act will replace the duty in s.47(1) from April 2015. The Care Act requires local authorities to conduct a needs assessment where it appears to the authority that the adult may have need for care and support.

Responsible health bodies should seek to:

- Designate a health lead responsible for developing and maintaining a diagnostic pathway;
- Establish and maintain autism diagnostic pathways, working with partners in local authorities:
- Ensure that GPs, as the gatekeepers to diagnostic services, have adequate training specifically in autism beyond general awareness training 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;
- Follow 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].¹⁰

National Health Service and Community Care Act 1990 http://www.legislation.gov.uk/ukpga/1990/19/section/46

Jointly, Local Authorities and health bodies should seek to:

Ensure that both clinical diagnostic services and pathways to further assessment
of need and support services are in line with best practice including the National
Institute for Health and Care Excellence (NICE) guidance and NICE Quality Standard
on autism. This should include ensuring the provision of an autism diagnostic
pathway for adults 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.

Additional information on good practice in delivering diagnosis effectively

NICE guidelines

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

NICE has also produced:

- An Implementation Pack:¹¹ developing a multi-agency local autism team, to support local areas;
- A series of costing tools;¹²
- Support for Commissioning,¹³
 which outlines the key actions that
 commissioners should take to deliver the
 quality improvement outlined in the NICE
 quality standard; and
- 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
- 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
- QS51 Autism: support for commissioning https://www.nice.org.uk/guidance/qs51/resources/qs51-autism-support-for-commissioning

- A Quality Standards on Autism,14 describing the high-priority areas for quality improvement in the defined care area of autism support. Each standard consists of a prioritised set of specific, concise underpinning, comprehensive set of recommendations, designed to support the measurement of improvement. 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 coexisting 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.
- NHS England local audit teams should look at people's experiences of the autism diagnostic process locally and assure themselves that this is acceptable.

Autism NICE quality standards [QS51] http://www.nice.org.uk/quidance/gs51

Guidance for Commissioners of Diagnostic Services for Adults with Autism

The Joint Commissioning Panel for Mental Health (JCP-MH) will publish soon a guide to support Clinical Commissioning Groups 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.

While local authorities will lead commissioning for a considerable proportion of services and support 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).

Questions for consultation

We would like your views about the proposed guidance around assessment and diagnosis needs. Please write your answers in the answer booklet.

- 2.1 Do you think this guidance explains the responsibilities that local authorities and NHS bodies have around assessment and diagnosis of autism for NHS and local authority staff and is sufficiently clear about what they should be doing?
- 2.2 If you are a commissioner of local care services, are you clear about what your responsibilities are? Are they reasonable?
- 2.3 If you are a CCG or other health body, are you clear about what your responsibilities are? Are they reasonable?
- 2.4 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 2.5 Have you any other comments on this section?

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

Transition to adulthood is a crucial period for young people with autism. Good transition support for 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. Local authority Adult Services cannot do this in isolation, as children's services in health and social care need to play their part.

From the 1st September 2014, local authorities have been required to develop a 'local offer'. This will give information on provision for children and young people with special educational needs (SEN) or disabilities both in and outside the local area. Local authorities must consult children and young people with SEN or disabilities, their parents/ carers, schools and service providers in developing the 'local offer'.

The local offer should:

- Be clear, comprehensive, accessible and transparent;
- Engage local interested parties in its development and review.

For young people, there are also radical new provisions in the Children and Families Act 2014 for special educational needs and disability support, and on the health and social care support young people with special educational needs and disabilities receive.

Under the provisions of the Act, young people (those who are over compulsory school age up to the age of 25) can request an

assessment of their Education, Health and Care (EHC) needs with a view to an EHC plan being drawn up for them and for the special educational, care and health provision set out in the plan to be made for them. They can further expect to be able, when an EHC plan is being drawn up, to request which school or further education (FE) college they want to go to and to go to that school or college, unless some limited conditions apply. These are that the school or college must be suitable to the child or young person's age, ability, aptitude or SEN and that attendance at the school or college would not be incompatible with the efficient education of others and the efficient use of resources. They will be given the opportunity of a personal budget to control some of the provision set out in an EHC plan.

Young people with autism, whether they have EHC plans or not, can expect to be helped with their transition from school or college to adulthood. Local authorities can meet their statutory duties around transition assessment through an annual review of a young person's EHC plan that includes the above elements. Indeed, EHC plans must include provision to assist in preparing for adulthood from Year 9 (age 13 to 14).

Local authorities must:

Under the Children and Families Act 2014, generally for children and young people with SEN and disabilities, including those with autistic spectrum conditions:

- Take account of the views, wishes and feelings of children, young people and parents when carrying out their SEN and disability functions;
- Jointly commission, with health commissioning bodies, provision for disabled children and young people and those with SEN;
- Keep the educational and care provision for these children and young people under review;
- 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;
- Make their local offer widely available and accessible, and it must be on a website;
- Publish arrangements for those without access to the internet about how they can get the information;
- Make sure that it is accessible for different groups, including disabled people and those with different types of SEN Under the Children and Families Act 2014, for individual children and young people with SEN;
- Where necessary, carry out Education, Health and Care assessments and draw up EHC plans;
- Review EHC plans, and from at least year 9, the annual review must include a consideration of the preparation for adulthood, including employment, independent living and participation in society: transition planning must be built into the plan;
- Focus on progress towards the achievement of outcomes in the plan, and for those over 18 assess whether the educational or training outcomes have been achieved;
- Make sure that the services they provide co-operate to help the young person achieve a successful transition;
- Co-operate with health services to ensure that young people's EHC plans and health care plans are aligned;
- Co-operate with CCGs in supporting the transition to adult services;
- Provide information and advice about how those needs may be met where a young person is not eligible for adult services and about the provision and support that young people can access in their local area. Local authorities should ensure this information is incorporated into their local offer;
- Under the Care Act 2014, local authorities must carry out an adult care transition assessment where the young person is likely to need care after turning 18, and, if they do, assess what those needs are likely to be and which are likely to be eligible needs.

They must also continue to provide children's services until a conclusion is reached about the young person's situation as an adult and put in place a statutory care and support plan for young people with eligible needs for adult care and support.

Local authorities should seek to:

- Include 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;
- Work with schools and 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 wellinformed choices.

Health bodies must, under the Children and Families Act 2014:

- Have regard to the Special and Education Needs and Disability Code of Practice: 0 to 25 years;15
- Co-operate with local authorities, for example, when Education, Health and Care assessments are being carried out or when transition to adulthood is being discussed for children with EHC plans;
- Jointly commission services for disabled children and young people and those with SEN:
- Arrange the health provision set out in an EHC plan;
- Where necessary, co-operate with the local authority when local authorities carry out the special educational provision set out in the Education, Health and Care plans.

Questions for consultation

We would like your views about the proposed guidance around transitions. Please write your answers in the answer booklet.

- Do you think that this guidance appropriately summarises the responsibilities from the Children and Families Act that local authorities and their partners have around transition from child to adult services for young people with autism?
- 3.2 In terms of young people with autism approaching transition without SEN statements or Education Health and Care Plans, is there anything further we should be highlighting in the guidance to ensure they receive appropriate support?
- 3.3 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 3.4 Have you any other comments on this section?

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

Think Autism sets out a number of recommendations and expectations about the planning of services for adults with autism. It highlights that local areas should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. In doing so, local authorities, Foundation Trusts and NHS bodies should develop local commissioning plans for services for adults with autism, and review them annually.

In addition, local commissioning plans should set out how local authorities will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of health and social care. The strategy sets out that "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 have greater choice and control over where and how they live locally and sets a clear direction for improved services", which fundamentally promotes the independence and opportunities of people with autism to have a fulfilling life. 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.

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. 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.

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 a personalised approach with targeted support. In addition, Health and Well-being Boards should work with NHS bodies to raise awareness and enable reasonable adjustments to enable people to access their local community.

Health and Wellbeing Boards

Health and Wellbeing Boards have a crucial role to play in overseeing implementation of the Adult Autism Strategy, [albeit that the statutory obligations do not apply to them directly]. As a local health and wellbeing system leader, bringing together partners from NHS England, Clinical Commissioning Groups, 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.

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.

Health and Social care services should recognise how autism affects an individual's life including any additional needs such as a learning disability or mental health. 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 seek to:

- 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 community care services for adults with autism in the area, known as the autism lead. This person 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;
- Make sure that the local autism lead provides (at least) an annual update to the local authority and local health bodies, for example through their Health and Wellbeing Board. The Health and Wellbeing Board could also consider making their local Autism Partnership Boards a sub-group of the Health and Wellbeing Board and appointing a member of the HWB as the Autism Champion to provide clear and visible leadership;
- Allocate responsibility for appropriate high-level partnership, for example allocating signing off, and monitoring delivery of local autism strategies to the Health and Wellbeing Board.

In line with duties in sections 3, 6 and 7 of the Care Act 2014 local authorities and their partners should:

- Where appropriate, co-operate with housing officers in specific cases for adults with autism;
- Provide integration between the provision of care and support, health service, and health related services such as housing, for example, by ensuring that the local housing strategy identifies autism and planning of local housing takes into account the needs of adults with autism.

Local authorities, Foundation Trusts and health bodies should jointly seek to:

- Ensure that the numbers of people with autism in their area of responsibility are appropriately recorded and analysed (e.g. through the JSNA process), to ensure appropriate levels of commissioning and improve services;
- 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).

However, 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.

Key professionals to engage in this evidence gathering are:

- Community care professionals;
- GPs:
- Job centre managers;
- Employment support providers;
- Local autism groups and branches of national autism organisations.

Promoting the rights of people with autism

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

In line with the Care Act, local authorities should seek to:

- 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;
- Get the views of people from across the autism spectrum using a variety of methods;
- Ensure social workers assist them in carrying out a supported self-assessment if that is what they wish;
- Involve them in decision making;
- Arrange access to an independent advocate if they need them; and
- Identify the outcomes they wish to achieve for their lives in their needs assessments and carer's assessment.

Additional information on good practice in planning and commissioning effectively

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 statutory services. This may be because they are not eligible for statutory services 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, services have also not collected comprehensive data about this population. However, from April 2014, 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.

There is other action that local areas 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 (Projecting Adult Needs and Service Information),¹⁶ a database that uses national data to make projections on the possible impact of demography and certain conditions on local populations.

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. Housing can play a vital role in supporting people with autism to maintain good health, independence and improve quality of life. The Care Act places a duty on local authorities to provide and arrange services to prevent delay or reduce the needs for care and support. The Care Act will require local authorities to ensure the co-operation of their officers who exercise care and support functions with housing officers both generally and in specific cases. Further, local authorities are required to ensure integration between the provision of care and support, health services, and health related services when planning housing.

Questions for consultation

We would like your views about planning and leadership for the provision of services for adults with autism locally. Please write your answers in the answer booklet.

- 4.1 Are responsibilities for leading and joining up local partnership arrangements sufficiently clear?
- 4.2 If you have autism, or are a parent or carer of someone who has, is there anything further that organisations should do to ensure that your voice is heard in local planning?
- 4.3 Is any further advice or guidance needed on data collection and using data to plan effectively?
- 4.4 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 4.5 Have you any other comments on this section?

5. Preventative support and safeguarding in line with the Care Act

Preventative support is important for people with autism. When people with autism do not have the right preventive 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.

Furthermore, changes such as bereavement, moving home, getting married and divorced, having children or becoming unemployed can have a significant effect on someone with autism. Preventative support can help people with autism to manage such events better.

The Care Act places 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 ensure they are looking at the needs of their local autism population, including those who do not meet the eligibility threshold for care and support.

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 preventive support systems. Such support should be accessible and provide choice, for example by ensuring there are a number of support options across a geographical area.

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. Providing information and advice is a requirement under the Care Act.

Local authorities should seek to:

- Prevent, delay or reduce the care needs of adults with autism or their carers by providing "lower level" local preventative support and enabling people with autism to be connected with peers and with other local community groups in line with Care Act duties:
- 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.

Health bodies should seek to:

- Ensure that amongst those health staff who support people at these critical potential trigger points in life such as GPs, psychiatrists, counsellors and psychiatric nurses, staff are available who are trained beyond general basic awareness about autism, and counselling is adapted as appropriate;
- Ensure that people with autism are not automatically precluded from local psychological therapy services such as Improving Access to Psychological Therapies (IAPT services) and ensure people with autism have no lesser entitlement or access than other people to receive treatment for depression and/or anxiety. 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 very detrimental impact on individuals and can be very costly for services.

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 without additional learning disabilities or mental health issues can access such advice and information easily in a way that is for them. One such example could be a one-stop shop; these have successfully been implemented

in some parts of the UK and have received positive feedback from adults with autism.

It is hoped that low-level, preventative services and projects coming out of the Autism Innovation Fund will provide good-practice examples of services providing information and advocacy, travel training, and one-stop shops for people across the autism spectrum. These should be available in the latter half of 2015.

Mental health

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 access can prevent people with autism going into a crisis.

The Green Light Toolkit 2013, updates the original Green Light Toolkit published in 2004, and consists of an audit framework and guidance for making service improvements. Both reports were commissioned by the NHS Confederation, and written by the NDTi.

Both reports can be downloaded from: www.ndti.org.uk/major-projects/current/green-light-toolkit-2013/

A database of reasonable adjustments to mental health services is also available at: www.ihal.org.uk/mhra/

Although some people may have their needs more appropriately met in specialist learning disability or autism services, this should by no means be standard practice, and mental health services need to get better at meeting people's needs in the community, as problems with using services are one reason why people with autism experience health inequalities.

A Revised Mental Health Act 1983 Code of Practice is due for publication at the end of 2014.

Helping people with autism to keep safe

The Care Act makes safeguarding statutory, in recognition of the need to proactively promote the right of people, including people with autism, to keep safe. 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 equip local agencies with relevant care and support functions both to prevent abuse and to respond when it occurs.

Local authorities must:

In line with duties in the Care Act:

- Ensure all assessors are appropriately trained in an individual's disability or condition to carry out assessments;
- Play a lead role in coordinating local safeguarding activity, with responsibility for making enquiries to help stop abuse and neglect taking place;
- Carry out a safeguarding enquiry, where they have reasonable cause to suspect a
 person is experiencing or at risk of abuse or neglect; consider what if any actions are
 needed, and who should carry these out.

Local authorities should seek to:

Support people with autism and their carers to understand risk and manage risk; to speak up and complain and report problems. An example is when people with autism are transitioning from children's services and may not be eligible for social care support. It is important however, that they are linked to services such as GPs and others who can advise them as part of their transition plan.

Questions for consultation

We would like your views on preventive support for the provision of services for adults with autism. Please write your answers in the answer booklet.

- 5.1 Are the new duties on delivering preventative support at each tier of prevention under the Care Act sufficiently clear in relation to autism services, including how to promote wellbeing for a young person transitioning to adulthood?
- 5.2 Do you agree with the description of preventative services provided?
- 5.3 Is it clear how to develop preventative services according to local needs?
- 5.4 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 5.5 Have you any other comments on this section?

6. Reasonable adjustments

For many people with autism, mainstream public services can be hard to access. Some of this is due to a lack of understanding of autism among staff in those services but this is not the only factor. Many people with autism 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.

Under the Equality Act 2010,17 all public sector organisations, including employers and providers of services, are required to make reasonable adjustments to services to ensure they are accessible to disabled people, including people with autism. People with autism have a right to access mainstream services just like anyone else. This is, at its core, about equal rights.

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.

Local authorities, Foundation Trusts and health bodies must:

- As required under the Equality Act 2010 make reasonable adjustments to their services, including those provided under contract to them, to ensure they are accessible to people with autism;
- As required under the Health and Social Care Act 2012 tackle health inequalities, which CCGs/NHS England specifically have a legal duty to address, and put reasonable adjustments in place to do so;
- Tailor their services so that disabled people are not disadvantaged, as required by the Equality Act 2010;
- Avoid unlawful discrimination, as required by the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 which requires that registered providers should 'avoid unlawful discrimination including, where applicable, by providing for the making of reasonable adjustments in service provision to meet the service user's individual needs'.

Health bodies should also seek to:

 As stated in Monitor's risk assessment framework 3, 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

Reasonable adjustments can include changes to:

- premises taking account of hypersensitivities and providing quiet or lower-light areas;
- processes scheduling appointments at less busy times, allocating extra time to adults with autism and being flexible about communication methods, for example, less reliance on telephonebased services;
- face-to-face communications avoiding ambiguous questions, asking follow-up questions where further information is

- needed and being aware of sensitivity to touch, provide written information in advance of meetings;
- 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/;
- 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.

Reasonable adjustments may also include using new technology to help increase and maintain independence. This includes equipment to help people who have problems with speaking, hearing, sight, moving about, getting out and about, socialising, memory, cognition (thought processes and understanding) and daily living activities such as dressing and preparing meals. All service providers have a statutory duty to make reasonable adjustments and should think about technological enablers as part of this. Providers of specific specialist services to people with autism should be exploring the use of assistive technologies with the people they support to help develop their confidence, sense of achievement and independence.

Reasonable adjustments include making changes to communication, the environment, policies, procedures, staff training, service delivery, and providing auxiliary aids where required, and should be planned in advance. Health and social care services should not wait until someone with learning disabilities or autism walks through the door before thinking about what they should do. They should also have systems in place to check if their services are reasonably adjusted as set out in chapter 6 of the Equality Act 2010 Code of Practice. See: http://www.equalityhumanrights.com/sites/default/files/publication_pdf/servicescode.pdf

Questions for consultation

We would like your views on reasonable adjustments for the provision of services for adults with autism locally. Please write your answers in the questionnaire booklet.

- 6.1 Is the approach to reasonable adjustments for people with autism sufficiently explained?
- 6.2 Are the responsibilities of public services clear in regard to making reasonable adjustments to support people with autism?
- 6.3 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 6.4 Have you any other comments on this section?

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

Transforming Care, 18 the Government's response to the abuse of people at Winterbourne View hospital, set out to ensure that people with learning disabilities and autism and complex needs get goodquality, safe care when in hospital, and where appropriate, are helped to live with support in the community.

A third of people at Winterbourne View had autism. They experienced a very poor model of care often far from family and friends. 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.

Having complex needs does not mean people should go into assessment and treatment centres. People should live in their own homes with support to live independently if that is the right model of care for them. Evidence shows 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 therefore only be offered as a last resort, when essential and only for short-term assessment and

treatment. Commissioning community-based services that can meet the needs of people with complex needs is essential to minimising the use of secure health settings.

The Winterbourne View Concordat¹⁹ includes action for local authorities and health bodies to:

- review all current inpatient placements and support everyone found to be inappropriately placed in a hospital setting to move to community-based support; and
- put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour. This should include appropriate housing in the community.

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 community care assessors and in the NHS need to have a good understanding of the Mental Capacity Act (2005)²⁰ in order to help people with autism.

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

Winterbourne View Review: Concordat: A Programme of Action (2012) https://www. gov.uk/government/uploads/system/uploads/ attachment data/file/213217/Concordat.pdf

Mental Capacity Act 2005 http://www.legislation. gov.uk/ukpga/2005/9/contents

Local authorities and health bodies should seek to:

- Work in partnership to ensure there is a substantial reduction in reliance on inpatient care for people with autism. This requires personalised care planning, the provision of alternative community based settings and crisis intervention and support;
- Ensure that locally agreed joint plans for high-quality care and support services for people of all ages with challenging behaviour and complex needs accords with the model of good care;
- Ensure staff have a good understanding of the Mental Capacity Act and how it relates to people with autism;
- 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;
- Consider how to promote the right to family life 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;
- Only deprive people of their liberty where this is necessary and proportionate, and only with appropriate legal safeguards (Deprivation of liberty safeguards (DoLS)²¹ or detention under the Mental Health Act);
- 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;
- 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;
- Provide independent advocacy where a person with autism has substantial difficulty in being involved in their needs assessment and or preparation and review of their care and support plan and there is nobody appropriate to support them. This will require knowing in advance where such services can be commissioned.

This includes:

- a good understanding of: supported decision making;
- the principle that people should not be treated as lacking capacity simply because they make an unwise decision; and considering their wishes and feelings;
- all health and social care organisations need to understand the principle of least restrictive care – which means identifying a range of care options and a range of interventions and seeking the least restrictive ones for people with autism.

Deprivation of liberty safeguards (DoLS) https://www.gov.uk/government/publications/ deprivation-of-liberty-safeguards-supreme-courtjudgments

In addition, in April 2014 new Department of Health guidance Positive and Proactive Care: reducing the need for restrictive interventions²² was published. The aim of the guidance is:

- to provide a framework within which adult health and social care services can develop a culture where restrictive interventions are only ever used as a last resort and only then for the shortest possible time;
- to identify key actions that will better meet people's needs and enhance their quality of life, reducing the need for restrictive interventions;

to set out mechanisms to ensure accountability for making these improvements, including effective governance, transparency and monitoring.

This guidance forms a key part of the wider new 'Positive and Safe' programme, which aims to end the use of inappropriate restrictive interventions across all adult health and social care, including services for those with autism.

Questions for consultation

We would like your views on the following questions about the proposed guidance about supporting people with autism and learning disabilities whose behaviour others may find challenging. Please write your answers in the answer booklet provided.

- 7.1 Do you think that this section of the guidance is sufficiently clearly worded and will be understood by health and social care professionals, commissioners, people with autism and parents/carers?
- 7.2 If not, what changes would you propose?
- 7.3 Does it cover all relevant requirements on the Mental Capacity Act, and the Mental Health Act?
- 7.4 Is the guidance sufficiently clear about what NHS and local authority organisations and staff should be doing to improve services for people?
- 7.5 If you are a commissioner of local care services, are you clear about what your responsibilities are?
- 7.6 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 7.7 Have you any other comments on this section?

Positive and Proactive Care: reducing the need for restrictive interventions https://www.gov.uk/ government/publications/positive-and-proactivecare-reducing-restrictive-interventions

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8. Employment for adults with autism

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 well utilised in a range of different workplaces. 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 2010 strategy 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, both of which help disabled people, including people with autism, find employment and stay in work.

Local authorities can also play a key role in supporting adults with autism in their area to gain employment, linked to care planning processes, effective transition planning and provision of preventative support. They could also set the example locally by becoming an autism-friendly place to work and by actively recruiting and employing more people with autism.

Local Authorities should seek to:

- Include the employment support needs of the local population of adults with autism in local autism plans as part of supporting their health and wellbeing;
- Consult people with autism and their representatives about barriers to employment and examples of local good practice;
- Ensure that representatives from Jobcentre Plus and local employers join the local Autism Partnership Board. Developing employment support services will help a local authority meet its prevention duties under the Care Act;
- Ensure that transition plans for young people with autism include employment as a key outcome, as appropriate employment is part of the new SEN local offer requirement;
- Ensure that young people understand what employment is (e.g. how it will impact on their daily routine, their expectations), even if this is just basic awareness given at transition stage;
- Ensure that the work of the local authority itself in relation to promoting employment effectively addresses the issues and needs of people with autism;
- Play an active part in developing and promoting local autism apprenticeship schemes by proactively engaging employers and recruiting potential apprentices with autism;
- Ensure that the care planning process for adult social care needs considers employment as a key outcome, if appropriate, and looks at whether personal budgets can be used to support adults with autism to become work ready;
- Ensure that the assessment process for adult social care includes 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.

Health bodies should seek to:

• Ensure that occupational health providers have a sufficient understanding of the needs of people with autism in relation to accessing and maintaining employment.

Questions for consultation

We would like your views on helping adults with autism into work. Please write your answers in the answer booklet provided.

- 8.1 Do you think that this section of the guidance is clearly worded and will be understood by health and social care professionals, people with autism and parents/carers?
- 8.2 If not what changes would you propose?
- 8.3 Do you have any other comments on helping adults with autism into work?
- 8.4 How should local authorities ensure that social care support and planning for people with autism is working effectively with employment support, including Job centres?
- 8.5 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 8.6 Have you any other comments on this section?

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9. Working with the criminal justice system

People with autism need access to support whether they are a victim, or witness, or are suspected of committing a crime. This guidance does not apply to the criminal justice system agencies; it applies to local authorities and health bodies in their role to work with these agencies. 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, and local authorities should work with the criminal justice system to achieve this.

The role of local authorities

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.

The responsible authorities are under a statutory duty 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.

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 health bodies

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. If pilots are successful, Liaison and Diversion services, which will identify and refer people to help and support for a range of vulnerabilities, including autism, will be available in every police custody suite and criminal court in England by 2017/18.

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, to enable them to make more informed decisions about charging, case management and sentencing.

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.

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. Some people with autism who access Liaison and Diversion services will not be eligible for care and support. However, these individuals may also benefit from preventative services that local authorities have in place. In addition, information about the person with autism will 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.

Access to support in prison or other forms of detention

Local authorities and health bodies are required to meet the needs of people with autism when in prison or other forms of detention. NHS England, and usually the local NHS Trust, are responsible for meeting the health needs. 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.

Additional information on good practice to deliver effective criminal justice services

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. The website will be completed by October 2014.

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

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

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

It 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 and builds on the announcement earlier this year of an additional £25 million for the on-going development of liaison and diversion services, following an initial £50 million investment, with full rollout now scheduled for 2017.

Local authorities should seek to:

- Ensure local Liaison and Diversion services are in contact with the local authority autism lead, relevant community care assessment team(s), and local preventative services;
- Fulfil their current and new obligations under the Care Act, to assess the needs of people with autism in prisons in their local area.

Health bodies should seek to:

- 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;
- Fulfil their responsibility for offender health by ensuring that:
 - prisoners are able to access autism diagnosis in a timely way;
 - healthcare, including mental health support, takes account of the needs of people with autism;
 - funding for autism diagnostic services for prisoners is available.

Local authorities and health bodies should seek to:

- Alert 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.

Questions for consultation

We would like your views on the criminal justice sector and adults with autism. Please write your answers in the answer booklet provided.

- 9.1 What more could be included on how local authorities and the NHS should work with criminal justice system partners?
- 9.2 Is the process for Liaison and Diversion sufficiently explained?
- 9.3 Do you have any other comments on helping to support people with autism who come into contact with the criminal justice system?
- 9.4 For local authorities and health bodies is there anything in this section that you are not already doing or have not planned to do and therefore consider it unreasonable due to reasons of affordability?
- 9.5 Have you any other comments on this section?

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Getting involved: How to respond to the consultation

Timings

The consultation will run for a period of 6 weeks from 7th November 2014 to 19th December 2014.

To find out more go to: https://www.gov.uk/

How to respond

You can respond to the consultation in the following ways:

By e-mail to: autism@dh.gsi.gov.uk
Online at: http://consultations.dh.gov.uk/

In writing to:

Consultations Co-ordinator
Adult Autism Statutory Guidance Review
Consultation
Department of Health
3rd Floor Area 313A,
Richmond House
79 Whitehall
London SW1A 2NS

Printed copies of this document and answer booklet are available in an alternative colour paper and easy read version on request by emailing autism@dh.gsi.gov.uk, phoning 0207 210 5391 or in writing to the above postal address.

Remit

This consultation and the final statutory guidance relate to England only, although it may be of interest to readers in Scotland, Wales and Northern Ireland (who have their own legislation and strategies).

Summary of consultation responses

A summary of the responses to this consultation will be made available alongside any further action, such as the finalisation of this statutory guidance, and will be placed on the consultations website at www.gov.uk after the responses have been considered.

Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Consultations Co-ordinator
Department of Health
2E08 Quarry House
Leeds
LS2 7UE

email: consultations.co-ordinator@dh.gsi.gov.uk

Please do not send consultation responses to this address.

Confidentiality of information

We manage the information you provide in response to this consultation in accordance

with the Department of Health's Personal Information Charter.²³

Information we receive, including personal information, may be published or disclosed in accordance with access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act (DPA) and the Environmental Information Regulations 2004).

If you want the information you provide to be treated as confidential, please be aware that under the FOIA, there is a statutory code of practice which public authorities must comply with and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of information, we will take full account of your explanation, but we cannot give an assurance that confidentiality will be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department of Health will process your personal data in accordance with DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

Appendix A

The 2010 Autism Strategy – Key themes

Training

Autism awareness training must now be available to all staff working in health and social care. Additionally, local areas should develop or provide specialist training for those in key roles, such as GPs, community care assessors, personal assistants, occupational therapists or residential care workers. Organisations should seek to involve adults with autism, their families and carers and autism representative groups when planning or commissioning training.

Identification, diagnosis and assessment of need

We expect there to be a clear pathway to diagnosis in every area, and local areas should appoint a lead professional to develop diagnostic and assessment services. The pathway should be from initial referral through to assessment of needs. Diagnosis should lead to a person-centred assessment of need and should be recognised as a catalyst for a carer's assessment. Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ. Any assessment of needs should be carried out by a professional who has a good understanding of autism and reasonable adjustments made to the process to enable the adult with

autism to take part fully. All NHS practitioners should be able to identify signs of autism and refer for assessment and diagnosis if necessary. They should also then be able to understand how to adapt their behaviour and communication for a patient with autism.

Transition

Local areas must follow statutory duties around transition for children with SEN, which will include most young people with autism. Protocols should be in place in every area for the transition of clinical mental health care for children with autism in receipt of Child and Adolescent Mental Health Services.

Local planning and leadership in the provision of services

Local areas should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. Local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually. To develop such plans, it will typically be necessary to gather information locally about:

- The number of adults known to have autism in the area;
- The range of need for support to live independently;

 The age profile of people with autism in the area – including those approaching 65 or above working age and the number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time.

Local commissioning plans should set out how local authorities will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of social care. The strategy suggests that "local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services.

In summary, the requirements in the 2010 strategy were that local authorities, NHS bodies and FTs:

- should provide autism awareness training for all staff;
- should develop or provide specialist training for key staff, such as GPs and community care assessors;
- should formally offer a community care assessment for adults with autism (not only adults with a learning disability);
- must appoint an autism commissioning lead in their area;
- need to develop a clear pathway to diagnosis and assessment for adults with autism;
- need to commission services based on adequate population data.

Appendix B

Think Autism: an update to the strategy for adults with autism in England

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) In line with the Autism Act, we have undertaken a review of the Autism Strategy in 2013/14 and reflected what we heard from people with autism, their families and from services in the update;
- (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.

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 greater 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.

From Fulfilling and Rewarding Lives to Think Autism

Priority Challenges for Action as identified by people with autism

An equal part of my local community

- 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.
- 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

- 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.

Appendix C

Key changes to key legislation and health and social care reforms since 2010

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 on 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

CCGs were created following amendments to the NHS legislation introduced by the Health and Social Care Act in 2012²⁴ 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

NHS England was formed in April 2013. It is an executive non-departmental public body of the Department of Health. NHS England is the operating name of the NHS Commissioning Board and, before that, the NHS Commissioning Board Authority. It was set up as a special health authority of the NHS in October 2011. It 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.

Health and Wellbeing Boards

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 http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

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 coordination 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 Joint Strategic Needs Assessments (JSNAs); and a strategy to address these in Joint Health and Wellbeing Strategies (JHWSs). Section 116A requires the Local Authority and partner CCG to prepare a "joint health and wellbeing strategy" where there is a JSNA.

Joint Strategic Needs Assessments

The Health and Social Care Act established that Joint Strategic Needs Assessments functions are to be exercised by Health and Wellbeing Boards Under section 194 of the 2012 Act, a Local Authority must establish a Health and Well-being Board, a committee of the LA, 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 2007,25 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 LA 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

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 authorities to meet a person's eligible care and support needs, and to respond to any risk of abuse or neglect to the person. The provisions are set to 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.

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 people will

Local Government and Public Involvement in Health Act 2007 http://www.legislation.gov.uk/ukpga/2007/28/contents

be able to receive as direct payments if they wish. They will be central to planning their own care and support, and will be able to exercise control over how it is provided;

- 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 the people most in need 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

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 (over compulsory school age but under 25 years) 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 National Health Commissioning Board, any relevant clinical commission group, NHS trust or NHS foundation trust, local Health Board and Health and Wellbeing Board i.e. they must consult relevant NHS bodies.

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.

For children and young people with SEN but without statements 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.

The Act and the Code make clear that there needs to be planning to achieve longterm outcomes for all children and young people with SEN, including employment outcomes. The Code includes a new chapter on Preparing for Adulthood which 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.

