

## **Appendix Three–Autism Joint Commissioning Board Draft revised statutory guidance to implement the strategy for adults with autism in England**

Key points from the statutory guidance consultation to implement the strategy for adults with autism in England consultation document (Department of Health, November 2014)

### **Understanding the 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 exercise, or available qualitative research and information gathered during review and refresh of Autism strategy in 2013/14.

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

**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, suitably trained, to ensure continuity of service;
- Ensure that both general awareness and specialist autism training is provided on an on-going 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.

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

### **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, 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 grounds of the person's IQ. This is particularly important for some people with autism, including those with Asperger syndrome, who may face very significant challenges in their everyday lives, despite having average or above average IQ.

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 S47(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].

#### **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.

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

#### **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 well-informed 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;
- 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.

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

##### **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 overtime (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**

**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.

**5. Preventative support and safeguarding in line with 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.

**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.

## **6. Reasonable adjustments**

#### **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.

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

#### **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) 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.

## **8. Employment for adults 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.

**9. Working with the criminal justice system****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.