

# NICE support for commissioning for autism

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## 1 Introduction

Implementing the recommendations from NICE guidance and other NICE-accredited guidance is the best way to support improvements in the quality of care or services, in line with the statements and measures that comprise the NICE quality standards. This report:

- Highlights the key actions that local authorities and clinical commissioning groups (CCGs) should take to improve the quality of care for people with autism. Priority actions are outlined in [table 1](#).
- Identifies opportunities for collaboration and integration at a local level.
- Identifies the benefits and potential costs or savings from implementing the changes needed to achieve quality improvement.
- Directs commissioners and service providers to other tools that can help them implement NICE and NICE-accredited guidance.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. The statements draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. For more information see [NICE quality standards](#).

NHS England's [CCG outcomes indicator set](#) is part of a systematic approach to promoting quality improvement. The outcomes indicator set provides clinical commissioning groups (CCGs) and health and wellbeing boards with comparative information on the quality of health services commissioned by CCGs and the associated health outcomes. The set includes indicators

derived from NICE quality standards. By commissioning services in line with the quality standards, commissioners can contribute to improvements in the health and social care outcomes defined in national outcomes frameworks. For more information see [How this quality standard supports delivery of outcome frameworks](#) in the autism quality standard.

Commissioners can use the quality standards to improve services by including quality statements and measures in the service specification of the standard contract and establishing key performance indicators as part of tendering. They can also encourage improvements in provider performance by using quality standard measures in association with incentive payments such as [the commissioning for quality and innovation \(CQUIN\) payment framework](#). NICE quality standards provide a baseline against which improvements can be measured and rewarded, enabling commissioners to address gaps in service provision, support best practice and encourage evidence-based care.

This report on the autism quality standard should be read alongside:

- [Autism](#). NICE quality standard 51 (2014).
- [Autism: the management and support of children and young people on the autism spectrum](#). NICE clinical guideline 170 (2013).
- [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#). NICE clinical guideline 142 (2012).
- [Service user experience in adult mental health](#). NICE quality standard 14 (2012).
- [Autism diagnosis in children and young people: recognition, referral and diagnosis of children and young people on the autism spectrum](#). NICE clinical guideline 128 (2011).
- [Improving access to social care for adults with autism](#). Social Care Institute for Excellence (2011).

## 2 Overview of autism

The core features of autism are described as qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact.

In addition to the core features, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems. These can include a need for routine; difficulty understanding other people, including their intentions, feelings and perspectives; sleeping problems; eating problems; epilepsy; dyspraxia; motor coordination problems; sensory sensitivities; self-injurious behaviour and other challenging (sometimes aggressive) behaviours.

Autism is a spectrum condition meaning the condition affects people in different ways. Some exhibit mild characteristics of autism and may live independently, but others with more severe autism or coexisting conditions may require more intensive support. Living with autism can have a big effect on a person's quality of life and that of their families or carers.

A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion.

The provision of services for people with autism is varied across England and Wales, particularly with regard to services for adults. There is evidence that a lack of awareness of autism means that the condition is often not recognised, and that people with autism and their families can find it difficult to get help and support from health, social care, education and employment services.

### **2.1 National policy context and commissioning responsibilities**

CCGs and local authority social care and education commissioners should work together to commission person-centred care that is coordinated across all relevant agencies in the autism care pathway. Joint commissioning can be supported by using [joint-funding arrangements between local authority and](#)

[NHS commissioners](#). Health and wellbeing boards should support integration across the local autism care pathway.

The [Autism Act 2009](#) and [Fulfilling and rewarding lives: the strategy for adults with autism in England](#) (2010) require each local authority area to develop a local autism strategy. The strategy aims to support the development of health and social care services that help people with autism to live independently. A key role of the strategy is to help develop health and social care services that meet the needs of people with autism, including identifying a local lead to develop and commission services. [Progress in implementing the 2010 adult autism strategy](#) (National Audit Office 2012) notes that while considerable progress has been made in implementing the national strategy, developing local diagnostic pathways (statements 1 and 2) and facilitating more personalised care planning (statements 3 and 4) remain areas for improvement.

Local autism strategies should identify the mechanisms and resources required to commission local autism services (or to improve the quality of existing services) and to develop an autism diagnosis pathway. Diagnosis and access to support should be provided by an autism team, a multidisciplinary team of dedicated health and social care professionals as described in the definitions of terms for [statement 1](#) in the quality standard. The autism team can be configured from professionals with expertise in autism who are working in existing health, social care and education service, and so there may not be significant additional staff or establishment costs associated with setting up the team.

Commissioning care for people with autism, in line with the quality standard, should contribute to achieving the ambition of [Transforming care: a national response to Winterbourne View Hospital](#) (Department of Health 2012). The report calls on local authority and NHS commissioners to use integrated commissioning arrangements to transform care for vulnerable adults with learning disabilities and autism, and mental health conditions or behaviours described as challenging. This includes improving access to personalised

care (statements 3 and 4) and helping people to receive appropriate care and support in community settings (statements 5–8).

## **2.2      *Epidemiology of autism***

It is estimated that around 1.1% of the population have autism<sup>1</sup>. Despite a 25-fold increase in the diagnosis of autism in the last 30 years<sup>2</sup>, the diagnosed prevalence remains lower than population-level estimates: around two-thirds of children and 1 in 10 adults with autism have a diagnosis. Around 4 times more men than women have diagnosed autism, although this may be partly a result of under-recognition of autism in women.

Some people with autism also have other learning difficulties and mental health problems. Around 50% of people with autism have a learning difficulty. Approximately 70% of individuals with autism also meet diagnostic criteria for at least 1 other (often unrecognised) mental and behavioural disorder, and 40% meet diagnostic criteria for at least 2 disorders, mainly anxiety, attention deficit hyperactivity disorder and oppositional defiant disorder<sup>3</sup>.

## **3            **Summary of commissioning and resource implications****

This report summarises the key commissioning issues and the resource impact from commissioning and delivering improvements in the quality of care for children, young people and adults with autism, in line with the statements and measures that comprise the NICE quality standard for autism.

Achieving the quality standard may have a cost impact for the NHS and other agencies, including education and social care. Because autism services vary across the country, the cost impact will depend on current local practice and

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<sup>1</sup> Brugha T, Cooper SA, McManus S et al (2012) Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 adult psychiatric morbidity survey. Leeds: The Health and Social Care Information Centre.

<sup>2</sup> National Collaborating Centre for Mental Health (2012) [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum \(full guideline\)](#).

<sup>3</sup> Simonoff E, Pickles A, Charman T et al. (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity and associated factors. *Journal of the American Academy of Child and Adolescent Psychiatry* 47: 921–9.

the progress organisations have made in implementing NICE and NICE-accredited guidance and national policy.

But investment in local autism services also contributes to: a reduction in GP appointments, fewer emergency admissions and less use of mental health services in times of crisis, including the use of inpatient psychiatric services.

Table 1 summarises the commissioning and resource implications for commissioners working towards achieving this quality standard.

**Table 1 Priority commissioning actions and potential resource implications for autism**

Quality improvement area	Commissioning implications	Resource implications
Assessment and diagnosis (statements 1 and 2)	Local authorities should ensure that the local autism pathway clearly defines that the autism service is responsible for diagnosing autism in children, young people and adults. Local authorities should work with CCGs to commission assessment and diagnosis of people with autism. They should ensure that the autism service has capacity to begin diagnostic assessment within 3 months of referral and monitor performance.	There may be costs for: <ul style="list-style-type: none"> <li>• raising awareness</li> <li>• training staff to deliver assessment and diagnosis.</li> </ul> Earlier assessment could lead to an earlier diagnosis that could reduce repeat and avoidable appointments with GPs, mental health services and employment services, and help to improve behaviour management in schools. For example, each GP appointment avoided may release capacity for other healthcare services.
Care planning and coordination (statements 3 and 4)	Local authorities should ensure that the autism service provides personalised plans for all people with autism. Local authorities and CCGs should jointly commission key workers to aid better care coordination.	No costs anticipated unless further investment in autism teams or further training is needed. However, this ensures that appropriate interventions are provided and will save NHS and social care resources.
Interventions for autism (statements 5 and 6)	CCGs should work with local authorities to ensure that the autism pathway includes a range of mainstream and specialist services that can provide psychosocial interventions and support for people with autism. Experts suggest that drugs are not typically used to manage	Potential costs and benefits of improving access to psychosocial interventions are provided in the <a href="#">costing report</a> for NICE clinical guideline 142 and the <a href="#">costing statement</a> for NICE clinical guideline 170.

	the core features of autism. However, there is variation among services, and CCGs should assess and monitor local practice.	
Behaviour that challenges (statements 7 and 8)	Local authorities should ensure that the autism team can make assessments of triggers in people who develop behaviour that challenges, and work with CCGs to facilitate access to additional health or social care services, or environmental adaptations.	Identifying the possible triggers before any interventions start: <ul style="list-style-type: none"> <li>• may involve additional assessment costs</li> <li>• ensures that appropriate treatment is offered</li> <li>• helps avoid costs associated with inappropriate interventions</li> <li>• may reduce drug prescriptions and residential care costs.</li> </ul>

## 4 Commissioning and resource implications

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the NICE quality standard for autism.

### 4.1 *Assessment and diagnosis*

#### **Quality statement 1: Diagnostic assessment by an autism team**

People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

#### **Quality statement 2: Assessment and diagnosis**

People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

#### [Fulfilling and rewarding lives: the strategy for adults with autism in England](#)

(2010) includes a commitment to increasing awareness and understanding of autism. Improved awareness may contribute to increasing the number of people who are recognised as having possible autism and who are

subsequently referred for a diagnostic assessment. Local authorities and CCGs should work with relevant local providers to deliver staff development programmes to raise awareness of autism. These programmes should be made available to:

- mainstream services, such as general practice, welfare advice, employment services, education, criminal justice, housing, domiciliary care, primary and acute healthcare providers
- more specialist services, for example respite care, psychosocial intervention providers, residential care.

Local authorities should ensure that they have a diagnostic pathway for autism. This pathway should identify that the autism team is responsible for diagnosing autism in children, young people and adults.

Local authorities should work closely with CCGs to ensure that their autism service has the capacity to begin diagnostic assessment within 3 months of referral and to monitor performance. They may wish to specify the core components of the diagnostic assessment (see definitions of diagnostic assessment in [statement 1](#)).

Local authorities and CCGs should work together to agree referral protocols for people with autism and coexisting mental or physical health problems to be assessed by an appropriate healthcare professional. Examples include:

- for children: a member of child and adolescent mental health services (CAMHS), paediatrician, speech and language therapist, psychologist, neurologist, community dental services staff
- for adults: a member of the community mental health service, GP with a special interest in autism/behavioural problems.

There may be costs involved with raising staff awareness, and ensuring that assessments of people with possible autism are started within 3 months of a referral. Expert opinion suggests that some adults with possible autism may return for GP appointments many times without autism being investigated as



a potential cause of symptoms. Each GP appointment avoided may release capacity for other healthcare services.

Commissioners may find the NICE shared learning examples of [Autism management in children and young people – recognising and overcoming barriers to accessing care](#) and [Setting up Nottingham city's Asperger's syndrome service](#) useful.

The [costing report](#) for NICE clinical guideline 142 has more detail on the costs and savings associated with assessment and diagnosis.

The [Department of Health](#) and [National Autistic Society](#) have resources that can support autism training and awareness.

## **4.2 Care planning and coordination**

### **Quality statement 3: Personalised plan**

People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

### **Quality statement 4: Coordination of care and support**

People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Local authorities should work with CCGs to ensure that their autism service has the capacity to lead on developing new personalised plans for all people with diagnosed autism and/or to contribute to people's existing plans (such as [Education, Health and Care \(ECH\) plan](#) for children, [community care assessment](#), [care programme approach](#) care plan, health action plan or other person-centred approach to planning for adults).

Commissioners and providers may wish to agree the components that should be considered as part of the personalised plan (see the definition of the personalised plan in [statement 3](#) of the quality standard). The personalised plan should allow a [person-centred approach to care](#) and reflect the person's strengths and needs. Commissioners should ask their autism service to demonstrate that the personalised plans fulfil the following criteria:

- They are jointly developed between the autism service and the person with autism (also involving parents and carers of children and young people with autism, and carers if adults request this)
- They allow personalised approaches to care using tools such as personal budget holding across health, social care and education
- They are up-to-date documents that are reviewed regularly, within a timescale agreed with the person with autism and
- They include an independence/transition plan for young people with autism. Because thresholds for access to adult services are typically much higher than those for children, commissioners should ensure that all young people and their families receive support to help them prepare and plan for adulthood.

Personal plans should help people with autism and their families to understand the condition and to access advice that supports self-management and independence. A key component here is access to a named key worker.

Local authorities and CCGs should work together to explore different options for delivering a named key worker to every person with autism, while being aware that different people may need a different frequency and intensity of key worker support. The key worker should have knowledge of autism. The following professionals, linked to the autism service, may be appropriate as key workers:

- For children and young people with lower-level needs: nursery- or school-based special educational needs practitioners or speech and language therapists.

- For children with more complex needs: a member of CAMHS, paediatrician, nurse specialist, occupational therapist or educational psychologist.
- For adults with lower-level needs who do not meet local authority [Fair Access to Care \(FAC\)](#) thresholds: a bespoke autism care navigator service, social work assistant or GP.
- For adults with coexisting conditions and/or who meet local authority FAC thresholds: a social worker, nurse specialist or GP with special interest.

The [National Audit Office](#) maintains that considerable cost savings could be made if people with autism had access to better information, care planning and more timely interventions that met their needs.

Commissioners may wish to refer to the Joint Commissioning Panel for Mental Health [Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services](#).

Commissioners may find the NICE shared learning example of [Autism management in children and young people – recognising and overcoming barriers to accessing care](#) useful.

### **4.3 Interventions for autism**

#### **Quality statement 5: Treating the core features of autism: psychosocial interventions**

People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

#### **Quality statement 6: Treating the core features of autism: medication**

People with autism are not prescribed medication to address the core

features of autism.

Local authorities and CCGs should explore what psychosocial support is available locally because there is national inconsistency, and should check that this support is evidence-based. The NICE pathway for autism provides a good overview of the psychosocial interventions recommended for [children and young people](#) and [adults](#) with autism.

CCGs should work with relevant mainstream (non-autism specialist) services so that they can make the adjustments necessary for people to successfully access age-appropriate psychosocial interventions. Adjustments may need to be made for the person's development level and their patterns of communication and interaction, or to the physical environment (such as the lighting, noise levels or interior decoration).

Where there are gaps in availability of psychosocial support, CCGs may need to work together with the local authority to commission additional interventions. They could work with their autism service to determine what psychosocial interventions can be provided by trained staff within the service (with additional training if required). Some individually tailored psychosocial support may be needed to help people with autism to develop their social, communication and life skills.

It is unlikely there will be additional costs associated with documenting discussions about opportunities to take part in psychosocial interventions to address the core features of autism. However, if additional services are required, costs may be incurred to commission the necessary interventions.

The [costing statement](#) for NICE clinical guideline 170 highlighted that pharmacological treatments are not typically used to manage the core features of autism. If pharmacological treatments are used to treat autism and this is reduced and replaced by psychosocial interventions, there may be a cost at a local level.

CCGs may wish to:

- agree a local protocol so that only appropriate expert members of the autism team can prescribe drugs to manage behaviour or symptoms in people with autism (see also section 4.4)
- monitor prescribing in services that work with large numbers of people with autism, such as the autism service and residential settings for adults with complex needs, or settings where it is suspected that people are prescribed drugs to address core features of autism.

The [costing statement](#) for NICE clinical guideline 170 discusses the costs and benefits associated with psychosocial interventions for core features of autism in children and young people.

The [costing report](#) for NICE clinical guideline 142 discusses the costs and benefits associated with psychosocial interventions for core features of autism in adults.

#### **4.4 Behaviour that challenges**

##### **Quality statement 7: Assessing possible triggers for behaviour that challenges**

People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

##### **Quality statement 8: Interventions for behaviour that challenges**

People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Local authorities and CCGs should specify that their autism team can make assessments of potential triggers in people with autism who develop behaviour that challenges. The triggers, and agreed interventions and/or adaptations, should be documented in the person's personalised plan (see section 4.2). Commissioners should ensure that their autism team can:

- allow access to assessments for coexisting mental health or physical illness; some elements of assessment or ongoing support should be available within the autism team
- offer interventions that are specifically focused on reducing and managing challenging behaviours
- provide access to occupational therapy advice if environmental triggers are identified.

Assessing people with autism who display behaviour that challenges for any possible triggers for that behaviour could involve additional costs. However, because coexisting mental and behavioural conditions can impair psychosocial functioning, identifying the possible triggers before any interventions are started will ensure that appropriate treatment is offered. This would help avoid costs associated with inappropriate, avoidable or high-intensity interventions such as the use of drugs or residential care.

Evidence-based management of behaviour that challenges can help to improve the quality of care of people with autism and their carers, and to prevent an escalation of problems that may lead to costly or inappropriate use of residential care. [Transforming care: a national response to Winterbourne View Hospital](#) highlighted 'a widespread failure to design, commission and provide services which give people the support they need close to home, and which are in line with well established best practice'.

Local authority social care and CCG commissioners will need to work together to review their use of residential care for people with autism. Commissioners may wish to work with domiciliary care providers so that they can support greater numbers of people with autism and their families, and work in regional partnerships to develop better measures and monitoring of provider quality.

Not offering drug treatment for the behaviour that challenges, unless psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour, could reduce drug costs. The [costing statement](#) for NICE clinical guideline 170 highlights that drugs are currently used to manage behaviour that challenges when this impacts on the person and their family. Therefore, there may be a saving if there is reduced use of these drugs.

Commissioners may wish to refer to the [Winterbourne View Review: good practice examples](#) for examples of best practice in prevention, personalisation, advocacy and support and providing care closer to home.

## 5 Other useful resources

### 5.1 Policy documents

- Department for Education (2013) [Children and Families Bill 2013](#).
- Care Quality Commission (2012) [Health care for disabled children and young people – a review of how the health care needs of disabled children and young people are met by the commissioners and providers of health care in England](#).
- Department of Health (2012) [Transforming care: a national response to Winterbourne View Hospital](#).
- National Audit Office (2012) [Progress in implementing the 2010 Adult Autism Strategy](#).
- Improving Health and Lives: Learning Disabilities Observatory (2012) [Autism self assessment 2011: issues from local authorities](#).
- Health & Social Care Information Centre (2012) [Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey](#).
- Department for Education (2009) [Inclusion development programme: supporting children on the autism spectrum – guidance for practitioners in the Early Years Foundation Stage](#).

- National Autistic Society, British Association of Social Workers (2008) [Social care: assessment of need for adults with an autism spectrum disorder](#).

## **5.2 Useful resources**

- Joint Commissioning Panel for Mental Health (2013) [Guidance for commissioners of mental health services for people with learning disabilities](#).
- Joint Commissioning Panel for Mental Health (2012) [Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services](#).
- National CAMHS Support Service (2011) [Better mental health outcomes for children and young people: a resource directory for commissioners](#).
- Autism Education Trust (2011) [What is good practice in autism education?](#)
- SCIE (2010) [Implications for people with autistic spectrum conditions and their family carers](#).
- National Audit Office (2009) [Supporting people with autism through adulthood](#).

## **5.3 NICE implementation support**

- [Attention deficit hyperactivity disorder](#). NICE support for commissioning (2013)
- [Developing local autism teams: an action plan for change](#). (2013).

## **5.4 NICE pathways**

- [Autism](#)
- [Attention deficit hyperactivity disorder](#)
- [Antisocial behaviour and conduct disorders in children and young people](#)

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