

# Autism

## NICE quality standard

### Draft for consultation

September 2013

This quality standard covers autism in children, young people and adults, including both health and social care services. For more information see the [Autism topic overview](#).

### Why this quality standard is needed

The term autism describes 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 these features, people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; dyspraxia or motor coordination problems; and mental health problems such as anxiety, depression, problems with attention, sensory sensitivities, self-injurious behaviour and other challenging, sometimes aggressive, behaviours. These can substantially affect the person's quality of life, and that of their families or carers, and lead to social vulnerability.

The clinical picture of autism is variable because of differences in the severity of autism itself, the presence of coexisting conditions and differing levels of cognitive ability, which can range from profound intellectual disability in some people to average or above average intellectual ability in others.

Around 70% of people with autism also meet diagnostic criteria for at least 1 other (often unrecognised) psychiatric disorder that further impairs psychosocial functioning, for example, attention deficit hyperactivity disorder (ADHD) or anxiety disorders. Approximately 50% of people with autism also have intellectual disability (IQ below 70).

## How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- [The Adult Social Care Outcomes Framework 2013–14](#) (Department of Health, November 2012)
- [NHS Outcomes Framework 2013/14](#)

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1** [The Adult Social Care Outcomes Framework 2013–14](#)

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like.* (PHOF 1.18)
3 Ensuring that people have a positive experience of care and support	3A. Overall satisfaction of people who use services with their care and support 3B. Overall satisfaction of carers with social services 3D. The proportion of people who use services and carers who find it easy to find information about support 3E: (Placeholder) Improving people's experience of integrated care** (NHSOF 4.9)
<b>Alignment across the health and social care system</b>	
* Indicator shared with Public Health Outcomes Framework (PHOF)	

**Table 2 [NHS Outcomes Framework 2013/14](#)**

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for people with long-term conditions	<p><b>Overarching indicator</b></p> <p>2 Enhancing quality of life for people with long-term conditions**</p> <p><b>Improvement areas</b></p> <p><b>Ensuring people feel supported to manage their condition</b></p> <p>2.1 Proportion of people feeling supported to manage their condition**</p> <p><b>Improving functional ability in people with long-term conditions</b></p> <p>2.2 Employment of people with long-term conditions</p> <p><b>Enhancing quality of life for carers</b></p> <p>2.4 Health related quality of life for carers ** (ASCOF 1D)</p>
4 Ensuring that people have a positive experience of care	<p><b>Overarching indicator</b></p> <p>4. Ensuring people have a positive experience of care.</p> <p><b>Improvement areas</b></p> <p>4.7 Patient experience of community mental health services</p> <p>4.9 (Placeholder) People's experience of integrated care*** (in development).</p>
<p><b>Alignment across the health and social care system</b></p> <p>** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)</p> <p>*** Indicator shared with Adult Social Care Outcomes Framework</p>	

## Coordinated services

The quality standard for autism specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole autism care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with autism and their families and carers.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality autism service are listed in 'Related quality standards'.

## ***Training and competencies***

The quality standard should be read in the context of available national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, caring for and treating people with autism should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

## **List of quality statements**

[Statement 1](#) People with possible autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral.

[Statement 2](#) People having a diagnostic assessment for autism are assessed for coexisting physical health conditions and mental health problems.

[Statement 3](#) People with autism have a personalised management plan that takes into account their strengths and needs.

[Statement 4](#) People with autism have a designated professional to oversee and coordinate their care and support.

[Statement 5](#) People with autism are not prescribed drugs to treat the core symptoms of their autism.

[Statement 6](#) People with autism who develop behaviour that challenges are assessed for possible triggers, including physical and medical problems, before any interventions for behaviour that challenges are started.

[Statement 7](#) People with autism and behaviour that challenges are offered drug treatment for their behaviour that challenges only if psychosocial interventions are not effective or appropriate.

## **Questions for consultation**

### ***Questions about the quality standard***

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

## Quality statement 1: Assessment and diagnosis

### ***Quality statement***

People with possible autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral.

### ***Rationale***

There are several different routes by which someone with possible autism can be referred to an autism service for a full diagnostic assessment. Once the referral has been accepted it is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered. The team conducting the assessment should be a specialist integrated autism team with age-appropriate expertise.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people with possible autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral

**Data source:** Local data collection.

#### **Process**

Proportion of people with possible autism needing a diagnostic assessment by an autism service who have the assessment started within 3 months of their referral.

Numerator – the number of people in the denominator who have a diagnostic assessment started within 3 months of referral to the autism team.

Denominator – the number of people with possible autism referred to and accepted by an autism service for assessment.

**Data source:** Local data collection. [NICE clinical audit support tool: Autism: recognition, referral and diagnosis of children and young people on the autism](#)

[spectrum](#); includes criterion 1 concerning autism diagnostic assessments starting within 3 months of the referral to the autism team.

### ***What the quality statement means for service providers, health and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place for people with possible autism needing a diagnostic assessment by an autism service to have the assessment started within 3 months of their referral.

**Health professionals and social care practitioners working within an autism service** ensure that people with possible autism who need a diagnostic assessment by an autism service have the assessment started within 3 months of their referral.

**Commissioners** ensure that they commission autism services for children, young people and adults that start diagnostic assessments within 3 months of accepting a referral for assessment.

### ***What the quality statement means for service users and carers***

**People who are referred for and accepted for an assessment for autism** have the assessment started within 3 months.

### ***Source guidance***

- Autism in adults (NICE clinical guideline 142), recommendation [1.2.5](#)
- Autism spectrum disorders in children and young people (NICE clinical guideline 128), recommendation [1.5.1](#)

### ***Definitions of terms used in this quality statement***

#### **People needing a diagnostic assessment**

People with possible autism who have been referred to the specialist autism team, which agrees with the referral and accepts the person for a diagnostic assessment.

#### **Autism service – children and young people**

The core staff of the service should include a:

- paediatrician and/or child and adolescent psychiatrist

- speech and language therapist
- clinical and/or educational psychologist.

The autism team should either include or have regular access to the following professionals:

- paediatrician or paediatric neurologist
- child and adolescent psychiatrist
- clinical psychologist
- occupational therapist
- other professionals who may assist with the assessment, for example a specialist health visitor or nurse, specialist teacher or social worker.

### **Autism service – adults**

A local adult autism service should provide access to:

- clinical psychologists
- primary care services
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, to support access to housing, educational and employment services, financial advice, and personal and community safety skills).

### **Diagnostic assessment – children and young people**

The following should be included in every autism diagnostic assessment:

- detailed questions about parents' or carers' concerns and, if appropriate, the child or young person's concerns
- details of the child or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with the International Statistical Classification of Diseases and Related



Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V) criteria (consider using an autism-specific tool to gather this information)

- assessment (by interacting with and observing the child or young person) of social and communication skills and repetitive and stereotyped behaviours, including sensory sensitivities, focusing on features consistent with the ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination
- consideration of the differential diagnosis (see NICE clinical guideline 128, [recommendation 1.5.7](#))
- systematic assessment for conditions that may coexist with autism (see NICE clinical guideline 128, [recommendation 1.5.15](#))
- developing a profile of the child or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- communicating assessment findings to the parent or carer and, if appropriate, the child or young person.

### **Diagnostic assessment – adults**

During a comprehensive assessment, enquire about and assess:

- core autism signs and symptoms (difficulties in social interaction and communication, stereotypic behaviour, resistance to change or restricted interests, and also strengths) that were present in childhood and have continued into adulthood
- early developmental history, if possible
- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities and attention to detail

- core autism signs and symptoms (assess by direct observation) especially in social situations, include observation of risk behaviours and safeguarding issues.

### ***Equality and diversity considerations***

In cases where people do not have access to a specialist autism team near to their homes, additional provision may be required for people who have difficulty in travelling long distances either due to the financial cost or for other characteristics.

## Quality statement 2: Assessment and diagnosis

### ***Quality statement***

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

### ***Rationale***

People with autism may have coexisting mental health problems or physical health conditions. If these are not identified and treated, support or interventions for autism can be impeded.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people having a diagnostic assessment for autism are assessed for coexisting physical health conditions and mental health problems.

***Data source:*** Local data collection.

#### **Process**

The proportion of people having a diagnostic assessment for autism who are assessed for coexisting physical health conditions and mental health problems.

Numerator – The number of people in the denominator that are assessed for coexisting physical health conditions and mental health problems

Denominator – The number of people having a diagnostic assessment for autism.

***Data source:*** Local data collection.

#### **Outcome**

Reduced morbidity from unidentified physical health conditions and mental health problems that have been affecting the person's functioning.

***Data source:*** Local data collection

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place to ensure that people having a diagnostic assessment for autism are assessed for coexisting physical health conditions and mental health problems

**Health professionals and social care practitioners** ensure that when they carry out a diagnostic assessment for autism they also assess the person for coexisting physical health conditions and mental health problems

**Commissioners** ensure that they commission services where systems are in place to assess for coexisting physical health conditions and mental health problems when a diagnostic assessment for autism is carried out.

### ***What the quality statement means for service users and carers***

**People having an assessment for autism** also have assessments for other mental health conditions and physical health problems.

### ***Source guidance***

- Autism in adults (NICE clinical guideline 142), recommendation [1.2.10](#)
- Autism spectrum disorders in children and young people (NICE clinical guideline 128), recommendation [1.5.15](#)

### ***Definitions of terms used in this quality statement***

#### **Assessment for coexisting physical and mental health conditions in children and young people**

Assessment for coexisting physical conditions and mental health problems in children and young people should include the following:

- Mental and behaviour problems and disorders:
  - attention deficit hyperactivity disorder (ADHD)
  - anxiety disorders and phobias
  - mood disorders
  - oppositional defiant behaviour

- tics or Tourette’s syndrome
- obsessive–compulsive disorder
- self-injurious behaviour.
- Neurodevelopmental problems and disorders:
  - global delay or intellectual disability
  - motor coordination problems or developmental coordination disorder
  - academic learning problems, for example with literacy or numeracy
  - speech and language disorders.
- Medical or genetic problems and disorders:
  - epilepsy and epileptic encephalopathy
  - chromosome disorders
  - genetic abnormalities, including fragile X
  - tuberous sclerosis
  - muscular dystrophy
  - neurofibromatosis.
- Functional problems and disorders:
  - feeding problems, including restricted diets
  - urinary incontinence or enuresis
  - constipation, altered bowel habit, faecal incontinence or encopresis
  - sleep disturbances
  - vision or hearing impairment.

### **Assessment for coexisting health and mental health conditions in adults**

Assessment for coexisting physical health conditions and mental health problems in adults should include the following:

- other neurodevelopmental conditions (use formal assessment tools for learning disabilities)
- mental health problems (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders

- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- and hypo-sensory sensitivities.

## Quality statement 3: Personalised management plan

### ***Quality statement***

People with autism have a personalised management plan that takes into account their strengths and needs.

### ***Rationale***

The needs of people with autism can be complex and involve support from a range of professionals. A personalised management plan based on the individual needs of the person with autism and recognising their strengths should ensure that the support provided is coordinated and focused on the person's needs and the best possible outcomes for them. The personalised management plan will need to be updated and reviewed as the person's needs and circumstances change.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people with autism have a personalised management plan that takes into account their strengths and needs.

***Data source:*** Local data collection.

#### **Process**

The proportion of people with autism who have a personalised management plan that takes into account their strengths and needs.

Numerator – The number of people in the denominator who have a needs-based management plan that takes into account their strengths and needs.

Denominator – The number of people diagnosed with autism.

***Data source:*** Local data collection.

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place for all people with autism to have a needs-based management plan that takes into account their strengths.

**Health professionals and social care practitioners** ensure that all people with autism have a needs-based management plan that takes into account their strengths.

**Commissioners** ensure that they commission services that have systems in place for all people with autism to have a needs-based management plan that takes into account their strengths.

### ***What the quality statement means for service users and carers***

**People with autism** have a management plan that sets out what their strengths are and what support they should receive.

### ***Source guidance***

- Autism in adults (NICE clinical guideline 142), recommendation [1.2.13](#)
- Autism spectrum disorders in children and young people (NICE clinical guideline 128), recommendation [1.5.5](#) (key priority for implementation)
- Improving access to social care for people with autism ([SCIE Guide 43](#)), section Personalising services, page 37.

### ***Definitions of terms used in this quality statement***

#### **Needs-based management plan**

A needs-based management plan should be based on an assessment of needs, taking into consideration the person's strengths, skills, mental and physical impairment and needs, their family and social context, and for children and young people their educational context. It should also include a risk management plan for people with challenging behaviour or complex needs. For people younger than 18 the plan should also include the management of transition from child to adult services.



## Quality statement 4: Care and support coordination

### ***Quality statement***

People with autism have a designated professional to oversee and coordinate their care and support.

### ***Rationale***

The needs of people with autism are broad and varied, and can involve services from a number of providers. A designated professional can ensure that people with autism are using all the services detailed in their management plan in an integrated way. The designated professional should also help people with autism to review and anticipate their changing needs in an integrated and timely manner. The health or social care professional identified as the designated professional will depend on the severity and type of need the person has.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements for people with autism to have a designated professional to oversee and coordinate their care and support.

***Data source:*** Local data collection.

#### **Process**

The proportion of people with autism who have a designated professional to oversee and coordinate their care and support.

Numerator – The number of people in the denominator who have a designated professional to oversee and coordinate their care and support.

Denominator – The number of people with autism.

***Data source:*** Local data collection.

#### **Outcome:**

a) Patient experience of coordinated care.

b) Parent or carer experience of coordinated care.

**Data source:** a) and b) Local data collection.

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place for people with autism to have a designated professional to oversee and coordinate their care and support.

**Health professionals and social care practitioners** ensure that the care and support of people with autism is overseen and coordinated by a designated professional appropriate to the care setting the person is receiving care and support from.

**Commissioners** ensure that they commission services with systems in place for people with autism to have a designated professional to oversee and coordinate their care.

### ***What the quality statement means for service users and carers***

**People with autism** have a single, named social or healthcare professional, based in the main service they receive care from, to oversee and coordinate their care.

### ***Source guidance***

- Autism in adults (NICE clinical guideline 142), recommendation [1.8.10](#)
- [Autism: management of autism in children and young people](#) (NICE clinical guideline 170), recommendation [1.1.4](#)

### ***Definitions of terms used in this quality statement***

#### **Designated professional to oversee and coordinate care**

In services for children and young people, the longer-term designated professional is likely to be described as a case manager or key worker. They may be a member of the autism team or someone from local community services who is identified by the autism team as suitable for the needs of the child or young person. Adults receiving care from or services recommended by the local autism team should also have an

identified key worker or case manager. For adults not receiving care from the specialist autism team, mental health or learning disability services, the designated professional should be a member of the social care or primary healthcare team. The role of the designated professional should include ensuring that a care plan is developed for the person covering all the care, support and adjustments they need. The designated professional should also help them gain access to the services they need and support transitions between services.

## Quality statement 5: Treatment

### *Quality statement*

People with autism are not prescribed drugs to treat the core symptoms of their autism.

### *Rationale*

Drugs have not been shown to be effective in treating the core symptoms of autism and therefore are not recommended. Health and social care professionals should consider potential alternatives such as psychosocial interventions.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with autism are **not** prescribed drugs to treat the core symptoms of their autism.

**Data source:** Local data collection.

#### **Process**

The proportion of people with autism who are prescribed drugs to treat the core systems of their autism.

Numerator – The number of people in the denominator who are prescribed drugs to treat the core systems of their autism.

Denominator – The number of people with autism.

**Data source:** Local data collection NICE clinical audit tool: Autism in adults: biomedical interventions includes an Audit standard on the use of biomedical interventions for the core symptoms of autism

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place to **avoid** the prescription of drugs for the core symptoms of autism.

**Health professionals and social care practitioners** ensure that they **do not** prescribe drugs for the core symptoms of autism.

**Commissioners** ensure that they commission services that **do not** prescribe drugs for the core symptoms of autism.

### ***What the quality statement means for service users and carers***

**People with autism** are not prescribed medication to help manage the core symptoms of their autism.

### ***Source guidance***

- [Autism: management of autism in children and young people](#) (NICE clinical guideline 170), recommendation [1.3.2](#)
- Autism in adults (NICE clinical guideline 142), recommendations [1.4.13](#), [1.4.16](#), [1.4.21](#) and [1.4.22](#).

### ***Definitions of terms used in this quality statement***

#### **Drugs not recommended for the core symptoms of autism**

These include:

- antipsychotics
- antidepressants
- anticonvulsants
- drugs designed to improve cognitive functioning (for example, cholinesterase inhibitors).

#### **Core symptoms of autism**

The core symptoms of autism are described as qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted and stereotyped interests and activities, and rigid and repetitive behaviours.

## Quality statement 6: Behaviour that challenges

### ***Quality statement***

People with autism who develop behaviour that challenges are assessed for possible triggers, including physical and medical problems, before any interventions for behaviour that challenges are started.

### ***Rationale***

People with autism can sometimes present with behaviour that is challenging to manage. The causes of behaviour that challenges for a person with autism can be multifactorial, and can involve physical, emotional and environmental factors. An assessment should take all these factors into account before appropriate interventions are agreed.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people with autism who develop behaviour that challenges are assessed for possible triggers before any interventions for behaviour that challenges are started.

**Data source:** Local data collection.

#### **Process**

The proportion of people with autism who develop behaviour that challenges who are assessed for possible triggers before any interventions for behaviour that challenges are started.

Numerator – The number of people in the denominator who are assessed for possible triggers before any interventions for behaviour that challenges are started.

Denominator – The number of people with autism who develop behaviour that challenges.

**Data source:** Local data collection. Included in NICE [Clinical audit tool: Autism in adults: challenging behaviour](#) audit standards 1 and 2

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place for people with autism who develop behaviour that challenges to be assessed for possible triggers before any interventions for behaviour that challenges are started.

**Health professionals and social care practitioners** ensure that people with autism who develop behaviour that challenges are assessed for possible triggers before any interventions for behaviour that challenges are started.

**Commissioners** ensure that they commission services that assess people with autism who develop behaviour that challenges for possible triggers before any interventions for behaviour that challenges are started.

### ***What the quality statement means for service users and carers***

**People with autism who behave in a challenging way** (for example, becoming distressed, agitated, disruptive or violent) have an assessment, before any treatment is started, to find out what causes them to behave in this way.

### ***Source guidance***

- [Autism: management of autism in children and young people](#) (NICE clinical guideline 170), recommendation [1.4.1](#) key priority for implementation
- [Autism in adults](#) (NICE clinical guideline 142), recommendations [1.2.20](#) and [1.5.1](#)

### ***Definitions of terms used in this quality statement***

#### **Behaviour that challenges**

Behaviour that challenges includes but is not limited to: physical aggression towards self (self-injury); severe levels of 'habitual behaviours' such as rocking and head-banging; aggression towards others; destruction of property; temper outbursts; high levels of oppositionality and defiance; and verbal aggression. Patterns of behaviour that challenge are extremely variable; behaviours may be frequent or rare and individual acts can have minor or severe consequences for the person and others.

**Assessment for possible triggers**

When assessing behaviour that challenges carry out a [functional analysis](#), including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

- physical disorders
- the social environment (including relationships with family members, partners, carers and friends)
- the physical environment, including sensory factors
- coexisting mental disorders (including depression, anxiety disorders and psychosis)
- communication problems
- changes to routines or personal circumstances
- developmental change, including puberty (in children and young people)
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges
- absence of predictability and structure.



## Quality statement 7: Behaviour that challenges

### ***Quality statement***

People with autism and behaviour that challenges are offered drug treatment for their behaviour that challenges only if psychosocial interventions are not effective or appropriate.

### ***Rationale***

The first line intervention for behaviour that challenges should be psychosocial interventions. If people with behaviour that challenges have not responded to psychosocial interventions, or if the severity of the behaviour means that emergency interventions are needed in the first instance, drug treatment can help manage the behaviour and reduce the associated risks.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements for people with autism and behaviour that challenges to be offered drug treatment only if psychosocial interventions are not effective or appropriate.

**Data source:** Local data collection.

#### **Process**

The proportion of people with autism and behaviour that challenges having drug treatment for their behaviour that challenges in whom psychosocial interventions were deemed to be ineffective or not appropriate.

Numerator – The number of people in the denominator for whom psychosocial interventions were deemed to be ineffective or not appropriate.

Denominator – The number of people with autism and behaviour that challenges currently receiving drug treatment to manage their behaviour that challenges.

**Data source:** Local data collection. [Included in NICE clinical audit tool – Autism in adults – challenging behaviour](#), audit standards 3 and 4

### ***What the quality statement means for service providers, health professionals and social care practitioners, and commissioners***

**Service providers** ensure that systems are in place for people with autism and behaviour that challenges to be offered drug treatment for their behaviour that challenges only if psychosocial interventions are not effective or not appropriate.

**Health professionals and social care practitioners** ensure that they offer people with autism and behaviour that challenges drug treatment for their behaviour that challenges only if psychosocial interventions are not effective or not appropriate.

**Commissioners** ensure that they commission services that offer psychosocial interventions for people with autism and behaviour that challenges, and offer drug treatment only if psychosocial interventions are not effective or not appropriate.

### ***What the quality statement means for service users and carers***

**People with autism who behave in a challenging way that puts themselves or others at risk** are offered medication to help manage their behaviour only if psychological or social support has not worked well enough or is not appropriate for them.

### ***Source guidance***

- [Autism: management of autism in children and young people](#) (NICE clinical guideline 170), recommendation [1.4.10](#) key priority for implementation
- [Autism in adults](#) (NICE clinical guideline 142), recommendation [1.5.6](#) and [1.5.8](#)

### ***Definitions of terms used in this quality statement***

#### **Behaviour that challenges**

Behaviour that challenges includes but is not limited to: physical aggression towards self (self-injury); severe levels of 'habitual behaviours' such as rocking and head-banging; aggression towards others; destruction of property; temper outbursts; high levels of oppositionality and defiance; and verbal aggression. Patterns of behaviour that challenges are extremely variable; behaviours may be frequent or rare and individual acts can have minor or severe consequences for the person and others.

## **Psychosocial interventions**

Psychosocial interventions might be effective in helping certain groups of people with autism and challenging behaviour to manage their behaviour. In some cases the psychosocial interventions alone are not effective and for some people with severe behaviour it would not be appropriate to try psychosocial interventions in the first instance until their behaviour is more under control. Psychosocial interventions for challenging behaviour should include:

- clearly identified target behaviour(s)
- a focus on outcomes that are linked to quality of life
- assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour
- a clearly defined intervention strategy
- a clear schedule of reinforcement, and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour
- a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- a systematic measure of the target behaviour(s) taken before and after the intervention to ascertain whether the agreed outcomes are being met

## **Drug treatment**

Antipsychotic<sup>1</sup> medication should be considered for managing behaviour that challenges in people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. The drug treatment should be delivered in accordance with the NICE Autism guidelines by a suitably qualified expert.

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<sup>1</sup> At the time of the guideline development (Publication 2012), no antipsychotic medication had a UK marketing authorisation for use in children, young people or adults for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Good practice in prescribing medicines – guidance for doctors for further information.

## **Status of this quality standard**

This is the draft quality standard released for consultation from 2 September 2013 to 30 September 2013. It is not NICE's final quality standard on autism. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 30 September 2013. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from February 2014.

## **Using the quality standard**

### ***Quality measures***

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [What makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

### ***Levels of achievement***

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

### ***Using other national guidance and policy documents***

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered by commissioners, providers, health and social care practitioners, patients, service users and carers alongside the documents listed in 'Development sources'.

## **Diversity, equality and language**

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health and social care practitioners and people with autism is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with autism should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

## **Development sources**

Further explanation of the methodology used can be found in the quality standards [process guide](#) on the NICE website.

## ***Evidence sources***

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [Autism: management of autism in children and young people](#). NICE clinical guideline 170 (2013)
- [Autism in adults](#). NICE clinical guideline 142 (2012)
- [Autism spectrum disorders in children and young people](#). NICE clinical guideline 128 (2011)
- [Improving access to social care for adults with autism](#). Social Care Institute for Excellence (2011)

## ***Policy context***

It is important that the quality standard is considered alongside current policy documents, including:

- 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 for Education (2012) [Children and Families Bill](#)
- Department of Health (2012) [Transforming care: a national response to Winterbourne View Hospital Department of Health review: final report](#)
- Department of Health, 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](#)
- The Information Centre for Health and Social Care (2012) [Estimating the prevalence of autism spectrum conditions in adults: Extending the 2007 Adult Psychiatric Morbidity Survey](#)
- Autism Education Trust (2011) [What is good practice in autism education?](#)
- Department for Education (2009) [Inclusion development programme: supporting children on the autism spectrum – guidance for practitioners in the early years](#)

- National Autistic Society, British Association of Social Workers (2008) [Social care: assessment of needs for adults with autism](#)
- National Autistic Society (2006) [Is no news good news? Exploring potential quality indicators in autism education](#)
- Sheffield School of Health & Related Research University of Sheffield (2005) [Sheffield survey of the health and social care needs of adolescents and adults with Asperger syndrome](#)

### ***Definitions and data sources for the quality measures***

Definitions developed from the stated evidence source recommendations with input from specialist committee members where further clarification was required.

## **Related NICE quality standards**

### ***Published***

- [Patient experience in adult NHS services](#). NICE quality standard 15 (2012).
- [Service user experience in adult mental health](#). NICE quality standard 14 (2011).

### ***In development***

- [Conduct disorders in children and young people](#). Publication expected April 2014.

### ***Future quality standards***

This quality standard has been developed in the context of [all quality standards referred to NICE](#), including the following topics scheduled for future development:

- Coordinated transition between social care and health care services.
- Coordinated transition from children's to adults' services for young people with social care needs.

## **Quality Standards Advisory Committee and NICE project team**

### ***Quality Standards Advisory Committee***

This quality standard has been developed by the following members of the [Quality Standards Advisory Committee 3](#):

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## **About this quality standard**

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. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).