

Autism

Quality standard

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This standard is based on CG128, CG142 and CG170.

This standard should be read in conjunction with QS39, QS14, QS15, QS59, QS101 and QS169.

Introduction

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. These can include a need for routine and difficulty understanding other people, including their intentions, feelings and perspectives. Approximately 50% of people with autism have an intellectual disability (IQ below 70), and around 70% of people with autism also meet diagnostic criteria for at least 1 other (often unrecognised) physical or mental health problem, such as sleep problems, eating problems, epilepsy, anxiety, depression, problems with attention, dyspraxia, motor coordination problems, sensory sensitivities, self-injurious behaviour and other behaviour that challenges (sometimes aggressive). These problems 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 the differing levels of cognitive ability, which can range from profound intellectual disability in some people to average or above average intellectual ability in others.

The provision of services for people with autism is varied across England and Wales. The [Autism Act \(2009\)](#) requires each local authority area to develop a local autism strategy for the provision of health and social care services for people with autism (aged 14 years and older). A key role of the strategy is to facilitate the development of services to meet the needs of people with autism, including identifying a local lead to oversee service provision. The NICE guidelines on autism (and the [NICE Pathway on autism](#)) make similar recommendations. This quality standard should be used

alongside the strategy and NICE guidelines, as a tool to inform the commissioning of autism services for children, young people and adults focusing on the key areas for improving the quality of existing services.

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 2014 to 2015](#)
- [NHS Outcomes Framework 2014 to 2015](#)

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 the [related NICE quality standards section](#).

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 working with, 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. The specialist committee members who contributed to the development of this quality standard emphasised the importance of people with autism being involved in the delivery of

training to health, social care and education practitioners.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with autism. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

List of quality statements

Statement 1 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.

Statement 2 People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3 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.

Statement 4 People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5 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.

Statement 6 People with autism are not prescribed medication to address the core features of autism.

Statement 7 People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8 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.

Quality statement 1: Diagnostic assessment by an autism team

Quality statement

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.

Rationale

There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. 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.

Quality measures

Structure

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

Data source: Local data collection.

Process

Proportion of people with possible autism referred to an autism team for a diagnostic assessment 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 an autism team for a diagnostic assessment.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that they are part of a transparent diagnostic pathway for autism, and that people with possible autism who are referred to an autism team for a diagnostic assessment have the assessment started within 3 months of their referral.

Health and social care practitioners working within an autism team ensure that people with possible autism who are referred for a diagnostic assessment have the assessment started within 3 months of their referral.

Commissioners should work with local health, social care and education partners to commission an autism diagnostic pathway that includes provisions for people referred for a diagnostic assessment by an autism team to have the assessment started within 3 months of their referral.

People who are referred for an assessment because they may have autism are seen by a specialist autism team and have their assessment started within 3 months.

Source guidance

- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE guideline CG128](#) (2011, updated 2017), recommendation 1.5.1
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142](#) (2012, updated 2016), recommendation 1.2.5

Definitions of terms used in this quality statement

Autism team

The team conducting the assessment for children, young people or adults should be a specialist integrated autism team with age-appropriate expertise, and should be part of the local autism diagnostic pathway (as required by the [Autism Act 2009](#)).

Children and young people

The core staff of the autism team for children and young people should include:

- paediatricians and/or child and adolescent psychiatrists

- speech and language therapists
- clinical and/or educational psychologists.

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

- paediatricians or paediatric neurologists
- child and adolescent psychiatrists
- clinical and educational psychologists
- occupational therapists
- other professionals who may assist with the assessment, for example specialist health visitors or nurses, specialist teachers or social workers.

[Adapted from [NICE's guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), recommendations 1.1.3 and 1.1.4]

Adults

A local adult autism team should include:

- 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).

[Adapted from [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#), recommendation 1.1.13]

Diagnostic assessment

This definition describes the autism diagnostic assessment for people who the autism team decide need an assessment. Some people who are referred for assessment will not receive a diagnostic assessment if the team's initial review of the referral suggests that the person does not have autism. For these people the autism team will either refer the person to another service and/or inform the practitioner who made the initial referral.

Children and young people

The following should be included in every autism diagnostic assessment for children and young people:

- 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-5) 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 diagnoses (see [NICE's guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), recommendation 1.5.7).
- Systematic assessment for conditions that may coexist with autism (see [NICE's guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), recommendation 1.5.15).

- Developing a profile of the child or young person's strengths, skills, impairments and needs, including: intellectual ability and learning style, academic skills, speech, language and communication, fine and gross motor skills, adaptive behaviour (including self-help skills), mental and emotional health (including self-esteem), physical health and nutrition, sensory sensitivities, and behaviour likely to affect day-to-day functioning and social participation. This profile can be used to create a personalised plan, taking into account family and educational context. The assessment findings should be communicated to the parent or carer and, if appropriate, the child or young person.

[Adapted from [NICE's guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), recommendations 1.4.1 to 1.4.8, 1.5.5 and 1.5.8]

Adults

During a comprehensive diagnostic 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 and in the community (for example, in education or in employment)
- past and current physical and mental health problems
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities.

Carry out direct observation of core autism signs and symptoms, especially in social situations. Include observation of risk behaviours and safeguarding issues. [Adapted from [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#), recommendations 1.2.5 to 1.2.7 and 1.2.12]

Equality and diversity considerations

If the local autism team does not have the expertise to carry out an assessment, or in complex situations, a person may need to be referred to the regional (national specialist) team.

If a person does not have access to a specialist autism team near their homes, and has difficulty travelling long distances (because of the financial cost or other reasons), support may be needed to help them access the service.

Quality statement 2: Assessment and diagnosis

Quality statement

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

Rationale

People with autism may have coexisting physical health conditions and/or mental health problems that, if unrecognised and untreated, will further impair the person's psychosocial functioning and could place additional pressure on families and carers. Because of their social communication difficulties, some people with autism may find it particularly difficult to communicate their needs and to access mainstream health and social care services.

Quality measures

Structure

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

Numerator – The number of people in the denominator who have an assessment 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 affect the psychosocial functioning of the person with autism.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that there is sufficient provision of staff with suitable experience to ensure that people having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Health and socialcare practitioners ensure that people having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems, and that any findings are shared with the person and their family and carers (if appropriate) and are taken into account in the agreed personalised plan (see [quality statement 3](#)).

Commissioners commission services in which people having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

People who are having an assessment because they may have autism are also assessed to see if they have any other physical health conditions and/or mental health problems. If any other conditions are found the person is told about these.

Source guidance

- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE guideline CG128](#) (2011, updated 2017), recommendation 1.5.15
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142](#) (2012, updated 2016), recommendation 1.2.10

Definitions of terms used in this quality statement

Assessment for coexisting physical health conditions and mental health problems

Note that if an autism team does not have the relevant expertise to conduct these assessments, the child, young person or adult should be referred to services that can conduct the assessment.

Children and young people

The assessment could include the following:

- Mental health and behavioural 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 type 1.
- 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.

[Adapted from [NICE's guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), recommendation 1.5.15]

Adults

The assessment could 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, obsessive–compulsive disorder and eating disorders)
- neurological disorders (for example, epilepsy or processing problems)
- physical health conditions
- communication difficulties (for example, speech and language problems, and selective mutism)

- hyper- and hypo-sensory sensitivities.

[Adapted from [NICE's guideline on autism spectrum disorder in adults: diagnosis and management, recommendation 1.2.10](#)]

Quality statement 3: Personalised plan

Quality statement

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.

Rationale

The needs of people with autism are varied, with some people needing complex levels of support from a range of professionals and some people not wanting or needing any ongoing support. A personalised plan that is informed by the full diagnostic assessment and the individual needs of the person with autism, and recognises 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 plan will need to be updated and reviewed as the person's needs and circumstances change. It will also need to take into account, inform and be consistent with any other plans or care packages they may have, including Education, Health and Care plans for children and Community Care Assessments for adults.

Quality measures

Structure

Evidence of local arrangements to ensure that 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.

Data source: Local data collection.

Process

a) The proportion of people with autism who have a personalised plan that is developed in a partnership between them and their family and carers (if appropriate) and the autism team.

Numerator – The number of people in the denominator who have a personalised plan that is developed in a partnership between them and their family and carers (if appropriate) and the autism team.

Denominator – The number of people diagnosed with autism.

Data source: Local data collection.

b) The proportion of people with autism who have their personalised plan implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Numerator – the number of people in the denominator who have their personalised plan implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Denominator – the number of people with autism who have a personalised plan developed.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that when a person is diagnosed with autism, the autism team works in partnership with them and (if appropriate) their family and carers to develop and implement a personalised plan that takes into account and is consistent with any other plans or packages of care they may have.

Health and social care practitioners ensure that they work in partnership with people diagnosed with autism and (if appropriate) their family and carers to develop and implement a personalised plan.

Commissioners from across health, social care and education agencies work together to commission services in which, when a person is diagnosed with autism, the autism team works in partnership with the person and (if appropriate) their family and carers to develop and implement a personalised plan.

People with autism and (if appropriate) their family and carers have the opportunity to work together with their autism team to develop and implement a personalised plan that sets out what support they need and how best that support should be provided.

Source guidance

- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE guideline CG128](#) (2011, updated 2017), recommendations 1.5.5 (key priority for implementation) and 1.5.8
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142](#) (2012, updated 2016), recommendation 1.2.13
- [Improving access to social care for adults with autism. SCIE guide 43](#), Personalising services section, page 37

Definitions of terms used in this quality statement

Personalised plan

A personalised plan should be based on an assessment of needs, taking into account the person's strengths, skills, mental and physical impairment, family and social context, and for children and young people their educational context. The plan should cover:

- any post-diagnostic support that the person and their family and carers need
- what interventions, support and timescales are most appropriate for the person; these include clinical interventions and social support, such as support in relation to education, employment or housing
- preventative action to address triggers that may provoke behaviour that challenges
- any further interventions for identified coexisting conditions.

The plan should also include a risk management plan for people with behaviour that challenges or complex needs. For young people under 18 years the plan should also include managing the transition from child to adult services. [Adapted from [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#), recommendations 1.2.12 and 1.2.13; and [NICE's guideline on autism spectrum disorder in under 19s: support and management](#), recommendation 1.4.2]

Quality statement 4: Coordination of care and support

Quality statement

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

Rationale

People with autism have broad and varied needs, and their care can involve services from a number of providers. People with autism will need different levels of care and support, as detailed in their personalised plan, and a named key worker can help to ensure that they receive an integrated package of care. If a young person or adult, or a parent or carer on behalf of a younger child, accepts the offer of a named key worker to help coordinate their care, they should be involved in the decision about which professional is the most appropriate to provide that support.

Quality measures

Structure

Evidence of local arrangements for people with autism to be offered a named key worker to coordinate the care and support detailed in their personalised plan

Data source: Local data collection.

Process

The proportion of people with autism who are having the care and support detailed in their personalised plan coordinated by a named key worker.

Numerator – The number of people in the denominator who are having their care and support coordinated by a named key worker.

Denominator – The number of people with autism with an agreed personalised plan.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that they have sufficient staffing capacity and protocols in place with local partners to offer all people with autism a named key worker to coordinate the care and support detailed in their personalised plan.

Health and social care practitioners ensure that they offer all people with autism a named key worker to coordinate the care and support detailed in their personalised plan.

Commissioners from across health, social care and education agencies commission services in which all people with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

People with autism are offered the chance to have a named 'key worker' – that is, a health or social care practitioner who will coordinate the care and support that is set out in their personalised plan. If they agree to having a named key worker, they are involved in deciding who that person will be.

Source guidance

- [Autism spectrum disorder in under 19s: support and management. NICE guideline CG170 \(2013\), recommendation 1.1.4](#)
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 \(2012, updated 2016\), recommendation 1.8.10](#)

Definitions of terms used in this quality statement

Named key worker

For children and young people with autism, the named key worker may be a member of the autism team, or someone from local community services identified by the autism team and the child or young person and their family and carers as being suitable to coordinate their care and support. Adults receiving care from the autism team should also have a named key worker. For adults not receiving care from the autism team, mental health or learning disability services, the key worker could be a member of the primary healthcare team.

Once someone has been diagnosed with autism, a named key worker should ensure that the person's personalised plan is implemented and reviewed as their circumstances and needs change. This should include ongoing responsiveness to changing needs, and in particular supporting the transition for young people as they move to secondary school, approach young adulthood and move from child to adult services. [Adapted from [NICE's guideline on autism spectrum disorder in under 19s: support and management](#), recommendation 1.1.4; and [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#), recommendation 1.8.7; additional information based on the expert opinion of specialist committee members]

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

Quality statement

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.

Rationale

Psychosocial interventions should be considered for people with autism and their families and carers, because evidence suggests that they can help in the management of the core features of autism for some people. Different types of psychosocial interventions should be considered, depending on the age and needs of the person. Current practice suggests that the availability of psychosocial interventions for people with autism is variable.

Quality measures

Structure

Evidence of local arrangements to ensure that all 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.

Data source: Local data collection

Process

The proportion of people with autism who 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.

Numerator – the number of people in the denominator who 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.

Denominator – the number of people with autism.

Data source: Local data collection

What the quality statement means for different audiences

Service providers ensure that there is sufficient availability of the appropriate psychosocial interventions for staff to be able to offer people with autism the opportunity to take part in psychosocial interventions to help address the core features of autism

Health and social care practitioners ensure that they have documented discussions with people who have autism about age-appropriate psychosocial interventions to help address the core features of autism.

Commissioners work with providers to ensure that age-appropriate psychological interventions to help address the core features of autism are available for people with autism.

People with autism and (if appropriate) their families and carers have a discussion with members of the autism team (or other health or social care practitioners) about whether they would benefit from taking part in activities to help them with the main signs of autism. For children these activities could include play-based learning and improving social skills. For adults they could include leisure activities, improving social skills, and help with day-to-day activities and with getting a job.

Source guidance

- [Autism spectrum disorder in under 19s: support and management. NICE guideline CG170 \(2013\), recommendation 1.3.1](#)
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 \(2012, updated 2016\), recommendations 1.4.1 to 1.4.12](#)

Definitions of terms used in this quality statement

Psychosocial interventions for children and young people

This describes social-communication interventions to address the core features of autism in children and young people, based on recommendation 1.3.1 in [NICE's guideline on autism spectrum disorder in under 19s: support and management](#), including play-based strategies with parents,

carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:

- be adjusted to the child or young person's developmental level
- aim to increase the parents, carers, teachers or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
- include techniques of therapist modelling and video-interaction feedback
- include techniques to expand the child or young person's communication, interactive play and social routines.

The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

Psychosocial interventions for adults

The most appropriate psychosocial interventions for adults with autism should be identified based on the person's specific needs. The decision-making process should be based on recommendations 1.3.1 to 1.3.5 in [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#). Recommendations 1.4.1 to 1.4.12 describe the different types of psychosocial interventions and how they should be delivered.

Core features of autism

The core features 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. [Adapted from [NICE's guideline on autism spectrum disorder in under 19s: support and management](#), recommendation 1.3.1; and [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#), recommendations 1.4.1 to 1.4.12]

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

Quality statement

People with autism are not prescribed medication to address the core features of autism.

Rationale

Drug treatments have been shown to be ineffective in addressing the core features of autism. They also carry significant potential risks.

Quality measures

Structure

Evidence of local arrangements to ensure that people with autism are not prescribed medication to address the core features of autism.

Data source: Local data collection.

Process

The proportion of people with autism who are prescribed medication to address the core features of autism.

Numerator – The number of people in the denominator who are prescribed medication to address the core features of their autism.

Denominator – The number of people with autism.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers work with their clinical staff to ensure that medication is not prescribed to address the core features of autism.

Health and social care practitioners ensure that they do not prescribe medication to address the core features of autism, and consider other treatments such as psychosocial interventions.

Commissioners ensure that they commission services in which staff do not prescribe medication to address the core features of autism, and that other treatments, such as psychosocial interventions, are available.

People with autism are not prescribed medication to treat the main signs of autism.

Source guidance

- [Autism spectrum disorder in under 19s: support and management. NICE guideline CG170 \(2013\)](#), recommendation 1.3.2
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 \(2012, updated 2016\)](#), recommendations 1.4.13, 1.4.16, 1.4.21 and 1.4.22

Definitions of terms used in this quality statement

Medication not recommended for the core features of autism

This includes:

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

It should be noted that [statement 8](#) in this quality standard refers to populations for which, in certain circumstances, medication may be appropriate for the short-term treatment of challenging behaviour. [Adapted from [NICE's guideline on autism spectrum disorder in under 19s: support and](#)

management, recommendation 1.3.2, and NICE's guideline on autism spectrum disorder in adults: diagnosis and management, recommendations 1.4.13, 1.4.16, 1.4.21 and 1.4.22].

Core features of autism

The core features 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. [Adapted from NICE's guideline on autism spectrum disorder in under 19s: support and management]

Quality statement 7: Assessing possible triggers for behaviour that challenges

Quality statement

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

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 health conditions, mental health problems and environmental factors (that is, relating to the person's social or physical environment). An assessment should take all these factors into account, and also consider the risk of harm to the person and others, before appropriate interventions are agreed for the behaviour and any identified physical health conditions or mental health problems.

Quality measures

Structure

Evidence of local arrangements to ensure that people with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Data source: Local data collection.

Process

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

Numerator – The number of people in the denominator who are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors

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

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that there is staffing capacity and capability so that people with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Health and socialcare practitioners ensure that people with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Commissioners work with provider services to ensure that there is sufficient staffing capacity and capability so that people with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

People with autism who behave in a way that other people find difficult (for example, becoming very upset or aggressive) have an assessment that looks for possible reasons why they are behaving in this way. These might include other physical health conditions and/or mental health problems, or any changes to their environment (for example, at home, school or work).

Source guidance

- [Autism spectrum disorder in under 19s: support and management. NICE guideline CG170](#) (2013), recommendation 1.4.1 (key priority for implementation), 1.4.2 and 1.4.3
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142](#) (2012, updated 2016), recommendations 1.2.20 and 1.5.1

Definitions of terms used in this quality statement

Behaviour that challenges

This is defined as culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour

which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. [[The Challenging Behaviour Foundation](#): Emerson, E (2001) Challenging Behaviour: Analysis and intervention in people with learning disabilities. Cambridge: Cambridge University Press]

Assessment for possible triggers

Children and young people

Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism. If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could provoke the behaviour, including:

- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- coexisting physical disorders, such as pain or gastrointestinal disorders
- coexisting mental health problems, such as anxiety or depression, and other neurodevelopmental conditions such as ADHD (attention deficit hyperactivity disorder)
- the physical environment, such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances
- developmental changes, including puberty
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges
- the absence of predictability and structure.

[Adapted from [NICE's guideline on autism spectrum disorder in under 19s: support and management](#), recommendations 1.4.1 to 1.4.3]

Adults

Before starting other interventions for behaviour that challenges, assess for any factors that may

trigger or maintain the behaviour, including:

- 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.

[Adapted from [NICE's guideline on autism spectrum disorder in adults: diagnosis and management, recommendation 1.2.20](#)]

Quality statement 8: Interventions for behaviour that challenges

Quality statement

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.

Rationale

The first-line intervention for behaviour that challenges should be appropriate psychosocial interventions or interventions to address any identified triggers for that behaviour. In some cases psychosocial or other interventions are not sufficient on their own, or they cannot be delivered because of the severity of the behaviour. In this situation a paediatrician or psychiatrist, working with the person with autism and their family and carers, might consider starting a trial of antipsychotic medication in an attempt to manage the behaviour that challenges. The professional should continue to monitor any subsequent use of antipsychotic medication.

Quality measures

Structure

Evidence of local arrangements to monitor the use of antipsychotic medication in people with autism and behaviour that challenges.

Data source: Local data collection.

Process

The proportion of people with autism and behaviour that challenges having antipsychotic medication for the treatment of their behaviour that challenges in whom psychosocial interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Numerator – The number of people in the denominator for whom psychosocial interventions are insufficient or cannot be delivered because of the severity of the behaviour.

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

Data source: Local data collection.

What the quality statement means for different audiences

Service providers ensure that staff working with people with autism and behaviour that challenges do not offer antipsychotic medication for the person's behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Health and socialcare practitioners ensure that they do not offer people with autism and behaviour that challenges 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. If antipsychotic medication is prescribed it should be monitored by a suitable expert.

Commissioners require providers to monitor the use of antipsychotic medication for the treatment of behaviour that challenges and look for evidence to ensure that when antipsychotic medication was prescribed, psychosocial or other interventions had been attempted or considered but had been insufficient or could not be delivered because of the severity of the behaviour.

People with autism who behave in a way that other people find difficult should not be offered medication to treat their behaviour unless other treatments are not helping or cannot be used, either because of the seriousness of the person's behaviour or because of the risk to the person or others.

Source guidance

- [Autism spectrum disorder in under 19s: support and management. NICE guideline CG170 \(2013\), recommendation 1.4.10 \(key priority for implementation\)](#)
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 \(2012, updated 2016\), recommendations 1.5.6 and 1.5.8](#)

Definitions of terms used in this quality statement

Behaviour that challenges

This is defined as culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. [[The Challenging Behaviour Foundation](#): Emerson E (2001) Challenging Behaviour: Analysis and intervention in people with learning disabilities. Cambridge: Cambridge University Press]

Psychosocial interventions

Psychosocial interventions for behaviour that challenges 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 starting 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 check whether the agreed outcomes are being met
- consistent application in all areas of a child or young person's environment (for example, at home and at school)
- for a child or young person, agreement among parents, carers and professionals in all settings about how to implement the intervention.

In addition to the above interventions, the assessment of potential triggers for behaviour that challenges referred to in quality statement 7 should also be carried out before introducing any treatment. [Adapted from [NICE's guideline on autism spectrum disorder in under 19s: support and](#)

management, recommendation 1.4.9; and NICE's guideline on autism spectrum disorder in adults: diagnosis and management, recommendation 1.5.6]

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.

For further information see [how to use NICE quality standards](#).

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 for this quality standard](#) are available.

Good communication between health and social care practitioners and people with autism, and their families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and 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, and their families or carers (if appropriate), 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](#).

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 spectrum disorder in under 19s: support and management. NICE guideline CG170 \(2013\)](#)
- [Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 \(2012, updated 2016\)](#)
- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE guideline CG128 \(2011, updated 2017\)](#)
- [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:

- [Department for Education. Children and Families Bill \(2013\)](#)
- [Care Quality Commission. 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 \(2012\)](#)
- [Department of Health. Transforming care: a national response to Winterbourne View Hospital Department of Health review: final report \(2012\)](#)
- [Department of Health, National Audit Office. Progress in implementing the 2010 Adult Autism Strategy \(2012\)](#)

- [Improving Health and Lives: Learning Disabilities Observatory. Autism Self Assessment 2011: issues from local authorities \(2012\)](#)
- [NHS Digital. Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey \(2012\)](#)
- [Autism Education Trust. What is good practice in autism education? \(2011\)](#)
- [Department of Health. Fulfilling and rewarding lives: the strategy for adults with autism in England \(2010\)](#)
- [Department for Education. Inclusion development programme: supporting children on the autism spectrum – guidance for practitioners in the early years foundation stage \(2009\)](#)
- [HM Government. The National Autism Act \(2009\)](#)
- [National Autistic Society, British Association of Social Workers. Social care: assessment of needs for adults with autism \(2008\)](#)
- [National Autistic Society. Is no news good news? Exploring potential quality indicators in autism education \(2006\)](#)
- [Sheffield School of Health & Related Research University of Sheffield. Sheffield survey of the health and social care needs of adolescents and adults with Asperger syndrome \(2005\)](#)

Definitions and data sources for the quality measures

Definitions were developed from the stated evidence source recommendations, with input from specialist committee members if further clarification was needed.

Related NICE quality standards

- [Transition from children's to adults' services. NICE quality standard 140 \(2016\)](#)
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs. NICE quality standard 136 \(2016\)](#)
- [Antisocial behaviour and conduct disorders in children and young people. NICE quality standard 59 \(2014\)](#)
- [Patient experience in adult NHS services. NICE quality standard 15 \(2012, updated 2019\)](#)
- [Service user experience in adult mental health. NICE quality standard 14 \(2011, updated 2019\)](#)

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by quality standards advisory committee 3. Membership of this committee is as follows:

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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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standard advisory committees](#) for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

This quality standard has been included in the [NICE Pathway on autism](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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Endorsing organisations

This quality standard has been endorsed by the following organisations, as required by the Health and Social Care Act (2012):

- [Department of Health and Social Care](#)
- [NHS England](#)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [British Psychological Society \(BPS\)](#)
- [Royal College of Occupational Therapists \(RCOT\)](#)
- [National Autistic Society](#)
- [Research Autism](#)
- [Royal College of General Practitioners \(RCGP\)](#)
- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Paediatrics and Child Health](#)
- [Royal College of Psychiatrists \(RCPsych\)](#)
- [Social Care Institute for Excellence](#)
- [Thinking Autism](#)