NICE National Institute for Health and Care Excellence

NICE quality standard

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.

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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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

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 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records. NHS Digital's Autism Waiting Time Statistics includes data on waiting time from referral to specialist mental health services for suspected autism to first care contact.

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 with 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 2021), 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
- psychologists with training and experience in working with autistic children and young people.

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

- paediatricians or paediatric neurologists
- child and adolescent psychiatrists
- psychologists with training and experience complementary to psychologists in the core team
- 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, recommendations 1.1.3 and 1.1.4]

Adults

A local adult autism team should include:

- psychologists with training and experience in working with autistic adults.
- 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 features suggesting possible autism (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 features suggesting possible autism, 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

Autistic people may have coexisting physical health conditions 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 autistic people may find it particularly difficult to communicate their needs and to access mainstream health and social care services.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

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 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Outcome

Morbidity from unidentified physical health conditions and mental health problems that affect the psychosocial functioning of the autistic person.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

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 social care 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 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 2021), 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. [Expert opinion]

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, growth or nutritional 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 and NICE's guideline on autism spectrum disorder in under 19s: support and management, recommendation 1.7.10]

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

Autistic people 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 autistic people 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 autistic person, 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 young people and community care assessments for adults.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that autistic people 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

a) The proportion of autistic people 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 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

b) The proportion of autistic people 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 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 autistic people who have a personalised plan developed.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

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.

Autistic people 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 and 1.5.8
- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), 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

Autistic people are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Rationale

Autistic people have broad and varied needs, and their care can involve services from a number of providers. Autistic people 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

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

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

Denominator – the number of autistic people with an agreed personalised plan.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

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 autistic people 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 autistic people 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 autistic people are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Autistic people 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, updated 2021), recommendation 1.1.4

- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), recommendation 1.8.10

Definitions of terms used in this quality statement

Named key worker

For autistic children and young people, 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; and expert opinion]

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

Quality statement

Autistic people 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 autistic people 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 autistic people is variable.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that all autistic people 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

The proportion of autistic people 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 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 autistic people.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

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 autistic people 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 autistic people 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 autistic people.

Autistic people 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, updated 2021), recommendation 1.3.1
- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), 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, 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. [NICE's guideline on autism spectrum disorder in under 19s: support and management, recommendation 1.3.1]

Psychosocial interventions for adults

The most appropriate psychosocial interventions for autistic adults 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, introduction]

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

Quality statement

Autistic people 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

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

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

Denominator – the number of autistic people.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

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.

Autistic people 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, updated 2021), recommendation 1.3.2
- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), 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 behaviour that challenges. [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, introduction]

Quality statement 7: Assessing possible triggers for behaviour that challenges

Quality statement

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

Rationale

Autistic people can sometimes present with behaviour that is challenging to manage. The causes of behaviour that challenges for an autistic person 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

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

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

Denominator – the number of autistic people who develop behaviour that challenges.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

What the quality statement means for different audiences

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

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

Autistic people 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 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, updated 2021), recommendations 1.4.1 to 1.4.3
- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), 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 autistic children and young people. 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

Autistic people with 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 autistic person 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols.

Process

The proportion of autistic people with 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 in the denominator for whom psychosocial interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Denominator – the number of autistic people with behaviour that challenges currently receiving antipsychotic medication to manage their behaviour that challenges.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

What the quality statement means for different audiences

Service providers ensure that staff working with autistic people with 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 social care practitioners ensure that they do not offer autistic people with 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.

Autistic people 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, updated 2021), recommendation 1.4.10
- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021), 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]

Update information

Minor changes since publication

August 2023: We updated the description of psychologists in the definition of 'autism team'. These reflect amendments to the source guidance, which were made in line with current practice and the British Psychological Society's best practice in psychology recruitment. In the section 'children and young people' we changed 'clinical and/or educational psychologists'to 'psychologists with training and experience in working with autistic children and young people' and 'clinical and educational psychologists' to 'psychologists with training and experience complementary to psychologists in the core team'. In the 'adults' section we changed 'clinical psychologists' to 'psychologists with training and experience in working with autistic adults'.

January 2022: We updated the quality standard to reflect changes in current terminology in line with changes made to the source guidance. We changed 'people with autism' to 'autistic people', 'challenging behaviour' to 'behaviour that challenges' and 'symptoms' to 'features'. We also updated the definition of 'assessment of coexisting physical health conditions and mental health problems' for children and young people in statement 2 to include 'growth and nutritional problems' to reflect the new recommendation on assessment and referral for children and young people with feeding problems and restricted diets in the NICE guideline on autistic spectrum disorder in under 19s: support and management.

The previous version of the quality standard for autism is available as a pdf.

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.

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 guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this

quality standard are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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.

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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
- 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