Autism spectrum disorder in adults: diagnosis and management

Clinical guideline

Published: 27 June 2012

www.nice.org.uk/guidance/cg142

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS51.

Introduction

Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities'). People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.

There is wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multi-professional working, assessment criteria and diagnostic practice for adults with features of autism. These factors contribute to delays in reaching a diagnosis and subsequent access to appropriate services.

When the diagnostic assessment process works well, professionals, the person with autism and their family, partner or carer(s) communicate right from the start and the person with autism is involved in the decisions relating to their care. This lays the foundation for a long-term understanding between the person with autism, their family, partner or carer(s) and the professionals supporting their needs. However, many adults with suspected autism have difficulties accessing a diagnostic assessment. Even if they manage to obtain a diagnosis they may receive no follow-up support because of the absence of appropriate services or an agreed care pathway.

In this guideline 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's

syndrome and atypical autism (or pervasive developmental disorder not otherwise specified). The Guideline Development Group recognises, however, that different individuals and groups prefer a variety of terms for autism including autistic spectrum condition, autistic spectrum difference and neurodiversity (in recent Department of Health, National Audit Office and Public Accounts Committee documents, 'autism' is used to cover all of these terms).

This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

A number of recommendations in this guideline have been adapted from recommendations in other NICE clinical guidelines. Where this occurred, the Guideline Development Group was careful to preserve the meaning and intent of the original recommendations. Changes to wording or structure were made in order to fit the recommendations into this guideline. In all cases, the original source of any adapted recommendations is indicated in a footnote.

The guideline will assume that prescribers will use a drug's summary of product characteristics (SPC) to inform decisions made with individual patients. In this guideline, drug names are marked with a footnote if they do not have a UK marketing authorisation for the indication in question at the time of publication. Prescribers should check each drug's SPC for current licensed indications.

Person-centred care

This guideline offers best practice advice on the care of adults with autism.

Support and care should take into account peoples' needs and preferences. People with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals. If adults with autism do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. In Wales, healthcare professionals should follow advice on consent from the Welsh Government.

Good communication between healthcare professionals and people with autism and their families, partners and carers is essential. It should be supported by evidence-based written information tailored to the person's needs. Support and care, and the information people are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

If the person with autism agrees, families, partners and carers should have the opportunity to be involved in decisions about support and care.

Families, partners and carers should also be given the information and support they need.

Care of young people in transition between paediatric services/child and adolescent mental health services (CAMHS) and adult services should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people.

Adult and paediatric healthcare/CAMHS teams should work jointly to provide assessment and services to young people with autism. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

General principles of care

- All staff working with adults with autism should:

  — work in partnership with adults with autism and, where appropriate, with their families, partners or carers

  — offer support and care respectfully

  — take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

- In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

Identification and assessment

- Consider assessment for possible autism when a person has:

  — one or more of the following:

    ◇ persistent difficulties in social interaction

    ◇ persistent difficulties in social communication

    ◇ stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**

  — one or more of the following:

    ◇ problems in obtaining or sustaining employment or education

    ◇ difficulties in initiating or sustaining social relationships

    ◇ previous or current contact with mental health or learning disability services

    ◇ a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

- For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores above six on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

- When assessing challenging behaviour carry out a functional analysis (see recommendation 1.5.3) including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

  — physical disorders

  — the social environment (including relationships with the family, partner, carer(s) and friends)

  — the physical environment, including sensory factors

  — coexisting mental disorders (including depression, anxiety disorders and psychosis)

  — communication problems

  — changes to routine or personal circumstances.

Interventions for autism

- For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

Organisation and delivery of care

- Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

  — developing clear policy and protocols for the operation of the pathway

  — ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway

  — making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services

  — supporting the integrated delivery of services across all care settings

  — supporting the smooth transition to adult services for young people going through the pathway

  — auditing and reviewing the performance of the pathway.

1 Guidance

The following guidance is based on the best available evidence. The full guideline gives details of the methods and the evidence used to develop the guidance.

1.1 General principles of care

Principles for working with adults with autism and their families, partners and carers

1.1.1 All staff working with adults with autism should:

- work in partnership with adults with autism and, where appropriate, with their families, partners and carers

- offer support and care respectfully

- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

1.1.2 All staff working with adults with autism should have an understanding of the:

- nature, development and course of autism

- impact on personal, social, educational and occupational functioning

- impact of the social and physical environment.

1.1.3 All health and social care professionals providing care and support for adults with autism should have a broad understanding of the:

- nature, development and course of autism

- impact on personal, social, educational and occupational functioning

- impact of and interaction with the social and physical environment

- impact on and interaction with other coexisting mental and physical disorders and their management

- potential discrepancy between intellectual functioning as measured by IQ and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

1.1.4　All health and social care professionals providing care and support for adults with autism should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management

- maintain continuity of individual relationships wherever possible

- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy read, and different colour and font formats)

- consider whether the person may benefit from access to a trained advocate.

1.1.5　All health and social care professionals providing care and support for adults with autism and their families, partners and carers should:

- ensure that they are easily identifiable (for example, by producing or wearing appropriate identification) and approachable

- clearly communicate their role and function

- address the person using the name and title they prefer

- clearly explain any clinical language and check that the person with autism understands what is being said

- take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the person with autism) if required.

1.1.6　All health and social care professionals providing care and support for adults with autism and their families, partners and carers should ensure that they are:

- familiar with recognised local and national sources (organisations and websites) of information and/or support for people with autism

- able to discuss and advise on how to access and engage with these resources.

1.1.7   Encourage adults with autism to participate in self-help or support groups or access one-to-one support, and provide support so that they can attend meetings and engage in the activities.

1.1.8   In all settings, take into account the physical environment in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour. If necessary make adjustments or adaptations to the:

- amount of personal space given (at least an arm's length)

- setting using visual supports (for example, use labels with words or symbols to provide visual cues about expected behaviour)

- colour of walls and furnishings (avoid patterns and use low-arousal colours such as cream)

- lighting (reduce fluorescent lighting, use blackout curtains or advise use of dark glasses or increase natural light)

- noise levels (reduce external sounds or advise use of earplugs or ear defenders).

  Where it is not possible to adjust or adapt the environment, consider varying the duration or nature of any assessment or intervention (including taking regular breaks) to limit the negative impact of the environment.

1.1.9   All health and social care professionals providing care and support for adults with autism should:

- be aware of under-reporting and under-recognition of physical disorders in people with autism

- be vigilant for unusual likes and dislikes about food and/or lack of physical activity

- offer advice about the beneficial effects of a healthy diet and exercise, taking into account any hyper- and/or hypo-sensory sensitivities; if necessary, support referral to a GP or dietician.

1.1.10   All staff working with adults with autism should be sensitive to issues of

sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the person with autism misunderstanding another person's behaviour or to their possible exploitation by others.

1.1.11   Ensure that adults with autism who have caring responsibilities receive support to access the full range of mental and physical health and social care services, including:

- specific information, advice and support to parents about their parenting role, including parent training if needed, by professionals experienced in the care of adults and children with autism

- social support, such as childcare, to enable them to attend appointments, groups and therapy sessions, and to access education and employment.

Structures for the organisation and delivery of care and interventions

1.1.12   In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

1.1.13   In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists

- nurses

- occupational therapists

- psychiatrists

- social workers

- speech and language therapists

- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

1.1.14   The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services

- specialist care and interventions

- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)

- support in accessing, and maintaining contact with, housing, educational and employment services

- support to families, partners and carers where appropriate

- care and interventions for adults with autism living in specialist residential accommodation

- training, support and consultation for staff who care for adults with autism in residential and community settings.

Involving families, partners and carers

1.1.15   Discuss with adults with autism if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have (see recommendation 1.1.5).

1.1.16   If the person with autism wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the person with autism and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis

- explain how families, partners and carers can help support the person with autism and help with care plans

- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the person with autism and their family, partner or carer(s).

1.1.17   Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management

- local support groups and services specifically for families, partners and carers

- their right to a carer's assessment of their own physical and mental health needs, and how to access this (see the NICE guideline on supporting adult carers).

1.1.18   If a person with autism does not want their family, partners or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care

- bear in mind that people with autism may be ambivalent or negative towards their family or partner. This may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse.

1.2   Identification and assessment

Principles for the effective assessment of autism

1.2.1   Staff who have responsibility for the identification or assessment of adults with autism should adapt these procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is delivered (see recommendation 1.1.8) and the duration and pacing of the assessment.

Identification and initial assessment of possible autism

1.2.2   Consider assessment for possible autism when a person has:

- one or more of the following:

  — persistent difficulties in social interaction

  — persistent difficulties in social communication

  — stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**

- one or more of the following:

  — problems in obtaining or sustaining employment or education

  — difficulties in initiating or sustaining social relationships

  — previous or current contact with mental health or learning disability services

  — a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

1.2.3   For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores above 6 on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

1.2.4   For adults with possible autism who have a moderate or severe learning disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member, partner or carer):

- difficulties in reciprocal social interaction including:

  — limited interaction with others (for example, being aloof, indifferent or unusual)

  — interaction to fulfil needs only

  — interaction that is naive or one-sided

- lack of responsiveness to others

- little or no change in behaviour in response to different social situations

- limited social demonstration of empathy

- rigid routines and resistance to change

- marked repetitive activities (for example, rocking and hand or finger flapping), especially when under stress or expressing emotion.

   If two or more of the above categories of behaviour are present, offer a comprehensive assessment for autism.

Comprehensive (diagnostic, needs and risks) assessment of suspected autism

1.2.5   A comprehensive assessment should:

- be undertaken by professionals who are trained and competent

- be team-based and draw on a range of professions and skills

- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development.

1.2.6   At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback.

1.2.7   During a comprehensive assessment, enquire about and assess the following:

- core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood

- early developmental history, where possible

- behavioural problems

- functioning at home, in education or in employment

- past and current physical and mental disorders

- other neurodevelopmental conditions

- hyper- and/or hypo-sensory sensitivities and attention to detail.

  Carry out direct observation of core autism signs and symptoms especially in social situations.

1.2.8   To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

- the following tools for people who do not have a learning disability:

  — the Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])

  — the Autism Diagnostic Interview – Revised (ADI-R)

  — the Autism Diagnostic Observation Schedule – Generic (ADOS-G)

  — the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)

  — the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)

- the following tools in particular for people with a learning disability:

  — the ADOS-G

  — the ADI-R.

1.2.9   To organise and structure the process of a more complex assessment, consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO), the ADOS-G or the ADI-R.

1.2.10   During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disabilities)

- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)

- neurological disorders (for example, epilepsy)

- physical disorders

- communication difficulties (for example, speech and language problems, and selective mutism)

- hyper- and/or hypo-sensory sensitivities.

1.2.11 Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment.

1.2.12 During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or a moderate or severe learning disability)

- rapid escalation of problems

- harm to others

- self-neglect

- breakdown of family or residential support

- exploitation or abuse by others.

  Develop a risk management plan if needed.

1.2.13 Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s).

1.2.14 Provide a 'health passport' (for example, a laminated card) for adults with autism, which includes information for all staff about the person's care and support needs. Advise the person to carry the health passport at all times.

1.2.15   As part of a comprehensive assessment consider developing a 24-hour crisis management plan, where necessary in conjunction with specialist mental health services, which should detail:

- the likely trigger(s) for a crisis

- the nature and speed of the reaction to any trigger(s), including details about the way in which autism may impact on a person's behaviour leading up to and during a crisis

- the role of the specialist team and other services (including outreach and out-of-hours services) in responding to a crisis

- advice to primary care professionals and other services on their responsibilities and appropriate management in a crisis

- advice for families, partners and carers about their role in a crisis

- the nature of any changes or adaptations to the social or physical environment (see recommendation 1.1.8) needed to manage a crisis.

1.2.16   Consider obtaining a second opinion (including referral to another specialist autism team if necessary), if there is uncertainty about the diagnosis or if any of the following apply after diagnostic assessment:

- disagreement about the diagnosis within the autism team

- disagreement with the person, their family, partner, carer(s) or advocate about the diagnosis

- a lack of local expertise in the skills and competencies needed to reach diagnosis in adults with autism

- the person has a complex coexisting condition, such as a severe learning disability, a severe behavioural, visual, hearing or motor problem, or a severe mental disorder.

1.2.17   On an individual basis, and using information from the comprehensive assessment and physical examination, and clinical judgement, consider further investigations, including:

- genetic tests, as recommended by the regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of a learning disability

- electroencephalography if there is suspicion of epilepsy

- hearing or sight tests, if there is suspicion of hearing or visual impairment

- other medical tests depending on individual signs and symptoms (for example, sudden onset of challenging behaviour, change in usual patterns of behaviour, sudden change in weight, or suspicion that the person might be in pain and is unable to communicate this).

1.2.18   Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require.

Assessment of challenging behaviour

1.2.19   Assessment of challenging behaviour should be integrated into a comprehensive assessment for adults with autism.

1.2.20   When assessing challenging behaviour carry out a functional analysis (see recommendation 1.5.3) including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

- physical disorders

- the social environment (including relationships with family members, partners, carers and friends)

- the physical environment, including sensory factors

- coexisting mental disorders (including depression, anxiety disorders and psychosis)

- communication problems

- changes to routines or personal circumstances.

1.3   Identifying the correct interventions and monitoring their use

1.3.1   When discussing and deciding on interventions with adults with autism, consider:

- their experience of, and response to, previous interventions

- the nature and severity of their autism

- the extent of any associated functional impairment arising from the autism, a learning disability or a mental or physical disorder

- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)

- the presence, nature, severity and duration of any coexisting disorders

- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed.

1.3.2   When discussing and deciding on care and interventions with adults with autism, take into account the:

- increased propensity for elevated anxiety about decision-making in people with autism

- greater risk of altered sensitivity and unpredictable responses to medication

- environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)

- presence and nature of hyper- and/or hypo-sensory sensitivities and how these might impact on the delivery of the intervention

- importance of predictability, clarity, structure and routine for people with autism

- nature of support needed to access interventions.

1.3.3   When discussing and deciding on interventions with adults with autism, provide information about:

- the nature, content and duration of any proposed intervention

- the acceptability and tolerability of any proposed intervention

- possible interactions with any current interventions and possible side effects

- the implications for the continuing provision of any current interventions.

1.3.4   When deciding on options for pharmacological interventions for challenging
         behaviour or coexisting mental disorders in adults with autism:

- be aware of the potential for greater sensitivity to side effects and idiosyncratic
  responses in people with autism **and**

- consider starting with a low dose.

1.3.5   For any intervention used in adults with autism, there should be a regular
         review of:

- the benefits of the intervention, where feasible using a formal rating of the target
  behaviour(s)

- any adverse events

- specific monitoring requirements of pharmacological interventions as highlighted by
  the summary of product characteristics

- adherence to the intervention.

1.4   Interventions for autism

Psychosocial interventions for the core symptoms of autism

1.4.1   For adults with autism without a learning disability or with a mild to moderate
         learning disability, who have identified problems with social interaction,
         consider:

- a group-based social learning programme focused on improving social interaction

- an individually delivered social learning programme for people who find group-based
  activities difficult.

1.4.2   Social learning programmes to improve social interaction should typically
         include:

- modelling

- peer feedback (for group-based programmes) or individual feedback (for individually
  delivered programmes)

- discussion and decision-making

- explicit rules

- suggested strategies for dealing with socially difficult situations.

1.4.3   Do not provide facilitated communication for adults with autism.

Psychosocial interventions focused on life skills

1.4.4   For adults with autism of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

1.4.5   For adults with autism without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme

- an individually delivered structured leisure activity programme for people who find group-based activities difficult.

1.4.6   A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)

- regular meetings for a valued leisure activity

- for group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants

- the provision of structure and support.

1.4.7   For adults with autism without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of adults with autism.

1.4.8   Anger management interventions should typically include:

- functional analysis of anger and anger-provoking situations

- coping-skills training and behaviour rehearsal

- relaxation training

- development of problem-solving skills.

1.4.9   For adults with autism without a learning disability or with a mild learning disability, who are at risk of victimisation, consider anti-victimisation interventions based on teaching decision-making and problem-solving skills.

1.4.10   Anti-victimisation interventions should typically include:

- identifying and, where possible, modifying and developing decision-making skills in situations associated with abuse

- developing personal safety skills.

1.4.11   For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

1.4.12   An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews

- training for the identified work role and work-related behaviours

- carefully matching the person with autism with the job

- advice to employers about making reasonable adjustments to the workplace

- continuing support for the person after they start work

- support for the employer before and after the person starts work, including autism awareness training.

Biomedical (pharmacological, physical and dietary) interventions and the core symptoms of autism

1.4.13   Do not use anticonvulsants for the management of core symptoms of autism in adults.

1.4.14   Do not use chelation for the management of core symptoms of autism in adults.

1.4.15   Do not use the following interventions for the management of core symptoms of autism in adults:

- exclusion diets (such as gluten- or casein-free and ketogenic diets)

- vitamins, minerals and dietary supplements (such as vitamin B6 or iron supplementation).

1.4.16   Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the management of core symptoms of autism or routinely for associated cognitive or behavioural problems in adults.

1.4.17   Do not use oxytocin for the management of core symptoms of autism in adults.

1.4.18   Do not use secretin for the management of core symptoms of autism in adults.

1.4.19   Do not use testosterone regulation for the management of core symptoms of autism in adults.

1.4.20   Do not use hyperbaric oxygen therapy for the management of core symptoms of autism in adults.

1.4.21   Do not use antipsychotic medication for the management of core symptoms of autism in adults.

1.4.22   Do not use antidepressant medication for the routine management of core symptoms of autism in adults.

1.5 Interventions for challenging behaviour

1.5.1   Before initiating other interventions for challenging behaviour, address any identified factors that may trigger or maintain the behaviour (see recommendation 1.2.20) by offering:

- the appropriate care for physical disorders (for example, gastrointestinal problems or chronic pain)

- treatment for any coexisting mental disorders, including psychological and pharmacological interventions (for example, anxiolytic, antidepressant or antipsychotic medication), informed by existing NICE guidance

- interventions aimed at changing the physical or social environment (for example, who the person lives with) when problems are identified, such as:

  — advice to the family, partner or carer(s)

  — changes or accommodations to the physical environment (see recommendation 1.1.8).

1.5.2   Offer a psychosocial intervention for the challenging behaviour first if no coexisting mental or physical disorder, or problem related to the physical or social environment, has been identified as triggering or maintaining challenging behaviour.

1.5.3   When deciding on the nature and content of a psychosocial intervention to address challenging behaviour, use a functional analysis. The functional analysis should facilitate the targeting of interventions that address the function(s) of problem behaviour(s) by:

- providing information, from a range of environments, on:

  — factors that appear to trigger the behaviour

  — the consequences of the behaviour (that is, the reinforcement received as a result of their behaviour)

- identifying trends in behaviour occurrence, factors that may be evoking that behaviour, and the needs that the person is attempting to meet by performing the behaviour.

1.5.4   In addition to the functional analysis, base the choice of intervention(s) on:

- the nature and severity of the behaviour

- the person's physical needs and capabilities

- the physical and social environment

- the capacity of staff and families, partners or carers to provide support

- the preferences of the person with autism and, where appropriate, their family, partner or carer(s)

- past history of care and support.

Psychosocial interventions for challenging behaviour

1.5.5   Psychosocial interventions for challenging behaviour should be based on behavioural principles and informed by a functional analysis of behaviour (see recommendation 1.5.3).

1.5.6   Psychosocial interventions for challenging behaviour should include:

- clearly identified target behaviour(s)

- a focus on outcomes that are linked to quality of life

- assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour

- a clearly defined intervention strategy

- a clear schedule of reinforcement, and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour

- a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)

- a systematic measure of the target behaviour(s) taken before and after the intervention to ascertain whether the agreed outcomes are being met.

Combined interventions for challenging behaviour

1.5.7   Consider antipsychotic medication in conjunction with a psychosocial intervention for challenging behaviour when there has been no or limited response to psychosocial or other interventions (such as environmental adaptations). Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

In June 2012 this was an off-label use of antipsychotic medication. See NICE's

information on prescribing medicines.

Pharmacological interventions for challenging behaviour

1.5.8 Consider antipsychotic medication for challenging behaviour on its own when psychosocial or other interventions could not be delivered because of the severity of the challenging behaviour. Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

In June 2012 this was an off-label use of antipsychotic medication. See NICE's information on prescribing medicines.

1.5.9 Do not routinely use anticonvulsants for the management of challenging behaviour in adults with autism.

1.6 Interventions for coexisting mental disorders

1.6.1 Staff delivering interventions for coexisting mental disorders to adults with autism should:

- have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders

- consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism.

Psychosocial interventions for coexisting mental disorders

1.6.2 For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

1.6.3 Adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders should include:

- a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')

- placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention

- making rules explicit and explaining their context

- using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations

- involving a family member, partner, carer or professional (if the person with autism agrees) to support the implementation of an intervention

- maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information).

Pharmacological interventions for coexisting mental disorders

1.6.4   For adults with autism and coexisting mental disorders, offer pharmacological interventions informed by existing NICE guidance for the specific disorder.

1.7   Assessment and interventions for families, partners and carers

1.7.1   Offer families, partners and carers of adults with autism an assessment of their own needs (see the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families, partners and carers).

1.7.2   When the needs of families, partners and carers have been identified, provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of people with autism. See the NICE guideline on supporting adult carers.

1.7.3   Offer information, advice, training and support to families, partners and carers if they:

- need help with the personal, social or emotional care of the family member, partner or friend, **or**

- are involved in supporting the delivery of an intervention for their family member, partner or friend (in collaboration with professionals).

1.8 Organisation and delivery of care

Developing local care pathways

1.8.1 Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals

- accessible and acceptable to all people in need of the services served by the pathway

- responsive to the needs of adults with autism and their families, partners and carers

- integrated so that there are no barriers to movement between different levels of the pathway

- outcome focused (including measures of quality, service user experience and harm).

1.8.2 Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway

- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway

- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services

- supporting the integrated delivery of services across all care settings

- supporting the smooth transition to adult services for young people going through the pathway

- auditing and reviewing the performance of the pathway.

1.8.3   The autism strategy group should develop local care pathways that promote access to services for all adults with autism, including:

- people with coexisting physical and mental disorders (including substance misuse)

- women

- people with learning disabilities

- older people

- people from black and minority ethnic groups

- transgender people

- homeless people

- people from the traveller community

- people in the criminal justice system

- parents with autism.

1.8.4   When providing information about local care pathways to adults with autism and their families, partners and carers, all professionals should:

- take into account the person's knowledge and understanding of autism and its care and management

- ensure that such information is appropriate to the communities using the pathway.

1.8.5   The autism strategy group should design local care pathways that promote a range of evidence-based interventions at each step in the pathway and support adults with autism in their choice of interventions.

1.8.6   The autism strategy group should design local care pathways that respond promptly and effectively to the changing needs of all populations served by the pathways. Pathways should have in place:

- clear and agreed goals for the services offered to adults with autism

- robust and effective means for measuring and evaluating the outcomes associated with the agreed goals

- clear and agreed mechanisms for responding promptly to identified changes to people's needs.

1.8.7   The autism strategy group should design local care pathways that provide an integrated programme of care across all care settings. Pathways should:

- minimise the need for transition between different services or providers

- allow services to be built around the pathway and not the pathway around the services

- establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)

- have designated staff who are responsible for the coordination of people's engagement with the pathway.

Improving access to care

1.8.8   There should be a single point of referral (including self-referral) to specialist services for adults with autism.

1.8.9   Support access to services and increase the uptake of interventions by:

- delivering assessment and interventions in a physical environment that is appropriate for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)

- changing the professional responsible for the person's care if a supportive and caring relationship cannot be established.

1.8.10   Support access to services and increase the uptake of interventions by:

- ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for adults with autism

- designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service).

Residential care

1.8.11   If residential care is needed for adults with autism it should usually be provided in small, local community-based units (of no more than six people and with well-

supported single person accommodation). The environment should be structured to support and maintain a collaborative approach between the person with autism and their family, partner or carer(s) for the development and maintenance of interpersonal and community living skills.

1.8.12   Residential care environments should include activities that are:

- structured and purposeful

- designed to promote integration with the local community and use of local amenities

- clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomy.

1.8.13   Residential care environments should have:

- designated areas for different activities that provide visual cues about expected behaviour

- adaptations to the physical environment for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)

- inside and outside spaces where the person with autism can be alone (for example, if they are over-stimulated).

1.8.14   Residential care staff should:

- understand the principles and attitudes underpinning the effective delivery of residential care for adults with autism

- work in collaboration with health and community care staff from a range of specialist services to support the delivery of a comprehensive care plan

- be trained in assessing and supporting the needs of adults with autism

- be consistent and predictable, but with some flexibility to allow change and choice

- be committed to involving families, partners and carers.

2 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of research recommendations is detailed in the full guideline.

2.1 Facilitated self-help for anxiety and depression in adults with autism

What is the clinical and cost effectiveness of facilitated self-help for the treatment of mild anxiety and depressive disorders in adults with autism?

Why this is important

Anxiety and depressive disorders commonly coexist in people with autism and are associated with poorer health outcomes and quality of life. This may occur because of the direct impact of the anxiety or depression but also because of a negative interaction with the core symptoms of autism. There is limited access and poor uptake of facilitated self-help by people with autism, largely due to limited availability but also because current systems for the delivery of such interventions are not adapted for use by people with autism. In adults without autism, facilitated self-help is an effective intervention for mild to moderate depression and anxiety. The development of novel methods for the delivery of facilitated self-help could make effective interventions available to a wider group of people.

The suggested programme of research would need to: (a) develop current methods for the delivery of self-help measures to take into account the impact of autism and possibly include developments in the nature of the materials, the methods for their delivery and the nature, duration and extent of their facilitation; (b) test the feasibility of the novel methods in a series of pilot studies; and (c) formally evaluate the outcomes (including symptoms, satisfaction and quality of life) in a large-scale randomised trial.

2.2 The structure and organisation of specialist teams

What structure and organisation of specialist autism teams are associated with improvements in care for people with autism?

Why this is important

The [Department of Health's autism strategy (2010)](#) proposes the introduction of a range of specialist services for people with autism; these will usually be built around specialist autism teams. However, there is little evidence to guide the establishment and development of these teams. There is uncertainty about the precise nature of the population to be served (all people with autism or only those who have an IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship with regard to non-statutory care providers. Therefore it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism. Given the significant expansion of services, this presents an opportunity for a large-scale observational study, which should provide important information on the characteristics of teams associated with positive outcomes for people with autism in terms of access to services and effective coordination of care.

2.3 Augmentative communication devices for adults with autism

What is the clinical and cost effectiveness of [augmentative communication](#) devices for adults with autism?

Why this is important

Many people with autism experience significant communication problems (for example, the absence of any spoken language or significant deficits in interpersonal skills), which have a profound effect on their ability to lead a full and rewarding life. It is probable that these problems are related to the core symptoms of autism and are likely to persist for most people given the life-long course of autism and the lack of effective interventions for these core symptoms. A number of communication devices have been developed for autism but few, if any, have been subjected to a proper evaluation in adults. Despite this lack of formal evaluation, individual services have made considerable investments in augmentative communication devices. Research that provides high-quality evidence on the acceptability and the clinical and cost effectiveness of augmentative communication devices could bring about significant improvements in the lives of adults with autism.

The suggested programme of research would need to identify current devices for which there is: (a) some evidence of benefit (for example, case series and small-scale pilot studies); (b) some evidence

that it meets a key communication need for people with autism (based on reviews of people's need in this area); and (c) indication that the device is feasible for routine use. The identified device(s) should then be formally evaluated in a large-scale randomised trial.

Glossary

Augmentative communication

An alternative way of helping people with communication difficulties by using assistive technology such as computers or other devices, such as a speech output device.

Behavioural principles

Ideas, such as reinforcement and function of behaviour, that underlie behavioural therapies and underpin many interventions teaching adaptive skills for community living for people with autism, including those with challenging behaviour.

Care pathway

A system designed to improve the overall quality of healthcare by standardising the care process and promoting organised efficient service user care based on best evidence to optimise service user outcomes.

Challenging behaviour

A term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety.

Chelation

A procedure that involves using one or more substances (chelating agents) to remove materials that are toxic, including heavy metals such as mercury, from the body.

Easy read

An accessible format for written communication designed for people with a learning disability. It uses simple jargon-free language, short sentences and illustrations.

Facilitated communication

A therapeutic intervention whereby a facilitator supports the hand or arm of a person with autism while using a keyboard or other devices with the aim of helping the person to develop pointing skills and to communicate.

Functional analysis

A method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour. The function of a particular behaviour can be analysed by typically identifying (1) the precursor or trigger of the behaviour, (2) the behaviour itself, and (3) the consequence of the behaviour.

Hyper- and hypo-sensory sensitivities

Being over-sensitive (hyper-sensitive) or under-sensitive (hypo-sensitive) to sound, light, colour, smell or taste, which can cause anxiety or even pain in a person with autism.

Informant

A family member, partner, carer or other third party known to the person with autism who is able to provide information about the person's symptoms and behaviour so that professionals can have a fuller picture of the person's developmental history. Some assessment tools for autism require information from informants.

Learning disability

Lower intellectual ability (usually defined as an IQ of less than 70) that leads to problems in learning, developing new skills, communication and carrying out daily activities. Learning disability severities are defined by the following IQ scores: mild=50–69, moderate=35–49 and severe=20–34. A person with a mild to moderate learning disability may only need support in certain areas. However, a person with a moderate to severe learning disability may have no speech or limited communication, a significantly reduced ability to learn new skills and require support with daily activities such as dressing and eating. Learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect. Learning disability is sometimes also called 'intellectual disability'.

Modelling

A technique used in behavioural therapy that utilises video and other media. The service user observes target behaviour on the video or computer screen, and repeats it.

Reinforcement

A technique used in behavioural therapy to teach 'rules' of social engagement through providing prompts for behaviour. Reinforcement may be by the person with autism or those working with or caring for them.

Update information

August 2016: The following research recommendations have been removed:

- What is the clinical and cost effectiveness of CBT for the treatment of moderate and severe anxiety disorders in adults with autism?

- What is the clinical and cost effectiveness of selective serotonin reuptake inhibitors (SSRIs) for the treatment of moderate and severe depression in adults with autism?

Minor changes since publication

July 2020: We have linked to the NICE guideline on supporting adult carers in recommendations 1.1.17, 1.7.1 and 1.7.2. We have incorporated footnotes into the recommendations.

October 2015: Title changed from 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum' to 'Autism spectrum disorder in adults: diagnosis and management', for clarity and consistency with other guidance on this topic.

Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on autism spectrum disorder.

To find NICE guidance on related topics, including guidance in development, see our topic page on autism.

For full details of the evidence and the guideline committee's discussions, see the full guideline. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see resources to help you put guidance into practice.

ISBN: 978-1-4731-2039-6

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