Autism: recognition, referral, diagnosis and management of adults on the autism spectrum

NICE guideline Draft for consultation, December 2011

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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Introduction

Autism¹ is a lifelong neurodevelopmental disorder the core features of which are a qualitative impairment in the reciprocity of social interaction and communication, combined with restricted interests or rigid and repetitive behaviour and activities. The way that autism is expressed in individual people will differ at different stages of life, in response to interventions and with the presence of coexisting conditions such as intellectual disability. People with autism commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties, stereotypic (rigid and repetitive) mannerisms and behaviour, emotional regulation difficulties, and a narrow and often highly focused range of interests and activities. These features may range from mild to severe (and may fluctuate over time or in response to significant changes in circumstances).

A significant proportion of adults with autism across the whole autistic spectrum are excluded both socially and economically. 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 health and medical health problems, other developmental conditions and adaptive impairments. 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.

¹ The guideline development group recognised that different individuals and groups prefer a variety of terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neurodiversity. 'Autism' is used to cover all of these terms in recent Department of Health, National Audit Office and Public Accounts Committee documents. In this guideline 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified). Autism in adults: NICE guideline DRAFT (December 2011)

When the diagnostic assessment process works well, professionals and families/carers 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 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.

A number of the recommendations in this guideline were adopted or adapted from recommendations in other NICE clinical guidelines. When recommendations were adapted, the Guideline Development Group were mindful that they had not reviewed the evidence for these recommendations and therefore when transferring them into this guideline were careful to preserve the meaning and intent of the original recommendation. Changes to wording or structure were made in order to fit the recommendation into this guideline. In all cases, the origin of any adopted or 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.

Good communication between healthcare professionals and people with autism and their families and carers is essential. It should be supported by evidence-based written information tailored to the person's needs. Treatment 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 intellectual disability, and to people who do not speak or read English.

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

Families 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 'Transition: getting it right for young people' (available from www.dh.gov.uk).

Adult and paediatric healthcare/CAMHS teams should work jointly to provide assessment and services to young people with autism. Diagnosis and Autism in adults: NICE guideline DRAFT (December 2011)



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 their families or carers
 - offer help, treatment and care respectfully
 - take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. [Error! Reference source not found.]
- A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users and the voluntary sector.² [1.1.7]

Identification and assessment

- Consider further assessment for possible autism when a person has:
 - persistent difficulties in reciprocal (two-way) social engagement or social communication and stereotypic (rigid and repetitive) behaviours or resistance to change and
 - one or more of the following:
 - oproblems in obtaining or sustaining employment or education
 - difficulties in initiating or sustaining social relationships
 - previous, or current contact with CAMHS or learning disability services
 - ♦ history of a neurodevelopmental disorder. [1.2.2]

² Adopted from 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (NICE clinical guideline 128). Available from www.nice.org.uk/guidance/CG128

For the further assessment of adults with possible autism who do not have a moderate or severe intellectual disability, use the Autism-Spectrum Quotient – 10 items (AQ-10)³. (If a person does not speak or read English, read out the AQ-10.) If a person scores above six on the AQ-10, or there is a high index of suspicion based on clinical judgement (including, where applicable, compelling evidence from an informant), offer a comprehensive assessment for autism. [1.2.3]

Psychosocial interventions

 For adults with autism of all ranges of intellectual ability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme. [1.4.11]

Challenging behaviours

- Assessment of challenging behaviour should be integrated into a
 comprehensive assessment for adults with autism (see recommendations
 1.2.5 to 1.2.11). When assessing challenging behaviour undertake a
 functional analysis (see recommendation 1.3.6) and consider identifying
 and evaluating any factors that may trigger or maintain the behaviour,
 including:
 - any physical health problems
 - the social environment (including relationships with friends, families and carers)
 - the physical environment, including sensory needs
 - coexisting mental health disorders (including depression and anxiety disorders)
 - communication problems
 - changes to routine or personal circumstances. [1.7.1]

³ Allison C, Auyeung B. Baron-Cohen S. Towards brief 'red flags' for autism screening: the short AQ and the short Q-CHAT in 1000 cases and 3000 controls. Journal of the American Academy of Child and Adolescent Psychiatry, in press. See appendix C. Autism in adults: NICE guideline DRAFT (December 2011)

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 and social care, housing, employment 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.⁴ [1.9.2]

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⁴ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123 Autism in adults: NICE guideline DRAFT (December 2011)

1 Guidance

The following guidance is based on the best available evidence. The full guideline (www.nice.org.uk) 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 and carers

- 1.1.1 All staff working with adults with autism should:
 - work in partnership with adults with autism and their families or carers
 - offer help, treatment and care respectfully
 - take time to build a trusting, supportive, empathic and nonjudgemental relationship as an essential part of care.
- 1.1.2 All staff working with adults with autism should have a basic understanding of the:
 - nature, development and course of autism
 - impact of autism on personal, social, educational and occupational functioning
 - impact of the social and physical environment on autism.
- 1.1.3 All health and social care professionals providing care and treatment to adults with autism specifically for the autism or related conditions should have an extensive understanding of the nature, development and course of autism and:
 - its impact on personal, social, educational and occupational functioning
 - its interaction with the social and physical environment
 - its impact on other coexisting mental and physical disorders and their management

- the 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.
- 1.1.4 All health and social care professionals providing care and treatment to adults with autism should:
 - aim to foster the person's autonomy, promote active participation in treatment decisions and support self-management
 - maintain continuity of individual relationships wherever possible
 - ensure that comprehensive information about the nature of, and treatments and services for, their problems is available in an appropriate language or format (including various visual, verbal and aural, easy read, colour and font formats)
 - offer access to a trained advocate.
- 1.1.5 All health and social care professionals providing care and treatment to adults with autism and their families or carers should:
 - ensure that they are easily identifiable (for example, by producing or displaying 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 of people with intellectual disability, sight or hearing problems or language difficulties, and provide independent interpreters⁵ or communication aids if required.

⁵ Someone who does not have a personal relationship with the person with autism. Autism in adults: NICE guideline DRAFT (December 2011)

- 1.1.6 All health and social care professionals providing care and treatment to adults with autism and their families or carers should ensure that they are:
 - familiar with local and national sources (organisations and websites) of information and/or support for people with autism
 - able to discuss and advise how to access these resources
 - able to discuss and provide support to people with autism to engage with these resources.

Structures for the organisation and delivery of treatment and care

- 1.1.7 A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users and the voluntary sector.⁶
- 1.1.8 The local autism multi-agency strategy group should have representation from the following services in addition to those specified in recommendation 1.1.7: primary healthcare, learning disabilities services, the criminal justice system, housing and, employment. There should be meaningful representation from people with autism and their families or carers.
- 1.1.9 In each area a specialist community-based multidisciplinary autism team should be established. The core membership should include:
 - clinical psychologists
 - nurses
 - occupational therapists
 - psychiatrists
 - social workers
 - speech and language therapists

⁶ Adopted from 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (NICE clinical guideline 128). Available from www.nice.org.uk/guidance/CG128

- support workers (focused on providing employment, further education, residential advocacy, social inclusion interventions and personal and community safety skills).
- 1.1.10 The multidisciplinary autism team should have a key role in providing:
 - specialist diagnostic and assessment services
 - specialist care and treatment services
 - coordination of specialist care and treatment while in the service
 - advice and training to other health and social care professionals on the diagnosis, assessment, care and treatment of adults with autism
 - support in accessing and maintaining housing, educational and employment services
 - support to families and carers
 - support, treatment and care 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 and carers

- 1.1.11 Discuss with adults with autism if and how they want their families or carers to be involved in their care. During discussions, take into account any communication needs the person may have (see recommendation 1.1.5).
- 1.1.12 If the person with autism wants their family or carer(s) to be involved, encourage this involvement and:
 - negotiate between the person with autism and their family or carer(s) about confidentiality and sharing of information on an ongoing basis
 - explain how families or carers can help support the person with autism and help with treatment plans

- make sure that no services are withdrawn because of families' or carers' involvement, unless this has been clearly agreed with both the person with autism and their family or carer(s).
- 1.1.13 If the person with autism wants their family or carer(s) to be involved, give the family or carer(s) accessible information about:
 - autism and its treatment
 - statutory and third sector, including voluntary, local support groups and services specifically for families and carers, and how to access these
 - their right to a formal carer's assessment of their own physical and mental health needs, and how to access this.
- 1.1.14 If a person with autism does not want their family or carer(s) to be involved in their care:
 - give the family or carers verbal and written information about
 - autism and its treatment
 - statutory and third sector, including voluntary, local support groups and services specifically for families or carers, and how to access these
 - who they can contact if they are concerned about the person's care and treatment
 - tell the family or carers about their right to a formal carer's assessment of their own physical and mental health needs, and how to access this
 - bear in mind that people with autism may be ambivalent or negative towards their family for many different reasons, including as a result of a coexisting mental health problem or prior experience of violence or abuse.
- 1.1.15 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 childcare to enable them to attend appointments, groups and therapy sessions.

1.2 Identification and assessment

Principles for the effective assessment of autism

1.2.1 All staff working in services used by adults with autism should have a basic understanding of any modifications that need to be made to the method for delivery of the assessment, the setting in which assessment is delivered, and the duration and pacing of the assessment.

Identification and initial assessment of possible autism

- 1.2.2 Consider further assessment for possible autism when a person has:
 - persistent difficulties in reciprocal (two-way) social engagement or social communication and stereotypic (rigid and repetitive)
 behaviours or resistance to change 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 CAMHS or learning disability services
 - history of a neurodevelopmental disorder.

- 1.2.3 For the further assessment of adults with possible autism who do not have a moderate or severe intellectual disability, use the Autism-Spectrum Quotient 10 items (AQ-10).⁷ (If a person does not speak or read English, read out the AQ-10.) If a person scores above six on the AQ-10, or there is a high index of suspicion based on clinical judgement (including, where applicable, compelling evidence from an informant), offer a comprehensive assessment for autism.
- 1.2.4 For the further assessment of adults with possible autism who have a moderate or severe intellectual disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member or carer):
 - poor reciprocal social interaction including:
 - limited interaction with others (for example, being aloof, indifferent or unusual)
 - interaction to fulfil needs only
 - social approaches that are naive or unusual
 - lack of responsiveness to others and/or one-sided interaction
 - little or no change in behaviour in response to different social situations
 - no or 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.

⁷ Allison C, Auyeung B. Baron-Cohen S. Towards brief 'red flags' for autism screening: the short AQ and the short Q-CHAT in 1000 cases and 3000 controls. Journal of the American Academy of Child and Adolescent Psychiatry, in press. See appendix C. Autism in adults: NICE guideline DRAFT (December 2011)

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, 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 how the outcome of the assessment will be fed back to them. Feedback should be individualised, and a family member, carer or advocate may be involved to support the person and help explain the feedback.
- 1.2.7 During a comprehensive assessment, enquire about and assess the following:
 - core autism symptoms (social interaction, communication and stereotypic behaviour) that may have been present at any age
 - early developmental history, where possible
 - behavioural problems
 - functioning at home, in education or in employment
 - past and current physical and mental health problems
 - other neurodevelopmental disorders, including intellectual disability
 - hyper- and hypo-sensory sensitivities.

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

- 1.2.8 Consider using a formal assessment tool to aid the diagnosis and assessment, such as:
 - the Autism Diagnostic Observation Schedule Generic (ADOS-G)⁸, the Asperger Syndrome (and high-functioning autism)
 Diagnostic Interview (ASDI)⁹ or the Ritvo Autism Asperger
 Diagnostic Scale Revised (RAADS-R)¹⁰ for people with intellectual ability within the normal range
 - the ADOS-G for people with intellectual disability.
- 1.2.9 During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting conditions, such as:
 - other neurodevelopmental disorders, including intellectual disability (use formal assessment tools) and attention deficit hyperactivity disorder
 - mental health 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 health problems
 - communication difficulties (for example, speech and language problems, and selective mutism)
 - hyper- or hypo-sensory sensitivities.

⁸ Lord C, Risi S, Lambrecht L, et al. The Autism Diagnostic Observation Schedule – Generic: a standard measure of social and communication deficits associated with the spectrum of autism. Journal of Autism and Developmental Disorders, 2000;30:205-223.

⁹ Gillberg C, Gillberg C, Rastam M, et al. The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. Autism, 2001;5:57-66.

¹⁰ Ritvo RA, Ritvo ER, Guthrie D, et al. The Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R): a scale used to assist the diagnosis of autism spectrum disorders in adults: an international validation study. Journal of Autism and Developmental Disorders, 2011;41:1076-1089.

- 1.2.10 Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment.
- 1.2.11 During a comprehensive assessment, assess the following risks:
 - self-harm (in particular in people with depression or moderate or severe intellectual 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.

- 1.2.12 Develop a care plan for adults with autism 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 families and carers.
- 1.2.13 As part of a comprehensive assessment (and in other settings, such as specialist mental health services), consider developing a 24-hour crisis management plan, 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 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 or carers about their role in a crisis

- the nature of any changes to the environment needed to manage a crisis.
- 1.2.14 Consider obtaining a second opinion (including referral to another specialist autism team if necessary), where there is uncertainty about the diagnosis or if any of the following apply after diagnostic assessment:
 - disagreement within the autism team about the diagnosis
 - disagreement with the person, their family, 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 intellectual, behavioural, visual, hearing or motor problem or a severe mental illness.¹¹
- 1.2.15 On an individual basis, and using the comprehensive assessment, 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 intellectual disability
 - electroencephalography if there is suspicion of epilepsy
 - hearing or sight tests
 - other medical tests depending on individual symptoms (for example, sudden onset of challenging behaviours or change in usual patterns of behaviour).

¹¹ Adapted from the 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (NICE clinical guideline 128). Available from www.nice.org.uk/guidance/CG128

1.3 Identifying the correct treatment and care options for adults with autism

- 1.3.1 When deciding on treatment or care interventions with adults with autism, consider:
 - experience of, and response to, previous interventions
 - the nature, severity and duration of autism
 - the extent of any associated functional impairment arising from the autism, any intellectual disability or physical health problem
 - 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, and nature, severity and duration, of any coexisting conditions
 - the identification of predisposing and possible precipitating factors that could lead to crises if not addressed.¹²
- 1.3.2 When discussing treatment and care interventions with adults with autism, take into account the:
 - increased propensity for elevated anxiety about decision-making in people with autism
 - greater risk of increased sensitivity to side effects of medications or other physical interventions
 - environment, for example whether it is suitably adapted for people with autism, in particular those with hyper- or hyposensory sensitivities
 - the presence and nature of hyper- or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
 - importance of clarity, structure and routine for people with autism
 - nature of support needed to access interventions.

¹² Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

- 1.3.3 When discussing treatment or care 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.¹³
- 1.3.4 Provide a 'health passport' (for example, a laminated card) as part of any care and treatment plan. The health passport should be carried by the person with autism at all times and should provide information for all staff about the person's treatment and care needs.
- 1.3.5 If adults with autism need social support, provide information about, and consider facilitating the use of, self-help groups, support groups, one-to-one support and other local and national resources.
- 1.3.6 When deciding on treatment and care interventions focused on a specific problem behaviour, perform a functional analysis of the behaviour, including:
 - observation and description, in a range of environments, of:
 - the internal and external stimuli that appear to trigger the behaviour
 - the consequences of the behaviour (that is, the reinforcement received as a result of their behaviour¹⁴)
 - review of the observational data to identify trends in behaviour occurrence, stimuli that may be evoking that behaviour, and the

¹⁴Reinforcement may be by the person with autism or those working with or caring for them. Autism in adults: NICE guideline DRAFT (December 2011)

¹³ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123

needs that the person is attempting to meet by performing the behaviour.

Use the analysis to target interventions at addressing the causes and function(s) of problem behaviour(s).

1.4 Psychosocial interventions for autism

Interventions to improve social interaction

- 1.4.1 For adults with autism of all ranges of intellectual ability, who have identified problems in social interaction, consider a social learning programme focused on improving social interaction.
- 1.4.2 Group-based social learning programmes to improve social interaction should typically include:
 - modelling
 - peer feedback
 - · discussion and decision-making.
- 1.4.3 For adults with autism who find group-based activities difficult, consider an individually-delivered social learning programme, which should typically include:
 - modelling
 - individual feedback
 - · discussion and decision-making.

Interventions to develop structured leisure activities

- 1.4.4 Consider a structured leisure activity programme for adults with autism of all ranges of intellectual ability.
- 1.4.5 A structured leisure activity programme should typically include:
 - a group who meet regularly for a valued leisure activity
 - a focus on the interests and abilities of the participants

the provision of structure and support.

Interventions to develop skills for daily living

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

Interventions to develop anti-victimisation skills

- 1.4.7 For adults with autism who are at risk of victimisation, consider antivictimisation interventions based on teaching cognitive decisionmaking and problem-solving skills.
- 1.4.8 Anti-victimisation interventions should focus on:
 - identifying and, where necessary, modifying situations associated with abuse
 - developing decision-making skills in these situations
 - developing personal safety skills.

Interventions to develop anger management skills

- 1.4.9 For adults with autism who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of adults with autism.
- 1.4.10 Anger management interventions should include the following key components:
 - functional analysis of anger and anger-provoking situations
 - coping-skills training and behaviour rehearsal
 - relaxation training
 - · development of problem-solving skills.

Interventions to support employment

- 1.4.11 For adults with autism of all ranges of intellectual ability, 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.

Facilitated communication

1.4.13 Do not offer facilitated communication to adults with autism.

1.5 Psychosocial interventions for coexisting conditions

- 1.5.1 For adults with autism and coexisting mental health disorders, offer a range of psychosocial interventions informed by existing NICE guidance for the specific condition.
- 1.5.2 Staff delivering interventions for coexisting conditions for adults with autism should have a basic understanding of autism and should seek advice from the specialist autism team regarding adapting interventions for people with autism.
- 1.5.3 Adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental health 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 and hypothetical situations
 - involving a family member or key worker as co-therapist (if the person with autism agrees) to improve the generalisation of skills
 - maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible.

1.6 Biomedical (pharmacological, physical and dietary) interventions

General principles

- 1.6.1 For any biomedical intervention used in adults with autism, a suitably qualified and experienced professional should regularly review:
 - the benefits of the intervention, preferably using a formal rating of the target behaviour(s)
 - · any side effects
 - specific monitoring requirements of pharmacological interventions as highlighted by the summary of product characteristics
 - adherence to the intervention
 - physical health (and in addition offer advice about the beneficial effects of diet and exercise).

1.6.2 When discussing options for pharmacological interventions with 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 lower dose.

Anticonvulsants

1.6.3 Do not use anticonvulsants for the treatment of core symptoms of autism or for the routine management of challenging behaviour in adults with autism.

Chelation

1.6.4 Do not use chelation (for example, zinc chelation) for the treatment of core symptoms of autism or for the management of challenging behaviour in adults with autism.

Diet, vitamins and supplements

- 1.6.5 Do not use the following for the treatment of core symptoms of autism in adults:
 - restrictive diets (such as gluten- and casein-free or ketogenic diets)
 - vitamins, minerals and dietary supplements (such as vitamin B6 or iron supplementation).

Drugs to improve cognition

1.6.6 Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the routine treatment of core symptoms of autism or associated cognitive or behavioural problems.

Drugs to manage hyperactivity and attention problems

1.6.7 For adults with autism and symptoms of hyperactivity, treatment of the hyperactivity should be informed by 'Attention deficit hyperactivity disorder' (NICE clinical guideline 72). Consider

atomoxetine¹⁵ because there is a higher adherence rate in people with autism compared with methylphenidate.

Hormonal interventions

- 1.6.8 Do not use oxytocin for the treatment of core symptoms of autism in adults.
- 1.6.9 Do not use secretin for the treatment of core symptoms of autism in adults.
- 1.6.10 Do not use testosterone regulation for the treatment of core symptoms of autism in adults or for the management of challenging behaviour in adults with autism.

Hyperbaric oxygen therapy

1.6.11 Do not use hyperbaric oxygen therapy for the treatment of core symptoms of autism or for the management of challenging behaviour in adults with autism.

Antipsychotic medication

- 1.6.12 Do not use antipsychotic medication for the treatment of core symptoms of autism.
- 1.6.13 Consider antipsychotic medication as part of a comprehensive treatment plan for the treatment and management of problem behaviour including irritability, aggression and self-harm in adults with autism (see recommendations 1.7.3 to Error! Reference source not found.).

Antidepressant medication

1.6.14 Do not use antidepressant medication for the routine treatment of core symptoms of autism in adults.

¹⁵ At the time of publication (date), atomoxetine did not have UK marketing authorisation for this indication. Informed consent should be obtained and documented. Autism in adults: NICE guideline DRAFT (December 2011)

1.6.15 For adults with autism and coexisting depression, the use of antidepressant medication should be informed by 'Depression' (NICE clinical guideline 90) and 'Depression in adults with a chronic physical health problem' (NICE clinical guideline 91).

Drugs for anxiety disorders

1.6.16 For adults with autism and a coexisting anxiety disorder, the use of anxiolytic medication should be informed by existing NICE clinical guidelines for the relevant anxiety disorder.

1.7 Challenging behaviours

Assessment of challenging behaviour

- 1.7.1 Assessment of challenging behaviour should be integrated into a comprehensive assessment for adults with autism (see recommendations 1.2.5 to 1.2.11). When assessing challenging behaviour undertake a functional analysis (see recommendation 1.3.6) and consider identifying and evaluating any factors that may trigger or maintain the behaviour, including:
 - any physical health problems
 - the social environment (including relationships with friends, families and carers)
 - the physical environment, including sensory needs
 - coexisting mental health disorders (including depression and anxiety disorders)
 - communication problems
 - changes to routines or personal circumstances.
- 1.7.2 Address any identified factors that may trigger or maintain challenging behaviour (see recommendation 1.7.1) before initiating any other intervention by offering:
 - the appropriate care for physical health problems (for example, gastrointestinal problems or chronic pain)

- interventions aimed at changing the environment when problems related to the physical or social environment are identified; for example, advice to families or carers, changes to the physical environment or accommodations such as wearing earplugs or dark glasses
- treatment for any coexisting mental health disorders informed by existing NICE guidance.

Interventions for challenging behaviour

- 1.7.3 Base the choice of interventions to address challenging behaviour on the nature and severity of the problem and a consideration of:
 - the person's physical needs
 - functional analysis of the behaviour
 - the physical and social environment
 - the preferences of the person with autism and their family or carer(s)
 - past history of treatment.
- 1.7.4 Offer psychosocial interventions based on behavioural principles, and informed by a functional analysis of behaviour as initial treatment for the management of challenging behaviour.
 Interventions should:
 - clearly identify the behaviours with agreed outcomes
 - assess and modify environmental factors that may trigger or maintain the behaviour
 - have a clearly defined intervention strategy
 - have a clear schedule of reinforcement and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour
 - have a specified timescale to meet treatment goals (modifying intervention strategies that do not lead to change within a specified time).

- 1.7.5 Psychotropic (anxiolytic, antidepressant or antipsychotic) medication should normally be used in conjunction with psychosocial interventions. Only consider psychotropic medication on its own when:
 - psychosocial or other interventions (such as environmental adaptations) alone have not been of benefit
 - psychosocial or other interventions could not be delivered because of the severity of the challenging behaviour
 - a diagnostic assessment or the functional analysis identified a problem central to the development of the challenging behaviour that may benefit from a pharmacological intervention.

1.8 Interventions for families and carers

- 1.8.1 Offer families and carers of adults with autism an assessment of their own needs including:
 - personal, social and emotional support
 - support in their caring role, including respite care and emergency plans
 - advice on and support in obtaining practical support
 - planning of future care for the person with autism.

- 1.8.2 Offer families and carers information on, and support accessing, a range of support groups including those specifically designed to assist the families of people with autism.
- 1.8.3 Offer parents who are involved in interventions for their autistic son or daughter specific training and support from professionals experienced in the care of adults with autism.
- 1.8.4 Offer parents who have autism specific advice and support in their parenting role by professionals experienced in the care of adults and children with autism.

1.9 Organisation and delivery of care

Developing local care pathways

- 1.9.1 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 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 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).¹⁶

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Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123 Autism in adults: NICE guideline DRAFT (December 2011)

- 1.9.2 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 and social care, housing, employment 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.
- 1.9.3 The autism strategy group should develop local care pathways that promote access to services for all adults with autism, including for people from certain groups such as:
 - people with coexisting mental and physical conditions (including substance misuse)
 - women
 - people with intellectual disabilities
 - older people
 - people from black and minority ethnic groups
 - transgender people
 - homeless people
 - people from the traveller community

Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123 Autism in adults: NICE guideline DRAFT (December 2011)

- people in the criminal justice system
- parents with autism.
- 1.9.4 When providing information about local care pathways to adults with autism and their families and carers, all professionals should:
 - take into account the person's knowledge and understanding of autism and its care and treatment
 - ensure that such information is appropriate to the communities using the pathway.¹⁸
- 1.9.5 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.¹⁹
- 1.9.6 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.²⁰

Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123
Adapted from 'Common mental health disorders: identification and pathways to care' (NICE)

¹⁹ Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123
²⁰Adapted from 'Common mental health disorders: identification and pathways to care' (NICE)

²⁰Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123
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- 1.9.7 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.²¹

General principles for improving access to care

- 1.9.8 There should be a single point of referral (including self-referral) to specialist services for adults with autism.
- 1.9.9 The specialist autism team should 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- or hyposensory sensitivities
 - changing the professional responsible for the person's care if an appropriate therapeutic relationship cannot be established.
- 1.9.10 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

²¹Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123 Autism in adults: NICE guideline DRAFT (December 2011)

 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).²²

Settings for the provision of care

- 1.9.11 If residential care is needed for adults with autism it should usually be provided in a small community-based unit. The environment should be structured to support and maintain a collaborative approach between the person with autism and their family or carer(s) for the development and maintenance of interpersonal and community living skills.
- 1.9.12 Residential care environments should include activities that are:
 - structured and purposeful
 - clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomous action.
- 1.9.13 Residential care environments should have:
 - designated areas for different activities in order to provide visual cues about expected behaviour
 - adaptations made to the physical environment (especially lighting, sound insulation and furnishings) to accommodate people with hyper- and hypo-sensory sensitivities
 - inside and outside spaces where the person with autism can be alone (for example, if they are over-stimulated).
- 1.9.14 Staff in residential care environments should:
 - be trained in assessing and supporting the needs of adults with autism

²² Adapted from 'Common mental health disorders: identification and pathways to care' (NICE clinical guideline 123). Available from www.nice.org.uk/guidance/CG123
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- demonstrate high levels of consistency and predictability, but with some flexibility to allow change and choice
- have a positive commitment to involving families and carers.

2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from www.nice.org.uk/CG/Wave23/1.

How this guideline was developed

NICE commissioned the National Collaborating Centre for Mental Health to develop this guideline. The Centre established a guideline development group (see appendix A), which reviewed the evidence and developed the recommendations. An independent guideline review panel oversaw the development of the guideline (see appendix B).

There is more information about how NICE clinical guidelines are developed on the NICE website (www.nice.org.uk/guidelinesprocess). A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

3 Implementation

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/CGXX)'.

4 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 (see section 5).

4.1 Guided self-instruction for anxiety and depression in 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? Autism in adults: NICE guideline DRAFT (December 2011)

Why is this 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.

4.2 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)²³ 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

²³ Department of Health (2010) Fulfilling and rewarding lives: the strategy for adults with autism. Available from

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH

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people with autism or only those who are 'high functioning'), 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, effective coordination of care and outcomes for service users and their families.

4.3 Augmented communication devices for adults with autism

What is the clinical and cost effectiveness of augmented communication devices for adults with autism?

Why is this important?

Many people with autism experience significant communication problems (for example, the absence of any spoken language, 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 lifelong 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 augmented communication devices. Research that provides high-quality evidence on the acceptability and the clinical and cost effectiveness of augmented 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.

5 Other versions of this guideline

5.1 Full guideline

The full guideline, ['Full guideline title' (in quotes, no italics)] contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health, and is available from [NCC website details to be added] and our website (www.nice.org.uk/CGXXfullguideline). [Note: these details will apply to the published full guideline.]

5.2 NICE pathway

The recommendations from this guideline have been incorporated into a NICE pathway, which is available from http://pathways.nice.org.uk/pathways/

Note: these details will apply when the guideline is published.

5.3 'Understanding NICE guidance'

A summary for patients and carers ('Understanding NICE guidance') is available from www.nice.org.uk/CGXXpublicinfo

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N1XXX). [Note: these details will apply when the guideline is published.]

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about autism.

6 Related NICE guidance

Published

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. NICE clinical guideline 128 (2011). Available from www.nice.org.uk/guidance/CG128
- Common mental health disorders. NICE clinical guideline 123 (2011).
 Available from www.nice.org.uk/guidance/CG123

- Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults. NICE clinical guideline 113 (2011). Available from www.nice.org.uk/guidance/CG113
- Depression in adults with a chronic physical health problem. NICE clinical guideline 91 (2009). Available from www.nice.org.uk/guidance/CG91
- Depression. NICE clinical guideline 90 (2009). Available from www.nice.org.uk/guidance/CG90
- Attention deficit hyperactivity disorder. NICE clinical guideline 72 (2008).
 Available from www.nice.org.uk/guidance/CG72
- Obsessive-compulsive disorder. NICE clinical guideline 31 (2005).
 Available from www.nice.org.uk/guidance/CG31
- Post-traumatic stress disorder (PTSD). NICE clinical guideline 26 (2005).
 Available from www.nice.org.uk/guidance/CG26

Under development

NICE is developing the following guidance (details available from www.nice.org.uk):

- Service user experience in adult mental health. NICE clinical guideline.
 Publication expected 2011.
- Social anxiety disorder. NICE clinical guideline. Publication expected 2013.

7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.

Appendix A: The Guideline Development Group, National Collaborating Centre and NICE project team

Guideline Development Group

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Appendix B: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

[NICE to add]

[Name; style = Unnumbered bold heading]

[job title and location; style = NICE normal]

Appendix C: the Autism-Spectrum Quotient-10 items (AQ-10)²⁴

Subscale	AQ Adult	AQ Adolescent	AQ Child
Attention to Detail	I often notice small sounds	S/he notices patterns	S/he often notice
	when others do not (5)	in things all the time	small sounds when
		(23)	others do not (5)
	I usually concentrate more	S/he usually	S/he usually
	on the whole picture, rather	concentrates more on	concentrates more on
	than the small details (28)	the whole picture,	the whole picture,
		rather than the small	rather than the small
		details (28)	details (28)
Attention Switching	I find it easy to do more	In a social group, s/he	In a social group, s/he
	than one thing at once (32)	can easily keep track	can easily keep track
		of several different	of several different
		people's	people's
		conversations (10)	conversations (10)
	If there is an interruption, I	If there is an	S/he finds it easy to
	can switch back to what I	interruption, s/he can	go back and forth
	was doing very quickly (37)	switch back to what	between different
	, , , , , , , , , , , , , , , , , , , ,	s/he was doing very	activities (32)
		quickly (37)	
		quanty (or)	
Communication	I find it easy to 'read	S/he frequently finds	S/he does not know
	between the lines' when	that s/he doesn't	how to keep a
	someone is talking to me	know how to keep a	conversation going
	(27)	conversation going	with his/her peers (26)
		(26)	

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²⁴ Allison C, Auyeung B. Baron-Cohen S. Towards brief 'red flags' for autism screening: the short AQ and the short Q-CHAT in 1000 cases and 3000 controls. Journal of the American Academy of Child and Adolescent Psychiatry, in press. The numbers following each statement refer to the question numbers in the longer 'Autism-Spectrum Quotient' (50 item version).

Subscale	AQ Adult	AQ Adolescent	AQ Child
		0	
	I know how to tell if	S/he is good at social	S/he is good at social
	someone listening to me is	chit-chat (38)	chit-chat (38)
	getting bored (31)		
Imagination	When I'm reading a story I	When s/he was	When s/he is reading
	find it difficult to work out	younger, s/he used to	a story, s/he finds it
	the characters' intentions	enjoy playing games	difficult to work out
	(20)	involving pretending	the characters'
		with other children	intentions or feelings
		(40)	(20)
	I like to collect information	S/he finds it difficult to	When s/he was in
	about categories of things	imagine what it would	pre-school, she used
	(e.g. types of car, types of	be like to be someone	to enjoy playing
	bird, types of train, types of	else (42)	games involving
	plant etc) (41)		pretending with other
			children (40)
Social	I find it easy to work out	S/he finds social	S/he find it easy to
	what someone is thinking	situations easy (11)	work out what
	or feeling just by looking at		someone is thinking
	their face (36)		or feeling just by
			looking at their face
			(36)
	I find it difficult to work out	S/he finds it hard to	S/he finds it hard to
	people's intentions (45)	make new friends (22)	make new friends (22)