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PRACTICE

GUIDELINES

Recognition, referral, diagnosis, and management of adults with autism: summary of NICE guidance

Stephen Pilling *professor and director*[1], Simon Baron-Cohen *professor and director*[2], Odette Megnin-Viggars *systematic reviewer*[3], Rachael Lee *research assistant*[3], Clare Taylor *senior editor*[3], on behalf of the guideline development group

[1]National Collaborating Centre for Mental Health and Centre for Outcomes Research and Effectiveness, University College London, London WC1E 7HB, UK; [2]Autism Research Centre, Psychiatry Department, Cambridge University CB2 8AH, UK; [3]National Collaborating Centre for Mental Health, Royal College of Psychiatrists, London E1 8AA

This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

Autism is a lifelong condition characterised by difficulties in social interaction and communication and by rigid or repetitive behaviours; it affects about 1.1% of adults.[1] Although some people's autism is diagnosed in childhood, for every three known cases, there are two individuals without a diagnosis who might need assessment, support, and interventions for autism at some point in their lives.[2] Four out of five adults with autism find that obtaining a diagnosis in adulthood is difficult or not possible,[3] and many who have all the core symptoms do not receive a formal diagnosis.[4] Particular problems arise in identifying high functioning autism (Asperger's syndrome), which may not be recognised until adulthood[5] or may be misdiagnosed as depression, personality disorder, or a psychotic illness. Inadequate identification and assessment of adults with autism not only leads to inadequate care but can also result in inadequate recognition and treatment of coexisting mental and physical health problems. Whereas care for children and young people is relatively well coordinated[6] this is often not the case for adults. Falling between and being passed around services is a particular problem for adults with autism who have an IQ over 70 and do not have severe and enduring mental illness, as they may be excluded from both learning disabilities and mental health services.[3] Social and economic exclusion affects a large proportion of adults with autism. Unemployment or underemployment is a considerable problem for adults with autism, including the 44% of those who do not have a learning disability,[7] with almost 90% of this group unemployed.[8]

This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) on autism in adults.[9]

Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in italic in square brackets.

General principles

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

- The nature, development, and course of autism
- The impact on personal, social, educational, and occupational functioning
- The impact of the social and physical environment.

[*Based on the experience and opinion of the Guideline Development Group (GDG) and on the evidence reviewed in the NICE guidance on improving the experience of care for people who use adult NHS mental health services.*[10]]

Assessment for autism

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:

Correspondence to: S Pilling s.pilling@ucl.ac.uk

-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.

[*Based on the experience and opinion of the GDG*]

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism Spectrum Quotient, 10 items (the AQ-10; figure⇓).[11] (If a person has reading difficulties, read out the AQ-10.) If a person scores above 6 on the AQ-10, or clinical judgment suggests autism (taking into account any history provided by an informant), offer a comprehensive assessment for autism. [*Based on low quality studies of the accuracy of diagnostic tests*]

During a comprehensive assessment, inquire 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 were present in childhood and have continued into adulthood
- Early developmental history, where possible
- Behavioural problems
- Functioning at home, in education, or in employment
- Past and current physical and mental disorders (for example, schizophrenia, depression, or other mood disorders; and anxiety disorders—in particular, social anxiety disorder and obsessive compulsive disorder)
- Other neurodevelopmental conditions
- Neurological disorders (for example, epilepsy)
- Communication difficulties (for example, speech and language problems, and selective mutism)
- Hypersensory and/or hyposensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations. [*Based on the experience and opinion of the GDG*]

Assessment of challenging behaviour

When assessing challenging behaviour, do a functional analysis (see "Interventions for challenging behaviour" below), 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.

[*Based on the experience and opinion of the GDG*]

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. [*Based on low quality evidence from quasi-experimental parallel group controlled trials and an economic model*]

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.

[*Based on low quality evidence from quasi-experimental parallel group controlled trials*]

For the management of core symptoms of autism in adults, do not use anticonvulsants, chelation, drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors), oxytocin, secretin, drugs for testosterone regulation, hyperbaric oxygen therapy, antipsychotic medication, or antidepressant medication. [*Based on low to moderate quality evidence from randomised controlled trials and observational studies, and the experience and opinion of the GDG*]

Interventions for challenging behaviour

When deciding on the nature and content of a psychosocial intervention for challenging behaviour, use a functional analysis. The functional analysis should facilitate the targeting of interventions by:

- Providing information, from a range of environments, on factors that seem to trigger the challenging behaviour; and on the consequences of the behaviour (that is, the reinforcement received as a result of their behaviour)
- Identifying trends in the occurrence of challenging behaviour, factors that may be evoking that behaviour, and the needs that the person is trying to meet by behaving in that manner.

[*Based on the experience and opinion of the GDG*]

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.

[*Based on the experience and opinion of the GDG*]

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 three to four weeks, and discontinue it if there is no indication of a clinically important response at six weeks. [*Based on low quality evidence from randomised controlled trials*]

Support for families and carers

Offer families, partners, 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. [*Based on the experience and opinion of the GDG*]

Offer information, advice, training, and support to families, partners, and carers if they need help with the personal, social, or emotional care of the person with autism; or if they are involved in supporting the delivery of an intervention (in collaboration with professionals). [*Based on the experience and opinion of the GDG*]

Overcoming barriers

Primary and secondary care professionals currently have a limited knowledge of autism and its various presentations,[12] and this lack will need specific attention if the recommendations in this guideline are to be of real benefit. Two areas are of particular concern: initial identification in primary care, and autism symptoms being masked by comorbid conditions in secondary care.[13] Training in the identification and assessment of autism should be more prominent in the undergraduate and postgraduate education of health and social care professionals.

People with autism, particularly those who are more disabled by it, often fall through the gaps between medical and social care, especially if they do not present with a mental health disorder or learning disability. This presents challenges in developing integrated health and social care services that engage people with autism. Access to treatment for adults with autism is also limited and extends beyond mental healthcare to physical healthcare. The establishment of local autism strategy groups (which should be responsible for developing and managing local care pathways) and of associated multiprofessional teams should help to resolve this problem of access to treatment, but care is needed to ensure that adults with autism have access to the full range of healthcare services. However, it is the families of adults with autism who provide much of the care and support. The guideline highlights that they too should receive specific support as without their involvement many interventions will be of limited benefit.

The members of the Guideline Development Group were Simon Baron-Cohen (chair), Stephen Pilling (facilitator), Gillian Baird, Carole Buckley, Peter Carpenter, Nadir Cheema, Juli Crocombe, Jackie Dziewanowska, Annie Foster-Jones, Naomi Glover, Marga Hogenboom, Patricia Howlin, Flora Kaminski, Rachael Lee, Katherine Leggett, Campbell Main, Ifigeneia Mavranezouli, Melissa McAuliffe, Odette Megnin-Viggars, Richard Mills, Joan Panton, Maggi Rigg, Sarah Stockton, Clare Taylor, Amina Udechuku, and Anya Ustaszewski.

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Further information on the guidance

Several areas of inconsistent practice prompted the development of this guideline, including the overuse of antipsychotic medication for the management of challenging behaviour[14] and the very limited provision of psychological interventions for problems arising directly from the autism or from coexisting conditions.[3] Specialist autism teams have been established in only a few areas in the UK, and consequently access to specialist assessment and advice for those who are less disabled, and longer term care and support for those who are more disabled, is very limited. Many young people with autism lose contact with services when they reach age 18,[3] and the benefits of previous support and intervention may be lost in the absence of effective services for adults, particularly for those who have high functioning autism.

Methods

This guideline was developed by the National Collaborating Centre for Mental Health using the NICE guideline methods (www.nice.org.uk/guidelinesmanual). The guideline review process involved comprehensive and systematic literature searches to identify relevant evidence for the clinical and economic reviews, with critical appraisal of the quality of the identified evidence. The limited evidence base required the development and refinement of existing methods, including procedures for extrapolating from other databases and the incorporation and adaptation of recommendations from other NICE guidelines. A multidisciplinary team (the Guideline Development Group (GDG)) comprising healthcare professionals (from psychiatry, psychology, paediatrics, general practice, and nursing) and representatives of service users and carers was established to review the evidence and develop recommendations. The guideline then went through an external consultation with stakeholders. The GDG considered the stakeholders' comments, reanalysed the data where necessary, and modified the guideline as appropriate.

NICE has produced three different versions of the guideline on autism in adults: a full version; a summary version known as the "NICE guideline"; and a version for adults with autism, their families and carers, and the public. All these versions, as well as a NICE pathway (an interactive tool that integrates both guidelines on autism (CG128[6] and CG142[9])), are available from the NICE website. Updates of the guideline will be produced as part of NICE's guideline development programme.

Future research

- The clinical and cost effectiveness of the following interventions for coexisting mental health problems:
  -Facilitated self help for mild anxiety and depressive disorders
  -Cognitive behavioural therapy for moderate and severe anxiety disorders
  -Selective serotonin reuptake inhibitors for moderate and severe depression
- The clinical and cost effectiveness of augmentative communication devices
- The optimal structure and organisation of specialist autism teams for improvements in care

Figure

	Please tick one option per question only	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
1	I often notice small sounds when others do not				
2	I usually concentrate more on the whole picture, rather than the small details				
3	I find it easy to do more than one thing at once				
4	If there is an interruption, I can switch back to what I was doing very quickly				
5	I find it easy to "read between the lines" when someone is talking to me				
6	I know how to tell if someone listening to me is getting bored				
7	When I'm reading a story I find it difficult to work out the characters' intentions				
8	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)				
9	I find it easy to work out what someone is thinking or feeling just by looking at their face				
10	I find it difficult to work out people's intentions				

Scoring: Only 1 point can be scored for each question. Score 1 point for Definitely or Slightly Agree on each of items 1, 7, 8, and 10. Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 5, 6, and 9. If the individual scores more than 6 out of 10, consider referring them for a specialist diagnostic assessment.

This test is recommended in *Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum* (NICE clinical guideline 142). www.nice.org.uk/CG142

Key reference: Allison et al[11]

Autism Spectrum Quotient—10 items (AQ-10): a quick referral guide for adults with suspected autism who do not have a learning disability