Autism Spectrum Disorder: The NICE guidelines

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Abstract

The National Institute for Health and Care Excellence (NICE) Guidelines on Autism consist of three publications *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum* (NICE clinical guideline 128), *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum* (NICE clinical guideline 142) and *Autism: the management and support of children and young people on the autism spectrum* (clinical guideline 170 published in 2013). As a suite of guidelines with associated information, including audit tools and pathways, the intention is to promote guidance for a seamless service across the life span. Autism is the term used in the guidelines to encompass all diagnoses of 'pervasive developmental disorder/autism spectrum disorder' and subgroups as in recent Department of Health, National Audit Office and Public Accounts Committee documents. The guidelines draw together systematic reviews and expert opinion to produce clinical practice recommendations covering recognition, referral, diagnosis, interventions, both psychosocial and pharmacological, as well as organisation of services for children, young people and adults. This article summarises the key practice recommendations, highlights where gaps remain in the evidence base and describes some of the challenges for implementing the guidelines in routine clinical practice.

Introduction

The term autism spectrum disorder (ASD) describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. Once thought to be an uncommon developmental disorder, recent studies have reported prevalence rates of at least 1% in children, young people and adults. Autism spectrum disorder is diagnosed more frequently in males.

Autism spectrum disorder is a behaviourally defined disorder, heterogeneous in both cause and manifestation. People with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability. Autism has a considerable economic impact on individuals with the condition, their family members and carers, health and social services, and the wider society. Knapp and colleagues in 2009 estimated that the annual cost of supporting children with autism reaches £2.7 billion, while the respective cost for adults with autism amounts to £25 billion (2006 prices). These estimates are based on 1% prevalence of autism across all ages and have taken into account costs associated with provision of health and social care, respite care, special education and day services, accommodation, voluntary organisation help, as well as productivity losses (lost employment) of parents and adults with autism, but do not include cost estimates on benefit payments or informal care.

Core autism behaviours are typically present in early childhood, although some features may not be manifest until a change of situation, for example, the start of nursery or school or, less commonly, the transition to secondary school, or sometimes in adult life following recognition of autism in offspring. Regression or stasis of language and social behaviour is reported for at least a third of children with autism. This usually, but not exclusively, occurs between the ages of 1 and 2 years, and appears to be one trajectory for onset. Later regression is rare and is more pervasive across language, social, cognitive and behavioural function for unknown reasons. The way in which autism is expressed will

differ across different ages and therefore for an individual may change over time with maturity, in response to environmental demands, in response to interventions, and in the context of coexisting conditions.

Diagnosis is usually based on accepted diagnostic criteria described in the International Classification of Diseases and Related Health Problems, tenth revision (ICD-10) and the Diagnostic and Statistical Manual of the American Psychiatric Association, fourth edition with revised text (DSM IV-TR) and now the fifth edition (DSM-5). The ICD 10 and DSM IV-TR use the term 'pervasive developmental disorder (PDD)' to group together diagnoses relating to the autism spectrum. There are several subcategories in both systems which have been removed in DSM-5 to create a single category of autism spectrum disorder with two domains of impairment: (i) reciprocal social interaction and social communication and (ii) restricted repetitive interests and activities (which now includes stereotyped speech and sensory sensitivities and interests as diagnostic features). Included is the recognition that ASD and other DSM-5 diagnoses can co-exist. All the NICE guidelines had regard to the DSM-5 revision (published May 2013) during production of the guidelines, recognising that the ICD is also undergoing similar revision (expected 2015).

As in the guidelines, the term autism is used in the rest of this article to encompass autism spectrum disorder.

Among reasons for producing the guidelines are comments by families that they find it difficult to get the support and access to autism expertise they require; that diagnostic services either do not exist or are slow to respond to concerns; that strengths and weaknesses are not individually assessed; that co-existing conditions are not recognised; that care services are not integrated (including with education and/or employment); that there is insufficient resource to meet mental health needs and provide interventions for behaviour that challenges; and that both health and social care services regularly fail to recognise the impact that autism has on both the young person and their families and carers. This shortfall relates not only to autism-specific interventions but also to medical and health care of a more general nature. All services, including GPs and community health provision, need to be mindful of the need to recognise that many presenting symptoms in children and young people with autism may signify additional medical needs that are in danger of being under-treated where professionals and services have not made necessary adaptations to their practice.

Methodology

The guidelines were developed by the National Institute for Health and Care Excellence (NICE) National Collaborating Centres for Women and Children and Mental Health using standard NICE methodology. NICE recommendations are based on systematic reviews of the 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. Details are given in the Guideline Manuals.

Recommendations

Key to the implementation of the recommendations for management, interventions and care is the strategic planning and organisation of services for effective delivery.

Services for children, young people and adults with autism and their families can be considered in four stages.

1. The Initial phase encompassing recognition, referral, diagnosis and post-diagnosis intervention and treatment for specific needs and support which might be at any age.
2. The review phase, which may have particular crisis points e.g. changing schools, entering employment.
3. The transition phase to adulthood.
4. Adulthood and into old age.

The guidelines recommend that a local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health, mental health services, education, social care, parent and carer service users, and the voluntary sector.

The local autism strategy group should undertake the following:

- Develop and evaluate (through audit) a local pathway for autism services that is accessible and acceptable, integrated and outcome focussed.
- Appoint a lead professional to be responsible for the local autism pathway.
- Make sure the relevant professionals (healthcare, social care, education and voluntary sector, housing and employment) are aware of the local autism pathway and how to access it.
- Raise awareness of the signs and symptoms of autism through multi-agency training.
- Support the smooth transition to adult services for young people.

Recognition, referral and diagnosis

Concern about possible autism arises most often from either a family member or from a primary care or education professional. The emphasis is on taking concerns seriously whether from a parent/carer or a young person/adult themselves. In recognition of the variation in manifestation of symptoms depending on age, intellectual ability and coexisting conditions, tables are provided of signs and symptoms in CG 128. The intention is that they are used in training rather than a 'tick list' of essential features to be met before referral. Included are common pitfalls. For example, autism should not be ruled out because of apparently good eye contact, smiling, and showing affection to family members, reported pretend play or normal language milestones. Autism is frequently missed in those with an intellectual disability and those who are verbally very able. It may be underdiagnosed in females for reasons that are currently debated.

A number of factors are associated with increased risk of autism, including having a sibling with ASD, valproate in pregnancy, medical conditions such as fragile X, neurofibromatosis, tuberous sclerosis and any condition that is associated with brain damage.

Certain symptoms are RED FLAGS for autism in young children, notably regression in language and social skills (but not motor skills) in the second year of life.

- Refer children younger than 3 years to the autism team if there is regression in language or social skills.
- Refer first to a paediatrician or paediatric neurologist (who can refer to the autism team if necessary) children and young people who are:
    - older than three years with regression in language
    - of any age with regression in motor skills.

Adult guidance is that assessment be considered for possible autism when a person has:
- persistent difficulties in reciprocal (two-way) social interaction 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 mental health or learning disability services
    - history of a neurodevelopmental disorder (including learning disability and attention deficit hyperactivity disorder) or mental disorder.

Primary population screening for autism was not examined by NICE as this is the role of the National Screening Committee which has concluded that screening the whole population for autism in the UK is not advised, although the use of screening tools for young children is encouraged in the USA. For secondary screening (i.e. if there is already a concern about autism), in adults who have no moderate or severe learning difficulties, the use of the autism quotient (AQ) should be considered. NICE does not

recommend the routine use of screening tools for secondary screening in children and young people but advises that they may be useful in gathering information about signs and symptoms of autism in a structured way noting that:

- a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism
- a negative score does not rule out autism.

Referral for diagnostic assessment

A key recommendation in the guidelines is a clear referral pathway for diagnostic assessment for autism to the 'autism team', a specialist group with the skills and competencies (or access to the skills and competences through a regional team) to:

- carry out an autism diagnostic assessment including in those with special circumstances such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders and looked-after children and young people
- communicate with children, young people and adults with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them.

Core team members for Children and Young People are:

- a paediatrician and/or child and adolescent psychiatrist
- a speech and language therapist
- a clinical and/or educational psychologist.

There should also be regular access to an occupational therapist.

For adults, core team members are:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, supporting access to employment, further education, residential services, financial advice, and personal and community safety skills).

There should be a single point of referral to the team.

Decision about referral of any individual to the team is through the primary care team for whom the following recommendations are made.

- To discuss referral with the parent carer and, where appropriate, the child or young person or adult.
- If concerns are insufficient to prompt a referral, consider a period of watchful waiting.
- Be self-critical about personal professional competence and seek advice if in doubt about the next step.

Important factors in whether to proceed with a diagnostic assessment are:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school or work)

- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child, young person or adult
- factors associated with an increased prevalence of autism
- the likelihood of an alternative diagnosis.

The autism diagnostic assessment should be started within 3 months of the referral to the autism team.

A case coordinator in the autism team should be identified for anyone who is to have an autism diagnostic assessment, to act as a single point of contact.

A comprehensive diagnostic assessment is multidisciplinary and includes the following:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's or adult's concerns
- details of the person's experiences of home life, education and social care
- a developmental history (where possible if an adult), focusing on developmental and behavioural features in different contexts consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information e.g. ADI, DISCO, 3Di, although evidence does not indicate any specific tool)
- assessment (through interaction with and observation of the person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV/ DSM-5 criteria (consider using an autism-specific tool such as the ADOS to gather this information)
- a medical history, including prenatal, perinatal and family history (where possible), and past and current health conditions
- a physical examination, including hearing and vision tests (if not done)
- consideration of the differential diagnosis
- systematic assessment for conditions that may coexist with autism, including mental and behaviour problems and medical conditions
- functioning at home, in education or in employment
- assessment of risk including self-harm, harm to others, harm from others including exploitation, rapid escalation of problems, self-neglect, breakdown of family or residential support
- communication of assessment findings to the parent or carer and, if appropriate, the individual.

An important role for NICE guidance is 'what not to do'.

Diagnosis should not be based on one tool alone, history and observation are necessary and diagnosis remains a clinical judgment after synthesising all sources of information. If there is discrepant information, further assessment, including other contexts (and other opinions), may be necessary.

Biological tests, genetic tests or neuroimaging should not be used routinely for diagnostic purposes but genetic tests, as recommended by the regional genetics centre, should be considered in individual circumstances, based on clinical judgment and physical examination e.g. if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability and electroencephalography considered if there is suspicion of epilepsy.

Management, intervention and care

This includes:

- information and support for individuals and families
- communicating needs with permission etc.

- improving the knowledge and competence of all who are involved in the care of those with autism
- making adjustments to the physical and social environment
- specific interventions for autism and co-existing conditions
- enabling full access to all health and social care including mental health, with adjustments as needed to the processes of care, e.g. timing of appointments, anticipating problems with hospital admission, having a health passport
- enabling individual and family participation in decisions about care and management.

A management and care plan should be developed following the comprehensive assessment of the person's strengths, skills, impairments and needs, incorporating the risk management plan and taking into account the needs of the family/carer(s).

Local autism teams have a key role in the delivery and coordination of specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation through:

- advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- advice and interventions to promote functional adaptive skills, including communication and daily living skills
- assessing and managing behaviour that challenges
- assessing and managing coexisting conditions
- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- supporting access to leisure and enjoyable activities
- supporting access to and maintaining contact with educational, housing and employment services
- providing support for families (including siblings) and carers, including offering short breaks and other respite care
- producing local protocols for:
  - information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
  -shared-care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained.

Specific interventions for the core features of autism

Following the diagnosis of autism, a social communication intervention is recommended for preschool and school-aged children. This should be delivered by a trained professional and include play-based strategies to increase joint attention, engagement, and reciprocal communication in the child or young person. For preschool children, parent, carer, or teacher mediation and for school-aged children peer mediation should be considered.

Strategies should:

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

This is based on evidence from meta-analyses with blinded outcome assessment for small to moderate effects of caregiver-mediated or preschool-teacher-mediated social-communication interventions

on social interaction, communication acts, parent-child joint attention and parent-child joint engagement, for young children with autism and peer-child joint engagement for older children (mean ages of 8-9 years).
For adults with autism who have no learning disability or a mild to moderate learning disability, but who have identified problems with social interaction, the adult guideline recommends considering a group-based social learning programme (and for people who find group-based activities difficult, an individually delivered social learning programme) focused on improving social interaction typically including:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules.

What should not be done:

Secretin, chelation, or hyperbaric oxygen therapy should never be used to manage autism in any context because there is no clear evidence that these are effective and because there is harm associated with their use.

Antipsychotics, antidepressants, anticonvulsants, and exclusion diets (such as gluten-free or casein-free diets) should not be used to manage the core features of autism because the balance of risks (especially with anticonvulsants and exclusion diets) and benefits did not favour their use.

Neither neurofeedback nor auditory integration training should be used to manage speech and language problems in children and young people with autism.

Co-existing conditions

Autism is strongly associated with a number of co-existing conditions which are not part of the diagnostic criteria but have an impact on the wellbeing of the child or young person and family.

Recent studies suggest that approximately 70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder, and 40% meet diagnostic criteria for at least two disorders, mainly anxiety, ADHD and ODD. Typically, these coexisting mental and behavioural conditions further impair psychosocial functioning.

Challenging behaviours, including aggression (to objects or people), destructiveness and self-injury (e.g. head-banging, hand or wrist-biting or skin-picking), are more common in autism than in other conditions with similar levels of intellectual impairment.

Intellectual disability (IQ<70) occurs in approximately 50% of young people with autism. Characteristic of autism is the gap between intellectual skills and adaptive skills (communication, socialisation and daily living/self-care skills) which are frequently markedly lower than general cognitive abilities in ASD. This has a significant impact on everyday functioning. Language disorders and specific learning difficulties (literacy, numeracy and other academic skills) are common. 10% of people with autism fail to develop speech. Developmental Coordination Disorder (DCD) also commonly co-occurs with autism (approx 50-73% of children with autism have significant motor delays manifesting as general clumsiness or an unusual gait). Handwriting is a particular frustration for many.

Intellectual ability and language skills remain the best predictors of outcome and around 25 to 30% of individuals with good intellectual skills are able to achieve well academically and find employment as adults.

Other medical conditions, including epilepsy, are more commonly found in autism, especially in

association with intellectual disability, may not be recognised and are associated with increased mortality. Functional problems are common and have a major impact on the child and family. 40%-86% of children with autism have reported sleep problems, affecting sleep onset, frequent waking for longer periods and reduced sleep duration. Eating difficulties (restricted and rigid food choices) may be the presenting feature of autism in early childhood. Gastrointestinal problems are frequently reported - particularly diarrhoea, abdominal pain and constipation.

The guidelines recommend offering psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in people with autism, informed by existing NICE guidance for the specific disorder.

For those who have the verbal and cognitive ability to engage in a cognitive behavioural therapy (CBT) intervention e.g. for anxiety, adaptations to the method of delivery of cognitive and behavioural interventions 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 or hypothetical situations
- involving a family member, partner, carer 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 (such as using computers to present information)
- emotion recognition training.

Psychosocial interventions based on behavioural principles are recommended for all young people and adults who need help with daily living and participation in leisure activities.

If the individual has a sleep problem, a stepped approach is recommended (based on the experience and expert opinion of the GDG) that identifies the following.

- What the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems, or sleepiness during the day).
- Day and night sleep patterns, and any change to those patterns.
- Whether bedtime is regular and what the sleep environment is like.
- Presence of comorbidities, especially those that feature hyperactivity or other behavioural problems.
- Levels of activity and exercise during the day.
- Possible physical illness (including snoring and possible obstructive apnoea) or discomfort.
- Effects of any medication.
- Individual factors such as emotional relationships or problems at school.

Institute a sleep hygiene plan

Do not use a pharmacological intervention to aid sleep unless:

- sleep problems persist despite following the sleep plan
- sleep problems are having a negative impact on the child or young person and their family or carers.

Behaviour that Challenges

The emphasis in the guidelines is that:

- in routine assessment and care planning, assess factors that may increase the risk of behaviour that challenges

• if a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could trigger or maintain the behaviour

including the following.

- Impairments in communication that may result in difficulty understanding situations or expressing needs and wishes.
- Coexisting physical disorders (such as pain or gastrointestinal disorders), mental health problems (such as anxiety or depression), and other neurodevelopmental conditions (such as ADHD).
- The physical environment, such as lighting and noise levels.
- The social environment, including home, school, employment and leisure activities.
- Changes to routines or personal circumstances.
- Developmental change, including puberty.
- Exploitation or abuse by others.
- The absence of predictability and structure.

[Based on the experience and expert opinion of the GDG].

• If no coexisting mental health or behavioural problem, physical disorder, or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer a psychosocial intervention (informed by a functional assessment of behaviour) as a first line treatment. *(Based on the experience and expert opinion of the GDG)*

• Based on low to moderate quality randomised controlled trials for efficacy, antipsychotic medication should be considered for managing behaviour that challenges when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist, who should:

- Identify the target behaviour
- Decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
- Review the effectiveness and any side effects of the medication after three to four weeks
- Stop treatment if there is no indication of a clinically important response at six weeks.

Transition to adult services

Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care and involves the young person and their parent carers in the process.

For young people aged 16 or older whose needs are complex or severe, use the care programme approach (10) in England (care and treatment plans in Wales) to coordinate their needs and as an aid to transfer between services.

Comment

There were few studies, particularly on interventions, that met the review's inclusion criteria, and few that were judged to be high quality according to the GRADE criteria, which prevented the meta-analyses of results across studies. In particular, psychosocial interventions are complex; adequate sample size can be a problem as is deciding on the best and most meaningful functional outcome; blindness to treatment is near impossible if parent ratings are to be used and follow-up periods tend to be short. The research recommendations focus on areas where there was some evidence and more studies would enable definitive guidance to be given, for example, on a keyworker approach, management of sleep problems, psychosocial interventions for core symptoms, treatment of anxiety and behaviour that challenges.

Challenges to implementation of the guidelines

In a time of huge change in service organisation in the NHS, in educational special needs and straitened economic times, the challenge will be to ensure that the local autism strategy group with all stakeholders can develop and maintain the lifetime integrated services. Since the national autism plan in 2002 there has been an increase in the number of district teams in the UK who have a formal autism assessment protocol: (32% in 2001 rising to 54% in 2007); more services are using a multidisciplinary/ multiagency team approach (48% in 2001 vs. 93% in 2007), and more teams have joint clinics with child mental health services (34% in 2001 vs. 57% in 2007). However, the current prevalence rates are a challenge to completing a diagnostic assessment and implementing interventions in a timely fashion for children, young people and adults with possible autism. Skills for the specific social communication intervention recommended may be lacking. The integrated coordinated care with a keyworker approach is absent for many families and tariff payment structures do not support integrated services. The primary care GP is frequently marginalised, although very important from the whole family perspective. Services for adequate assessment of the cause of behaviour that challenges and a functional assessment leading to psychosocial treatment are variable and often poorly integrated, with reliance in some places on pharmacological approaches alone. However, some places are providing good services and the guidelines should help to improve services for all.

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GP comment.

What have I learned from this paper?

This helpful and comprehensive paper highlights the complexities of the autistic spectrum and covers issues of diagnosis and management into adult life. Helpful points, from a Primary Care perspective, include referral 'red flags', sleep and behaviour management, the risks and benefits of medications and 'what not to do'. The recommendations about optimal service provision may be difficult to translate into practice, given cuts to NHS services, and I hope, therefore, that commissioners will give these guidelines careful consideration.

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[More extensive references are in the full NICE guidelines.]

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