

# Autism in children and young people



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## Welcome

In September 2011 NICE published a clinical guideline on the recognition, referral and diagnosis of children and young people with autism

# Autism in children and young people

**A**utism was once believed to be an uncommon disorder; however, recent studies have reported increased prevalence and now at least 1 in 100 children is thought to be autistic. This has led to increased demand for diagnostic services for children and young people of all ages in the health service.

Autism describes behavioural differences and difficulties with social interaction and communication, combined with restricted interests and rigid and repetitive behaviours. Children, young people and adults are diagnosed as being on the autism spectrum if these behaviours meet the criteria defined in the DSM-IV and ICD-10 and have a significant impact on function.

It is a lifelong disorder that has a great impact on the child or young person and their family or carers. For some, a correct diagnosis can bring a profound sense of relief from what can be an intense feeling of isolation from the rest of the world. It can also help them and their families or carers to get support from education, health services and voluntary organisations and make contact with others with similar experiences.

Levels of understanding among healthcare and other professionals and availability of services differ greatly across

the country and children and young people with certain co-existing conditions such as intellectual disability are less likely to be diagnosed with autism, leading to inequalities in healthcare and service provision.

The guideline emphasises the importance of effective coordination between health agencies and other key services such as education, social care and the voluntary sector. This guideline does not cover interventions for children and young people on the autism spectrum but aims to improve recognition, referral and diagnosis, and the experience of children, young people and those who care for them.

For clarity and consistency, the term 'autism' is used throughout the guideline, in keeping with the recent Department of Health, National Audit Office and Public Accounts Committee documents. However in the guideline 'autism' refers to 'autism spectrum disorders'.<sup>1</sup>

## Reference

1. Department of Health (DH). *Fulfilling and rewarding lives: the strategy for adults with autism in England*. London: DH; 2010.

## What NICE recommends

### STRATEGIC PLANNING

NICE advises that there should be local multi-agency strategy groups, responsible for the overall recognition, referral and diagnosis of autism in children and young people. The aims of the group should be to:

- Improve the early recognition of autism by raising awareness of the signs and symptoms through multi-agency training (see Appendix C of the NICE guideline for the full list of signs and symptoms).
- Ensure relevant professionals are aware of the local area's care pathway and how to access diagnostic services.
- Support the smooth transition to adult services for young people going through the diagnostic pathway.
- Ensure data collection and auditing of the pathway takes place.

The strategy group should have representation from managers, commissioners, child health and mental health services, education, social care, parent and carer service users and the voluntary sector. A lead professional should be appointed so that these objectives can be delivered effectively.

#### Local autism teams

Within local NHS settings, multidisciplinary groups of autism experts should be established. The core membership should include:

### BOX 1. FACTORS ASSOCIATED WITH AN INCREASED PREVALENCE OF AUTISM

- A sibling with autism
- Birth defects associated with central nervous system malformation and/or dysfunction, including
  - Cerebral palsy
  - Gestational age less than 35 weeks
  - Parental schizophrenia-like psychosis or affective disorder
  - Maternal use of sodium valproate in pregnancy
  - Intellectual disability
  - Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms
  - Chromosomal disorders such as Down's syndrome
- Genetic disorders such as fragile X

- Paediatrician and/or child and adolescent psychiatrist.
- Speech and language therapist.
- Clinical and/or educational psychologist.
- Occupational therapist.

In addition, the following should be considered or should be regularly accessible: paediatric neurologists, occupational therapists, specialist health



visitors, autism nurses, specialist teachers and social workers.

The autism teams should have the skills and competencies to carry out the autism diagnostic assessments and communicate with children and young people with suspected or known autism and sensitivel

A case co-ordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment. They will act as a single point of contact for parents or carers and will keep them up to date on the likely time and sequence of assessments.

## 'NICE guidelines should be used within the context of the child's overall development'

share the diagnosis with them and their parents or carers. This includes for children and young people who have special circumstances, such as visual or hearing impairments, motor disorders (eg, cerebral palsy), severe intellectual disability, complex language or mental health disorders, and those in care.

### **Recognising possible autism**

While the NICE guideline outlines the signs and symptoms that could indicate a possible diagnosis of autism (Appendix C of the guideline), these should be considered in the context of the child or young person's overall development.

What's more, the list is not exhaustive

and so it should be used as guidance only. For example, autism should not be ruled out because the child or young person has good eye contact, shows affection with family members, reaches normal language milestones, or if a previous assessment returned a negative diagnosis.

Nurses and other healthcare professionals should be critical about their professional competence and seek advice from a colleague if in doubt about the next step. Other factors that nurses should consider include that:

- Older children or young people may have previously masked their signs and symptoms through coping mechanisms and/or a supportive environment.
- Hearing difficulties or English not being the family's first language are not the only explanations for language delay.
- Autism may be under-diagnosed in girls, children with an intellectual disability or those who are verbally able.
- Signs and symptoms may not be accounted for by disruptive home experiences or parental/carer mental or physical illness.

### Referring to the autism team

When considering a referral, nurses and other relevant healthcare professionals should take into account the severity and duration of signs and symptoms, the extent to which they are present across different settings (eg, home and school), the impact that they have on the patient and his or her family, the level of parental or carer concern, the factors associated with increased prevalence (Box 1) and the likelihood of an alternative diagnosis. The referral letter to

### EVERY AUTISM DIAGNOSTIC ASSESSMENT SHOULD INCLUDE:

- Detailed questions about the parent's or carer's, and if appropriate the child's or young person's, concerns
- Details of the child or young person's experiences of home life, education and social care
- A developmental history, focusing on features consistent with ICD-10 or DSM-IV criteria
- Assessment (through interaction and observation) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A physical examination
- Consideration of a differential diagnosis – such as attention deficit hyperactivity disorder, anxiety, obsessive compulsive disorder, Rett syndrome, severe hearing or visual impairment, maltreatment, intellectual disability, or specific language delay

the autism team should include:

- Reported information from parents, carers and professionals.
- Your own observations.
- Antenatal and perinatal history.
- The factors associated with increased prevalence (Box 1).
- Relevant medical history and

investigations.

- Information from previous assessments.

If the concerns are insufficient to prompt a referral, nurses and other healthcare professionals should consider a period of watchful waiting.

### **The diagnostic assessment**

Children and young people who have possible autism should begin their diagnostic assessment within three months of their referral to the autism team.

If there are discrepancies during the assessment between the reported signs and symptoms and the findings of the autism observation in the clinical setting, healthcare professionals should consider gathering additional information from other sources and carrying out further autism-specific observations in different settings, such as school, nursery, or at home.

Healthcare professionals should be mindful that there may be uncertainty about the diagnosis, particularly in children under two years of age or those with a developmental age of less than 18 months, children lacking information about their early life (eg, some looked after or adopted children), older teenagers and those who have coexisting disorders (eg, ADHD or cerebral palsy).

ICD-10 and DSM-IV criteria are effective diagnostic tools, but they should not be used in isolation – information from all sources, together with clinical judgment is of paramount importance.

### **Following diagnosis**

If the diagnostic assessment clearly indicates that the child or young person

does not have autism, they should be referred to other services according to their clinical profile, if appropriate.

Children and young people with a diagnosis of autism should be offered a follow-up appointment with an appropriate member of the team within six weeks, for example to discuss the conclusions of the assessment and their implications. Details should be provided for:

- Local and national support organisations (which may provide an opportunity to meet other families with similar experience, or information about specific courses).
- Organisations that can advise on welfare benefits.
- Organisations that can advise on educational support and social care.
- Preparing for the future, eg, transition to adult services.

## **CONCLUSION**

The guideline offers practical, evidence-based advice for nurses and other healthcare professionals on how to care for a child or young person, and their families or carers, during their referral and diagnosis. It does not cover the long-term management of autism, or the diagnosis and management of the condition in adults – this will follow in further NICE guidance due to be published over the next two years.

To read the full recommendations in NICE's clinical guideline 128 on the recognition, referral and diagnosis of autism in children and young people, and to access tools to help nurses implement the recommendations and supporting advice please visit: [www.nice.org.uk/CG128](http://www.nice.org.uk/CG128)

