NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Centre for Clinical Practice

SCOPE

1 Guideline title

Autism: the management and support of children and young people on the autism spectrum

1.1 Short title

Autism: management of autism in children and young people

2 The remit

The Department of Health has asked NICE: ‘To produce a clinical guideline in collaboration with the Social Care Institute for Excellence on the management of autism spectrum disorder in children and young people’[1].

3 Clinical need for the guideline

3.1 Epidemiology

a) Autism is a spectrum of lifelong neurodevelopmental, biologically-based and genetically heritable conditions influenced significantly by environmental factors, diagnosed on the basis of a triad of behavioural impairments: impaired social interaction, impaired communication, and restricted and repetitive interests and activities.

[1] The scoping group recognises that different people 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 all of these.

b) In addition to these core features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, mental, emotional and behavioural problems, including a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. Some or all of these features substantially impact on the quality of life of the individual and lead to a social vulnerability especially in the most able group.

c) The clinical picture of autism is variable because of differences in autistic severity, coexisting conditions and levels of ability, from profound intellectual disability to an uneven cognitive profile with superior skills in some areas.

d) Diagnostic criteria are described and defined in the World Health Organization ICD-10 and the Diagnostic and Statistical Manual DSM-IV. Both the major diagnostic classification systems (DSM-IV and ICD-10) use the term 'pervasive developmental disorder', which encompasses autism, Asperger's syndrome and atypical autism (or ‘pervasive developmental disorder not otherwise specified’). For a diagnosis to be made, there must be the presence of impairments and an impact on the person’s adaptive function. Both classification systems are undergoing revision and have announced that the term 'autism spectrum disorder' will be used. For this guideline we will use the term ‘autism’ to include all autism spectrum disorders.

e) Although autism was once thought to be an uncommon developmental disorder, recent studies have reported prevalence rates of at least 1% of the child population. Autism is diagnosed more frequently in boys. As with many developmental and

behavioural disorders, the diagnostic criteria applied substantially affect estimates of prevalence.

f) The core autism behaviours are typically present in early childhood, although some features may not manifest until a change of situation, for example, the start of nursery or school or, less commonly, the transition to secondary school. Regression or stasis of language and social behaviour is reported for 20 to 30% of children with autism. This usually, but not exclusively, occurs between the ages of 1 and 2 years, and the reasons for regression and stasis are unknown.

g) The way in which autism is expressed will differ across different ages and thus for any person may change over time as they mature, in response to environmental demands, in response to interventions, and in the context of coexisting conditions.

h) Around 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that further impairs psychosocial functioning, for example, ADHD, anxiety disorders. Intellectual disability (IQ below 70) co-occurs in approximately 50% of children and young people with autism.

3.2 Current practice

a) Currently, autism is usually diagnosed within community health services although initial recognition may be made by parents or carers, teachers, health visitors or other members of the primary health care team. Different regions and areas have different referral policies, although in general young children will be referred to paediatricians at a child development centre or directly to speech and language therapy services, and older children to paediatricians or child and adolescent mental health services (CAMHS).

b) There is currently no cure for autism. However, there is general agreement that early diagnosis followed by appropriate therapeutic intervention can improve outcomes in later life for most people.

c) The heterogeneity of autism means that it is often difficult to be sure who will benefit from the many available therapies. The timing of the intervention and the age of onset of autism is also likely to affect outcomes.

d) A variety of therapeutic interventions have been proposed to improve symptoms associated with autism, including early intensive behavioural intervention, social skills training, sensory integration therapy, facilitated communication, music therapy, acupuncture, vitamins, and dietary supplements.

e) In routine practice, specialist behavioural and educational interventions have become the predominant therapeutic approach for social, adaptive, and behavioural functions in children with autism.

f) Drugs have also been used as an adjunct to behavioural interventions because of their effect on coexisting conditions such as hyperactivity, aggression, obsessive-compulsive behaviours, sleep disturbance, mood disorder, poor attention or concentration, and self-injurious behaviour.

g) Many of the available therapies are invasive, time-consuming and costly, and there is a paucity of evidence about their efficacy or potential to do harm.

h) NICE and the National Collaborating Centre for Women's and Children's Health have developed a clinical guideline covering recognition, referral and diagnosis of children and young people with autism. This NICE-SCIE guideline will cover the second part of the care pathway. Together with the one on recognition, referral and diagnosis, this will provide guidance to the NHS on the full

range of care for children and young people with autism: case identification, assessment and diagnosis; management; and support for children and young people, their families and other carers.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

a) Children and young people (from birth until their 19th birthday) with autism (across the full range of intellectual ability) and their families and carers

b) Consideration will be given to the particular management and support needs of:

- looked after children
- immigrant groups
- children with regression in skills

4.1.2 Groups that will not be covered

a) Adults (19 years and older).

4.2 Setting

a) Primary, secondary and tertiary health and social care. This guideline will also be relevant to other health and social care

settings (including forensic services and youth justice settings) although they are not explicitly covered.

b) The guideline will also address interventions relevant to early years services and educational settings.

4.3 Management

4.3.1 Key issues that will be covered

a) Psychosocial interventions, including:

- behavioural therapies (for example, applied behavioural analysis, applied behaviour intervention)
- educational interventions, carer- and peer-delivered interventions
- arts-based therapies (for example, dramatherapy, art and music therapy)
- sensory interventions (for example, auditory integration therapy, sensory integration)
- interventions that address communication and social interaction.

b) Pharmacological interventions, including:

- anticonvulsants
- antidepressants
- antipsychotics
- stimulants
- hormones
- cognitive enhancers
- chelation therapy.

Note that guideline recommendations normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a drug's

summary of product characteristics to inform decisions made with individual patients.

c) Physical interventions, including:

- acupuncture
- hyperbaric oxygen therapy
- exercise
- massage
- cranial osteopathy.

d) Nutritional interventions, including:

- diet
- vitamins
- supplements.

e) Modifications to the management of autism made necessary by the child or young person with autism having any of the following as a coexisting condition:

- mental and behaviour problems and disorders (including ADHD, anxiety disorders and phobias, mood disorders, oppositional defiant behaviour, tics or Tourette syndrome, OCD and self-injurious behaviour)
- neurodevelopmental problems and disorders (including global delay or intellectual disability, motor coordination problems or developmental coordination disorder, academic learning problems and speech and language disorder)
- medical or genetic problems and disorders (including epilepsy and epileptic encephalopathy, chromosome disorders, genetic abnormalities, tuberous sclerosis, muscular dystrophy and neurofibromatosis)
- functional problems and disorders (including feeding problems, urinary incontinence or enuresis, constipation, altered bowel

habit, faecal incontinence or encopresis, sleep disturbances and vision or hearing impairment).

f) Anticipating, preventing and managing behaviour that challenges.

g) Alterations needed to routine and acute healthcare.

h) Information for children and young people, and their families (including siblings) and carers, throughout the care pathway.

i) Support needs of children and young people, their families and carers throughout the care pathway (for example, case management).

j) Interface with other services within healthcare and outside for the optimal organisation and delivery of care.

4.3.2 Clinical issues that will not be covered

a) Recognition, referral and diagnosis.

b) Therapeutic intervention and management of the symptoms and behaviours associated with Rett syndrome.

c) Management of coexisting conditions, unless these affect interventions, management or support for autism.

4.4 Main outcomes

a) Quality of life.

b) Participation and functioning in social and educational settings.

c) Outcomes associated with core and non-core features of autism.

d) Effect on families including siblings.

e) Effective transition to adult services.

f) Experience of care, including experience of services and transition.

4.5 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY), but a different unit of effectiveness may be used depending on the availability of appropriate clinical and utility data for children and young people with autism. Costs considered will be from an NHS and personal social services (PSS) perspective in the main analyses.

Further analyses may be conducted to consider wider social costs associated with the care of children and young people with autism. Such costs may include, for example, cost of special education and training, voluntary sector respite care, and housing services. Economic analyses will ideally attempt to consider long-term outcomes and related financial implications of interventions for the management and support of children and young people with autism through adulthood. Further detail on the methods can be found in 'The guidelines manual' (see ‘Further information’).

4.6 Status

4.6.1 Scope

This is the final scope.

4.6.2 Timing

The development of the guideline recommendations will begin in December 2011.

5 Related NICE guidance

NICE is currently developing the following related guidance (details available from the NICE website):

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. NICE clinical guideline 128. September 2011.

- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. NICE clinical guideline. Publication expected June 2012.
- Looked after children and young people. NICE public health guidance 28. October 2010.

6 Further information

Information on the guideline development process is provided in: 'How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS'

- 'The guidelines manual'.

These are available from the NICE website (www.nice.org.uk/GuidelinesManual). Information on the progress of the guideline will also be available from the NICE website (www.nice.org.uk).