ADHD – background, assessment and diagnosis

The topic of this briefing is the nature and diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD), and the related disorder or sub-type, Hyperkinetic Disorder (HKD), among children and adolescents.

Key Messages

• If ADHD and its symptoms are not managed appropriately, this can have a detrimental effect on a child’s ability to interact with his or her peers and to develop socially and educationally

• It has been demonstrated that undiagnosed and untreated ADHD can lead to major social and behavioural difficulties

• A number of key tools to diagnose ADHD are available

• Guidance documents are available outlining recommended pathways and models of practice for the diagnosis of ADHD, and the roles of relevant professionals, but there are few actual required standards

• A number of local protocols on the diagnosis of ADHD are available

• Research and guidance literature stresses how diagnosis should be an extensive and thorough process, involving clinical examination and the collection and analysis of diagnostic information from as many relevant parties as possible, including teachers, parents and the children themselves

• The evidence suggests that diagnosis is very often made by health professionals with reference to information from teachers, social services and parents

• Access to specialist services for the formal diagnosis of ADHD lies with GPs, but has been found to rely especially heavily on parents’ perceptions of their child’s behaviour and its possible explanation by ADHD

• Research into the opinions of parents or children about assessment and diagnosis of ADHD is lacking
Introduction

This section introduces and defines the scope of the briefing and the topic.

A SCIE briefing provides up-to-date information on a particular topic. It is a concise document summarising the knowledge base in a particular area and is intended as a ‘launch pad’ or signpost to more in-depth investigation or enquiry. It is not a definitive statement of all evidence on a particular issue. The briefing is divided into the different types of knowledge relevant to health and social care research and practice, as defined by the Social Care Institute for Excellence (SCIE).

Title link http://www.scie.org.uk/publications/knowledge.asp

It is intended to help health and social care practitioners and policy-makers in their decision-making and practice.

The topic of this particular briefing is Attention Deficit/Hyperactivity Disorder (ADHD), and the related disorder or sub-type, Hyperkinetic Disorder (HKD), although the literature generally does not distinguish between the two in its recommendations or evaluations of assessment or management strategies. The client group being considered by this briefing is children and adolescents only. The behavioural disorder ADHD is characterised by early onset and three particular elements: hyperactivity, inattention and impulsiveness. There are three principal sub-types: predominantly inattentive type; predominantly hyperactive or impulsive type; and a combination of the two types. The basic definition of ADHD is “a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparative level of development”. The essential diagnostic criteria for ADHD demands that a child must be under seven years of age and demonstrate clear social and functioning impairment across more than one setting, for example, home and school, for more than six months. Diagnosis is often difficult because other problems, such as epilepsy, autism, oppositional defiant disorder (ODD), conduct disorder, anxiety, depression, and a range of learning difficulties, can result in similar behaviour to ADHD and/or mask symptoms.

Why this issue is important

This section summarises research findings relating to the impact or consequences of ADHD on the life of children, adolescents and families.

If ADHD and its symptoms are not managed appropriately, this can have a detrimental effect on a child’s ability to interact with his or her peers and also to develop socially and educationally. A recent large Canadian study found that children with ADHD can experience significantly more psychosocial problems concerning mental health, social functioning and self-esteem than children who do not have the disorder. This in turn can significantly affect their quality of life. Children with ADHD have also been shown to evoke “negative parenting”, which becomes cyclical, so that parents and children
“maintain each others negative patterns of interaction” (3). ADHD is also a persistent condition. Some of the symptoms of ADHD do alleviate over time (5), but it has also been demonstrated that undiagnosed or untreated ADHD can lead to major social and behavioural difficulties in adulthood (6,7,8). Research suggests that young people and adults with ADHD have higher rates of unemployment, criminality, substance misuse and antisocial behaviour than young people and adults without ADHD (3,9,10). The importance of early and accurate diagnosis is therefore widely accepted.

What do the different sources of knowledge show?

Organisational knowledge

This section lists and briefly summarises documents that describe the standards that govern the conduct of statutory services, organisations and individuals involved in the diagnosis and management of ADHD.

The full details of the diagnostic criteria which currently apply in the UK are provided by the following tools:

International Classification of Diseases 10 (ICD-10) (11)

Diagnostic and Statistical Manual IV (DSM IV) (1)

Both tools are used to diagnose ADHD, although the former is used more often by health professionals in the UK (29). Both diagnostic tools recognise “the same problem behaviours as the basis of diagnosis, in almost identical sets of eighteen symptoms”, but HKD requires some symptoms in all three areas of hyperactivity, inattention and impulsiveness; ADHD does not (7).

The principal rating tools or questionnaires to be used by teachers and parents both in diagnosis and the monitoring of medication for ADHD in the UK are as follows:

Strengths and Difficulties Questionnaire (SDQ)

Connors Teacher Rating Scale Hyperactivity Index (CTRS-HI) (12,13)
This tool is for use by teachers only.

Policy community knowledge

This section summarises documents describing proposed structural models for the delivery of policy and improved practice. These documents are
published by public policy research bodies, lobby groups, think tanks and related organisations.

Title link [http://www.mentalneurologicalprimarycare.org/downloads/primary_care/Attention_deficit_disorder.pdf](http://www.mentalneurologicalprimarycare.org/downloads/primary_care/Attention_deficit_disorder.pdf)  
This is part of the WHO Guide to Mental and Neurological Health in Primary Care. It is a protocol for the assessment, and diagnosis of ADHD, including advice to be given to parents of children with ADHD.

Department for Education and Skills (DfES); Mental Health Foundation (2003). Effective Joint Working Between Child and Adolescent Mental Health Services (CAMHS) and Schools.  
Title link [http://www.dfes.gov.uk/research/data/uploadfiles/RR412.pdf](http://www.dfes.gov.uk/research/data/uploadfiles/RR412.pdf)  
This document reports on a research project commissioned from the Mental Health Foundation by the DfES to explore joint working between schools and CAMHS in England, and identifies ways in which improvements may be made to working practices in this field.

Title link [http://www.teachernet.gov.uk/_doc/4619/mentalhealth.pdf](http://www.teachernet.gov.uk/_doc/4619/mentalhealth.pdf)  
This guidance document has been written for Local Education Authorities, pre-school settings, schools and Child and Adolescent Mental Health Services (CAMHS). It offers pointers to and examples of good practice in terms of the early identification of mental health problems in children and young people in pre-school and school settings. Sections 4.1 and 4.2 deal explicitly with conduct disorder/problems and attention deficit/hyperactivity.

Title link [http://www.sign.ac.uk/guidelines/fulltext/52/index.html](http://www.sign.ac.uk/guidelines/fulltext/52/index.html)  
This guideline offers a pathway for the diagnosis and assessment of ADHD. The guidance was due to be reviewed in August 2003.

The leading role in diagnosis is performed by a clinical health professional, usually a child psychiatrist or consultant paediatrician. The NICE guideline on pharmacological treatments states that “diagnosis . . . should be made by a child/adolescent psychiatrist or a paediatrician with expertise in ADHD” (14). It is recognised that a formal diagnosis requires information and support from other groups also, including teachers, parents and children (4). Policy-makers and reviewers all advocate the collection of information from teachers and parents to help inform diagnosis (3,4,14,15,16,30). Guidelines recognise that not every diagnosis can involve every agency or group, but assessment and management should try to involve as many as possible (4).
Practitioner knowledge

This section describes studies carried out by health and social care practitioners, documents relating their experiences regarding the topic, and resources produced by local practitioner bodies to support their work.


These guidelines serve as the minimum standards for practice in the assessment of ADHD according to local agreements between CAMHS and Primary Care Trusts in Berkshire.


This protocol summarises referral criteria; defines the role and responsibilities of the specialist, GP, parent, carer and teacher; and provides basic information on the prescription of Methylphenidate in the treatment of ADHD.

Each of the UK protocols listed here is based on the relevant NICE guidance (14).

Research knowledge

This section summarises the best available research literature. The focus is on studies undertaken in the United Kingdom, so that their findings are as relevant as possible to the intended audience of the briefing.

ADHD does not have any biological markers or physical characteristics, but is recognised by behaviour alone (6,17). Questions have been raised about whether ADHD is a distinct developmental or behavioural disorder, but it is now generally accepted to be a “robust clinical syndrome” that satisfies particular diagnostic criteria (5,9,17). The precise causes of ADHD are unknown. Research has indicated that ADHD is “highly heritable”, but the responsible gene(s) have not been identified (9,18). Research has also demonstrated that children and young people diagnosed with ADHD have common neurobiological problems and deficits (7,9,35).

The number of children in the UK who are reported as having been diagnosed as having ADHD is 1-5% (14), and 0.5-1% for HKD (14,19). ADHD is diagnosed more frequently in boys than in girls (10). However, reviews of the literature suggest that studies indicating a male to female ratio of more than 3:1 should be treated with caution (20,21). Children with ADHD are often found to have one or more other mental health disorders or learning disabilities also (3,4,22).
All of the research and guidance literature stresses how diagnosis should be an extensive and thorough process, involving clinical examination and the collection and analysis of diagnostic information from as many relevant parties as possible. An audit of current strategies within a locality in the UK demonstrated that teachers were consulted in only fifty-five percent of cases of diagnosed ADHD (19). However, another more recent UK audit and two surveys did find assessments being made with reference to multiple sources of information, including social workers, teachers and parents (16,29,32). However, one of these surveys also found that clinicians may also arrive at different diagnoses, despite using the same assessment criteria and procedures (29). It has also been pointed out that the reports of parents and teachers can be very subjective; their content should therefore be confirmed by the specialist seeking to diagnose ADHD by interviewing the parent or teachers concerned (7).

Under-diagnosis of ADHD has been demonstrated to be a potential problem. Research has demonstrated that GPs are the principal source of referrals to specialist services, but they may also lack awareness of ADHD and can fail to diagnose the disorder or refer independently (23,24,25). However, in one study, GPs did refer almost all cases when a parent made a request for referral (24). Access to specialist services for the formal diagnosis and treatment of cases of ADHD therefore lies with GPs, but has been found to rely especially heavily on parents’ perceptions of their child’s behaviour and its possible explanation by ADHD. However, there are also indications that parents may be reluctant to present their child to primary care if they feel the behaviour may be attributed to bad parenting (9,33). Concerns have been raised about over-diagnosis and over-medication of ADHD (26), although there is no evidence as yet to suggest over-diagnosis in the UK (9).

Occupational therapists are named by NICE (14) as one of the groups who may be involved in the assessment of ADHD, but recent research has demonstrated that very few occupational therapists working in CAMHS play any direct role in this (6). There is currently little in the way of formal training in ADHD for occupational therapists (6). Recently qualified child-care social workers have been demonstrated to have limited knowledge of the key diagnostic criteria of ADHD, but experienced social workers tend to be well informed (27).

User & Carer Knowledge

This section summarises the issues raised by users and carers in relation to this topic, both as described by the literature and as defined through local consultation.

Little research has been conducted in the UK into the opinions of parents or children about assessment and diagnosis of ADHD. A recent qualitative study to explore the views of parents of children with ADHD found that they felt their views about the causes of the disorder differed greatly from professionals and
Parents felt blamed for their children’s behaviour. They thought that others believed the disorder had a psychological and social basis, and so considered the parents to be responsible. They therefore aimed to encourage others to share their view that the disorder had a biological basis only. These differences of opinion were a cause of great distress to the parents (33).

Recent consultation with parents of children with ADHD, undertaken in the Trent region for this briefing, highlighted a number of additional issues. Parents felt that early formal diagnosis was important if any school-based or other provision was to be made, and if they were to be able to access potentially valuable means of support from social services, such as disability living allowance (DLA) and respite care (29). Some parents also reported that they benefited from help and support in completing the questionnaires designed to describe their child’s behaviour.

Useful Links

This section lists sources of information relevant to services users and professionals who work within this field.

ADDISS
http://www.addiss.co.uk/
ADDISS is the National Attention Deficit Disorder Information and Support Service. ADDISS provides information, training and support for parents, sufferers and professionals in the fields of ADHD and related learning and behavioural difficulties.

FOCUS
http://www.focusproject.org.uk/default.asp
FOCUS aims to promote clinical and organisational effectiveness in child and adolescent mental health services, with an emphasis on incorporating evidence-based research into everyday practice.

Mental Health Foundation
http://www.mentalhealth.org.uk/
The Mental Health Foundation is a UK charity working in mental health and learning disabilities. The Foundation makes available online a number of resources and publications on ADHD.

Royal College of Psychiatrists
http://www.rcpsych.ac.uk/info/mhgu/index.htm
This website offers a fact sheet for parents and teachers on ADHD. It can be found under the sections Mental Health Information and Mental Health and Growing Up.

YoungMinds
http://www.youngminds.org.uk/
YoungMinds is a national charity committed to improving the mental health of all children and young people. The website has sections for young people, children and parents, and an info centre, which contains materials and resources on both the diagnosis and management of ADHD.

Acknowledgements

Thank you to the experts and service users for their contributions to this briefing.

Reference List

1. **American Psychiatric Association** (1994). Diagnostic and Statistical Manual of Mental Disorders. Washington DC, APA.

   This manual contains full details of the tool for diagnosing ADHD.


   This guideline covers the following aspects of ADHD: definitions and concepts; assessment; pharmacological and non-pharmacological therapies; and information for patients.


   This guidance describes and defines professional roles in the diagnosis and treatment of ADHD.


This UK study reports the findings of a national survey to evaluate the involvement of OTs in the diagnosis and management of ADHD.


This is a review article covering the principal issues relating to the diagnosis and treatment of ADHD.


This is a US longitudinal study examining the likelihood of impaired social functioning among adolescents with ADHD. Abstract available http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=8824065


This is a discussion paper concerning the nature, concept and treatment of ADHD. Abstract available http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=14694701


This is the key US publication on ADHD.


This manual contains full details of a tool for diagnosing HKD.

   This article describes one of the principal tools for assessing the behaviour of children with suspected or diagnosed ADHD. Abstract available http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9700518&dopt=Citation


   This article describes one of the principal tools for assessing the behaviour of children with suspected or diagnosed ADHD. Abstract available http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=9700520


   This guidance describes and defines standards for the use of methylphenidate, including clinical need, the technology itself, the evidence, implications for the NHS, and clinical audit advice.


   This is a response to Sayal et al (2002).


   This study reports the findings of a survey of child and adolescent psychiatrists and their practices in the diagnosis and treatment of ADHD.


   This US paper reports a case study concerning the evidence-based diagnosis and management of a child with ADHD.

This is a UK review of the literature on the nature, assessment and treatment of ADHD.


This UK study describes the development of a pathway to aid diagnosis of ADHD. Full text available http://pb.rcpsych.org/cgi/reprint/26/4/148.pdf


This UK study examined the range of psychiatric disorders and psychiatric comorbidity among children and adolescents attending a primary mental health service (PMHS). This included ADHD. Abstract available http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=14694698


This document describes the principal findings of a brief survey of parents' views about ADHD conducted by ADDISS.


This paper discusses some of the issues surrounding diagnosis in the field of mental health. Full text available [http://bmj.bmjournals.com/cgi/content/full/324/7342/900](http://bmj.bmjournals.com/cgi/content/full/324/7342/900)


This study reports the findings of a survey of UK social workers with reference to ADHD.


This is a research and policy briefing defining and describing respite care for families with children with learning disabilities.


This practitioner article provides an overview of what professionals should expect from an assessment of ADHD. Abstract available


This study examines the effect of ADHD and comorbid disorders on the quality of life of children. Abstract available


This article reports on the findings of audit of an ADHD clinic in Peterborough.


This paper investigates parents' perceptions of ADHD and how they feel when faced by a diagnosis.


This study examines the value of a protocol for the assessment and treatment of children with ADHD on medication managed by a community clinic. Abstract available


This is a review of the causes and treatment of ADHD. Abstract available