

Best Practice in Attention Deficit Hyperactivity Disorder (ADHD): A Review of the Literature and Care Pathway



Making a positive difference



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Best Practice in Attention Deficit Hyperactivity Disorder (ADHD): A Review of the Literature

Overview

The purpose of this review is to identify best practice to support commissioners and providers in working with service users to produce care pathways for Attention Deficit Hyperactivity Disorder (ADHD). Necessarily this has involved consulting a wide range of literature, ranging from expert opinion and review, scientific evidence, to unpublished examples of practice.

Range and type of literature consulted

- Evidence of effectiveness: scientific studies published in peer reviewed journals, including clinical trials and policy documents based wholly or partly on scientific evidence.
- Expert opinion: theoretical or practice based publications ranging from peer reviewed journal articles to web based texts by leading practitioners from a range of fields, including voluntary sector; primary care, psychiatry, psychology and education.
- Effective practice: local reports and audit/evaluations, where available.
- User based material from voluntary and self help groups, mainly internet based.
- Other specialist sources, including the Centre Academy, Focus mailbox, Young Minds.

Literature sources

Databases searched: EMBASE, MEDLINE, PsycINFO via Ovid, ProQuest.

For non peer reviewed material, Internet searching used Boolean searching on Google and links followed from major expert/user sites such as ADDERS, ADDISS, Centre Academy.

How the range of material was used

We did not employ a systematic rating system (such as a formal critical appraisal or systematic review procedure) for the relevance and validity of sources but tried to give a balanced and rounded approach, not to favour scientific studies to the exclusion of more qualitative and experiential information. The intention was to achieve an overall view that includes service user and practitioner perspectives.

Sources from the UK were sought as the most reliable and relevant, particularly where the text included a service user or practitioner perspective, but where larger scale and methodologically sound research was concerned, sources from the USA, Canada, Australia, New Zealand and continental Europe were also used.

Experts

A panel of leading experts in the field was brought together to assess and review the draft stages of this document. This group comprised:

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How the report is organised

The outcome of this report is a care pathway that will assist commissioners and practitioners in meeting the needs of children with ADHD and their families. The literature review is therefore organised into sections that reflect broadly the stages of that pathway.

Given the diverse settings and various professional groups to which the care pathway will be of use, the early sections of the report provide a summary of the nature of ADHD, its causes and prevalence. Some readers will already be familiar with this information.

At the end of each section a summary is provided in plain English for readers who are less familiar with medical language and/or scientific research terminology.

I. The Nature of ADHD

Definition

ADHD is characterised by an early onset of significant inattention, poor concentration, impulsiveness and over-activity. These features need to be developmentally inappropriate and should be associated with functional impairment and not caused by any other disorder (Thapar and Thapar, 2003). Inattention may be understood as a difficulty or inability in “focusing deliberate, conscious attention to organising and completing a task or learning something new” (National Institute for Clinical Excellence, 2000). Hyperactivity refers to the inability to be still, to fidget and be continually in motion. It may also be expressed in incessant talking or other noise making. Impulsivity manifests itself as a difficulty in controlling immediate reactions or inability to think before acting (National Institute for Clinical Excellence, 2000). The expression of these behavioural features will vary according to the age and developmental stage of the child, so young children's hyperactivity may be expressed in terms of excessive climbing or running about, whilst in older children this may be associated with “out of seat” behaviours (in school) or fidgeting. In adolescents and adults over-talkativeness and subjective feelings of restlessness may be manifest.

In the UK, ADHD is normally recognised in children and young people, but there is growing evidence, largely but not exclusively from the USA, suggesting that it can persist into adult life (Elliot, 2002; Doyle, et al, 2002; Barkley, 1998; Mannuzza, et al, 1998).

Diagnosis

The area of diagnosis creates debate and some controversy due to a number of factors. There is professional disagreement about the most appropriate diagnostic criteria for the disorder, owing in some part to the range of behavioural presentations, which has led to two major classifications. Hill reports that until the 1970s professionals focused on the hyperactivity element, but that subsequent emphasis on inattention led to the adoption of the term “attention deficit” and in turn gave rise to Attention Deficit Disorder, or ADD (Hill, 1998). The term ADD is used less commonly and has been replaced in the American Psychiatric Association's (1994) Diagnostic and Statistical Manual, DSM-IV, by the category of Attention Deficit/Hyperactivity Disorder. DSM-IV is the most commonly used diagnostic tool in the UK, though the official scheme in the NHS is the World Health Organisation's (1992) International Classification of Mental and Behavioural Disorders, ICD-10, in which the emphasis on hyperactivity is reflected in the category of Hyperkinetic Disorder. As Hill points out, whilst inattentiveness remains important, there is no validated measure or diagnostic test for it and some research has led to this area being re-conceptualised as a deficit in “cognitive executive functioning” (Hill, 1998; Van de Meere, 1996; Sonuga-Barke, et al, 1992). Hill and Taylor (2001:404) state “The terminology of conditions characterised by overactivity, impulsivity, impatience and poorly managed attention is inconsistent.” They choose in their paper to use “the American term ADHD” as it is the most commonly used diagnostic classification.

Prevalence

Issues around diagnostic criteria inevitably affect interpretation of epidemiological data in assessing the extent to which ADHD exists within the population. A consequence of disparate diagnostic practices is that studies have found those receiving a diagnosis may not be a homogeneous group. Prevalence is therefore difficult to ascertain, although the most considered and accepted estimates suggest prevalence rates of ADHD (as determined by DSM-IV) at about 5% of school-age children. Hyperkinetic disorder, for which the criteria are more stringent, may be seen as a sub-set of ADHD and its prevalence is estimated as 1% of school age children (National Institute for Clinical Excellence, 2000).


ADHD is found to affect boys more than girls, where the male to female ratio has been estimated at 4:1 (Scottish Intercollegiate Guidelines Network, 2001). However girls may be under-diagnosed as they present with symptoms (cognitive impairments as opposed to behavioural problems) which have less impetus for referral (Williams, et al, 1999; Hill, 1998). General under-diagnosis of the condition is also reported to be a problem in the UK.

Causes

There are powerful indications that ADHD may be inherited, although the evidence is clearer for boys than for girls (Faraone, et al 1995; Goodman and Stevenson, 1989; Taylor, et al, 1996). Research also points to multiple risk factors, including both psychosocial and genetic factors (National Institute for Clinical Excellence, 2000). Whilst most researchers agree there is some hereditary element, what is not known is whether this is caused by a single gene or several (polygenic) and in either case whether it leads to a genetic predisposition which then interacts with environmental factors (Williams, et al, 1999). What is likely is that it occurs in those with a genetic predisposition towards the disorder when certain environmental triggers are also present.

Recurrent patterns of ADHD and similar or related disorders within families may be explained partly by shared environmental conditions, which may be specific, such as the effects of depression in the mother; foetal alcohol effects and low birth weight; or general, as in the case of social disadvantage (Hill, 1998; Taylor, et al 1991). Social disadvantage is known to be a risk factor for all mental health problems across the age spectrum. Anecdotal evidence suggests a belief among some professionals that poor family relationships can be a causal factor in ADHD, however Taylor, et al (1991) conclude that this is not the primary cause of the disorder, but an important aspect in maintaining the associated behaviours.

Promising developments in brain scanning, such as Magnetic Resonance Imaging (MRI), have identified differences in neural activity between the brains of children with ADHD compared with those of other children (Zametkin and Liotta, 1998). Williams, et al (1999) report studies comparing brain activity between children with ADHD and people with injury to the frontal lobes of the brain, indicating a similarity in the two groups. Whether there is an organic basis to ADHD remains debatable because it cannot be known whether



abnormality in parts of the brain are the cause of attention difficulty, or if it works in reverse, that attention difficulties, whatever their origin, cause those areas of the brain to function in a different way. It has been asserted that a persuasive factor for the view that there are biological mechanisms in ADHD is to be found in the results of the MTA trial, the largest and most rigorous to date (MTA Cooperative Group, 1999). The MTA findings demonstrate the effectiveness of (largely stimulant) medication and, as Thapar and Thapar state,

The mode of action by which stimulant medication is thought to act (dopamine transporter blockade as shown in imaging studies, leading to increased levels of extracellular dopamine) is compatible with the view that dopamine pathways are involved.

(Thapar and Thapar, 2003: 228)

Furthermore many studies have also shown that the deficits exhibited in ADHD are not found in children with behavioural problems where ADHD is not present, supporting the idea that ADHD has a separate and biologically based aetiology (Taylor, et al, 1991; Tannock, 1998).

Issues and debates

ADHD has been a controversial topic both in the UK and elsewhere, discussed in the popular media and by certain prominent figures and groups who feel it is a modern construct with no real medical basis and/or that our children are being over-medicated (Double, 2002; Jensen, et al, 1999, Safer, et al, 1996). A recent Young Minds debate recorded the view of a professor of childhood studies, who asserted that whilst some very disturbed children need medical intervention, "millions of others are being diagnosed with ADHD, who would not have been seen as sick a few years ago." (Anderson, 2003). The view is countered in the same publication by the statement that "To claim for example that psychiatrists are over-medicating the exuberance of youth is to trivialise a complex and debilitating condition." (Bilbow, 2003a). Parent information in a variety of media, including the internet, is unequivocal; the following is a typical example of information from the USA.

However, parents needn't waste limited emotional energy on self-blame. ADHD is a hereditary disorder, and is not caused by poor parenting or a chaotic environment.

(CHADD, 2003)

Despite fears in some quarters that ADHD is a modern invention, it is not a new phenomenon. The major features of the disorder were identified over a century ago (Still, 1902) and stimulant medication was being used in the USA as early as 1937 (Bradley, 1937, cited in Williams, et al 1999). The recent controversies, exemplified by the polarised views above, have prompted an international consensus statement by Dr. Russell Barkley and 74 other "prominent medical doctors and researchers" (Barkley, et al, 2002). The statement expresses a deep concern about the "periodic inaccurate portrayal of attention deficit hyperactivity disorder", fearing that this will lead to thousands of people not being treated for the disorder. In fact, despite the lack of homogeneity caused by variable diagnostic practices (Williams, et al 1999), it is more likely that ADHD is under-diagnosed (National Institute for Clinical Excellence, 2000; Taylor, 1995). The effects of having ADHD are presented starkly by Barkley, et al, as including school self-exclusion (32-40%), having few or no friends (50-70%) under performing at work (70-80%) and a tendency to engage in anti-social activity (40-50%). They go on to state, "studies indicate that less than half of those with the disorder are receiving treatment."

The significance of the public image of ADHD for a care pathway is in the effect that adverse publicity may have upon children and their families in deciding whether to seek professional help. There are also potentially harmful effects of ill-informed debate upon teachers and other professionals, leading to what Taylor (2003) refers to as "professional ideologies rather than responsiveness to individual children's needs.". Such effects have also been noted by Thapar and Thapar (2002), who state their concern that negative reports in the mass media will have an undue effect on the attitudes of doctors in primary care who see children with ADHD.

Summary

- ADHD is a disorder, primarily of childhood, but increasingly thought to affect adults too, which is characterised by inattention, over activity and impulsiveness.
- These features are pronounced and severe.
- Its cause is thought to be predominantly genetic, though there is also evidence that social and environmental factors play a part and further work needs to be carried out in this area.
- Biological differences between children with ADHD and those without the disorder have been observed by recording different levels of activity in the frontal areas of the brain.
- Diagnosis is by DSM-IV, whilst ICD-10 criteria are used for the more stringent diagnosis of hyperkinetic disorder (HD).
- Reliable estimates suggest 5% children of school age have ADHD (1% HKD).
- The disorder requires a specialist, qualified clinician to diagnose. Diagnosis is complex because the symptoms of ADHD are similar to those for other disorders and also because children with ADHD are more likely to have other co-existing disorders.
- It is believed that ADHD is under-diagnosed.
- The disorder evokes strong feelings and public debate, which, when ill-informed and/or ideological, may not be helpful to children with ADHD and their families.

2. Recognition and Referral

Recognising ADHD in the family and community

Owing to similarities in behavioural presentation, many other disorders can be mistaken for ADHD. Inattention and failure to concentrate may have physical causes such as hearing impairment or neurological illness, insufficient sleep due to sleep disorder and depression (Williams et al, 1999).

Whilst research into a biological basis for ADHD is yielding promising results, it remains true that the observed behaviour of a child in whom the disorder is suspected is different only in degree from that of normal children. Indeed it is this factor that may account partly for the belief in some quarters that we are simply pathologising normal childhood behaviour (Hazell, 2002). Views of this type lead inexorably to the presumption of parental failure and a desire to attribute blame. Kewley asserts,

Society has a deep-rooted belief that poor parenting is responsible for all problem behaviour in children ('just a lack of discipline': a view frequently expressed in the media).

Kewley (1999:28)

The reverse is true, according to Kewley, whereby family problems can be a result of the double pressures created by the presence of ADHD and the parents' perceptions of blame and failure directed at them by others. Still (1902), who is agreed to have first documented ADHD-type features in children, noted that both parents and teachers particularly observed an inability for sustained attention as something outside the norm.

Children must be observed carefully both at home and at school, whilst clinicians also need to take account of the effects of different environments. A child in a highly regulated school environment may present as hyperactive in that setting, but not elsewhere (O'Connell, 2003). Parents and carers are the first to be alerted to the signs of ADHD, and often the major element of an initial assessment is from information based upon parents' reports.

The experiences of young people and their families are not commonly reported in the professional literature, but may be found within the information materials of voluntary and self-help groups. One example yields the experience of a parent whose son was undiagnosed until the age of twelve, during which time the problems were attributed variously to postnatal depression, over-reaction due to the fact that his mother had been adopted and indirectly linked to the father having attended boarding school at a young age. When eventually a diagnosis was made the boy had been permanently excluded from school (Hensby, 2003).

Recognising ADHD can be difficult as parents and carers may have little knowledge of the disorder and this can be exacerbated by feelings of shame or failure. Furthermore the child's behaviour may not initially appear consistent across settings. In a young child for instance, inattention may be observed in the home, but be masked at nursery school by the presence of authority and the novelty of the environment, or less obvious because staff have a larger number of children to deal with.

Nursery school teachers are potentially well placed to detect possible ADHD, as they are able to observe whether a child stands out among other children in the same age group. There is clear potential here for links between child and adolescent mental health specialists and SureStart schemes. According to Spender, cited in O'Connell (2003) most child psychiatrists prefer to diagnose ADHD at age six or seven as "it is still better to wait until the child has been at primary school for a year, to be more certain". This does not however preclude a role for nursery nurses and other pre-school workers, who may be able to make a valuable contribution to assessment, at whatever age that takes place. One criticism of diagnosis is that it tends to be too cross-sectional, whereas

The pattern of behaviour over time is probably the key feature in distinguishing children with ADHD from those with other disorders or no developmental problems.

(Hazell, 2002:476)

For disorders that are pervasive and enduring both temporal and contextual factors play a part in diagnosis and should lead to early intervention if the social and educational problems associated with chronicity are to be avoided (Hill, 1998). If a parent or carer suspects ADHD, they may become far more informed than many of the other adults in their child's life. A study involving 140 referred children with ADHD and 120 controls showed that maternal reports of children's psychopathology provide a reliable and accurate means of assessment (Farone, 1995).

A recent survey of 50 child and adolescent psychiatrists and 75 paediatricians reported that 53% of respondents felt parents are not aware of ADHD and consequently do not visit their GP (ADDISS, 2003). Elsewhere the concern has been identified that GPs may not recognise children with ADHD where the parent or carer is reticent or lacking awareness and the authors, reporting a recent study of the GP role in an ADHD pathway, concluded that

Parental request for referral and thus parental recognition of hyperactive behaviour as a problem play a crucial part in accessing specialist services.

(Sayal et al, 2002:47)

The role of the school

It is often not until a child starts school that the possibility of ADHD is recognised fully. Unusual inattention and over-activity are more likely to be noticed in a classroom setting and teachers are well placed to judge the range of behaviour expected from children of the age they teach (Hill and Taylor, 2001). Yet, although there is agreement between major contributors that schools and teachers play an essential part in recognition of and referral for ADHD, most of the literature focuses on the role of education as a partner in and contributor to treatment, rather than on recognition.

A recent survey of paediatricians and psychiatrists identified teachers' lack of awareness as a major barrier to diagnosis (ADDISS, 2003). Ford (1996) has contrasted the diagnosis and treatment rates between the USA and the UK, concluding that the disparity cannot be attributed to epidemiology. He proposes the hypothesis that whilst American parents and schools seem more willing to view educational and behavioural problems as requiring treatment from doctors and psychologists, their UK counterparts have tended to regard them as a problem for teachers to deal with.

Ford asserts that historical factors and political ideologies have created a socio-educational model of ADHD, among other disorders, in the UK. He cites the work of Ideus (1995), who describes American teachers as professionally socialised to accept the authority of medicine and psychology in matters such as ADHD and contrasts this with his own analysis of British education from the 1960s onwards. Ford claims that various child-centred orthodoxies created teachers who believe the vast majority of emotional and behavioural difficulties arise from the child's familial, social and educational context.

A study of teachers in the USA found that years of teaching experience was the major factor in correctly identifying possible ADHD and that identification was strengthened when a teacher had previously been exposed to a child with ADHD (Sciutto, et al, 2000). Similarly in Canada it was found that experienced teachers were just as knowledgeable as newly qualified practitioners who had received ADHD education during their initial teacher training (Jerome, et al, 1999). Whilst the results of both studies should be treated with caution, given methodological concerns about sample sizes and generalisability, they both point in their conclusions to a need for in-service education and to make best use of experienced teachers, indicating that this is an area worthy of further investigation. Similarly there is a need for training and awareness raising for the special needs classroom assistant, who will spend significant amounts of time with an individual child.

The Special Educational Needs Code of Practice (Department for Education and Skills, 2001) recommends collaboration and partnership between agencies in providing comprehensive care for children with mental health problems, but despite the prevalence of the disorder, ADHD is not specified. The Standing Conference on Teacher Education North and South (SCOTENS), an organisation covering both Northern Ireland and the Republic of

Ireland, has produced a comprehensive set of role descriptions for the professionals involved in special educational needs, including behavioural problems, but not specifying ADHD (Standing Conference on Teacher Education North and South). Schools would benefit from more clear and authoritative guidance on ADHD, to enable them to deal with its complexities more effectively (O'Regan, 2003).

The role of the General Practitioner and other primary care professionals

Recent studies indicate that non-recognition of ADHD by GPs is the main barrier in the pathway to care (ADDISS, 2003; Sayal et al, 2002; Taylor, 1995; National Institute for Clinical Excellence, 2000). Since GPs are potentially at the gateway of a care pathway it is important to address this issue, particularly in light of the NICE guidance conclusion that:

The consequences of severe ADHD for children, their families and for society can be very serious. Children can develop poor self-esteem, emotional and social problems and their educational attainment is frequently severely impaired. The pressure on families can be extreme. The signs of ADHD may persist into adolescence and adulthood, and may be associated with continuing emotional and social problems, unemployment, criminality and substance misuse.

(National Institute for Clinical Excellence, 2000)

A survey of UK GPs found that only 6% had received formal training in ADHD, whereas 21% had taken information from media sources such as magazines, newspapers and television (Ball, 2001). Given the contentious nature of much of the coverage of ADHD, the reliance upon the media for information should give cause for concern (Thapar and Thapar, 2002).

Children with a hyperkinetic disorder are more likely to have visited a GP in the past year than children with no psychiatric disorder, yet 19% of those who fulfil the ICD-10 criteria for HKD have been found not to have contacted their GP at all in the previous twelve months (Meltzer et al, 2000). Thapar and Thapar (2003) propose that as recognition of the disorder increases, so inevitably will the expectations of parents and this will lead to greater reliance upon primary care, since secondary services are known to have limited capacity. Moreover the authors assert that children on the "fringes of diagnosis" will not be eligible for referral to specialist services and will need to be managed within primary care, with health visitors playing a crucial role (Thapar and Thapar, 2003:229). A potential development would be the design and implementation of screening tools to identify children who would benefit from referral to secondary care (Sayal, et al, 2002).



In a recent research report's recommendations for the future it is stated that GPs should receive education about ADHD in order to:

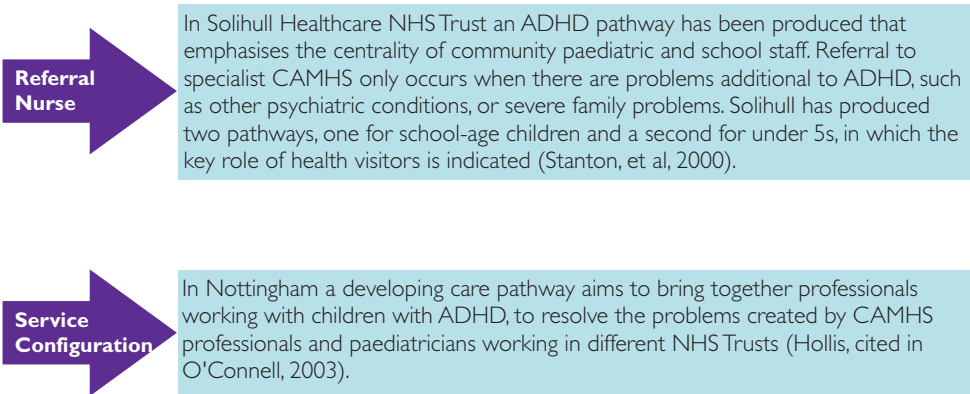
Improve the levels of appropriate referrals to secondary care for diagnosis and to ensure they can provide the ongoing observation and support needed for the child if a diagnosis is made.

(Addiss, 2003:13)

Osman and Parker (2003:82) suggest that the role of specialist nurses, who are developing increasingly complex and sophisticated skills, will become more important as the demand for ADHD services grows at a faster pace than the medical workforce. Laver-Bradbury (2003:78) outlines fourteen separate skills and techniques that nurses are uniquely well placed to develop in response to families where there is ADHD, stating, "The adaptability of nurses makes them ideally suited to the changing needs of a child with ADHD".

Examples from practice

It is recognised that there are many examples of good practice in localities. Gaining knowledge of and access to reports of these is challenging however: Apart from the FOCUS¹ electronic mail base, there is no national forum in which those involved in the mental health of children and families can exchange good practice and share learning routinely. The cases discussed here have not been selected from a larger sample and thus are not known to be particularly representative. They do however illustrate examples of good practice available through published material and that posted on the worldwide web.



Footnote 1: FOCUS is a child and adolescent mental health resource for professionals, coordinated by the Royal College of Psychiatrists, College Research Unit.



Assessment Link Nurse

At Royal Liverpool Children's NHS Trust an ADHD pathway places community paediatric staff at the heart of the process. Two main routes to assessment are seen as identification in school and/or identification in the home. These two routes converge at the point of liaison between the special needs teachers and the school nurse, mediated or coordinated by the new ADHD Link Nurse. The link nurse holds an advisory role and does not become involved in individual case management. Each stage of the pathway is accompanied by standardised procedures, for which proformas are provided; these include locally produced items, such as a classroom and playground observation schedule, as well as professionally validated items, including the Conners Questionnaire and the Strengths and Difficulties Questionnaire or SDQ.

Referral Routes

The Royal Liverpool pathway implies clearly that cases are held by the community paediatrician (school doctor) in all cases, unless or until concerns other than possible ADHD arise, or if after reviewing treatment, there are continuing professional or parental concerns. Only when those criteria are satisfied is the case referred to a specialist service (Steiger, 2003).

European Guidelines

A multi-professional ADHD pathway practice was set up in Cheshire, in 1999 including education, community paediatrics, child and adolescent mental health services and GPs (Burgess, 2002). The commitment to shared working was reflected in the joint funding between the Cheshire Community Healthcare Trust and Cheshire Education Authority.

Parent Held Records

The pathway is founded upon recommendations from the Royal College of Psychiatrists and European Guidelines (Taylor, et al, 1998). A community-based clinic is run by a community paediatrician and school nurse. Behavioural management is the first treatment option for children who meet DSM-IV criteria. In cases with other psychiatric or severe social and family conditions children are referred to the relevant specialist services, but are subsequently followed up in the community clinic. Burgess reports improved communication between professionals and services and more transparent processes. What also makes this case study particularly useful is that the pathway documentation is held by parents a significant shift in practice and in keeping with recommendations in the Caldicott report on security and ownership of health records. The other significant innovation is a training programme offered to all local health, social service and education organisations (White, 2002).

It is clear that examples of innovative practice exist, but to be of use in informing others and to avoid duplication of effort, greater use needs to be made of audit tools (as in the case of the Cheshire model) and external evaluations, so that the published results are available and of use to the wider professional community.

Summary

- **All individuals and groups within the family and community, professional or otherwise, require education, training and awareness raising about ADHD.**
- Parents are the most likely people to first be alerted to possible ADHD, although lack of awareness and adverse media coverage may prevent or delay their seeking help from the GP.
- ADHD is an early onset disorder and may also be observed by pre-school professionals such as nursery staff, health visitors and SureStart staff.
- Concerns are usually more pronounced when the child starts school.
- Teachers and other school staff have an important role to play in contributing to the assessment of suspected ADHD.
- Experienced teachers, especially those who have encountered it previously, are more likely to detect possible ADHD.
- The main gateway to families in gaining access to specialist services is through the GP.
- Reports from local areas indicate that many children with ADHD can be treated and managed within community paediatric services (school doctors and nurses) in liaison with schools.
- From recognition of the first indications of ADHD a care pathway is needed so that families understand the links between different services and the right care is provided at the right time.

3. Secondary care

There is agreement throughout the published literature on two major aspects of secondary care. The first is that assessment and diagnosis must be carried out by a skilled and appropriately qualified practitioner. Secondly, there is consensus that treatment must be multi-modal. Key documents in the UK have been the guidelines issued by the National Institute for Clinical Excellence (2000), Hill and Taylor (2001), the Scottish Intercollegiate Guidelines Network (2001) and the British Psychological Society (2000). Similarly guidelines have been published in the USA; the most cited in the literature are those produced by the American Academy of Child Adolescent Psychiatry (1997) and the American Academy of Pediatrics (2001).

It is also assumed that those sufficiently skilled and qualified will either be community paediatricians operating both from community clinics and school related settings, or members of the multi-disciplinary child and adolescent mental health service (CAMHS) team, delivering a Tier 2/3 service (NHS Health Advisory Service, 1995).

National developments in CAMHS

In the UK a number of recent key documents relating to the (mental) health of children will impinge upon the area of ADHD whilst not addressing it specifically. The Priorities and Planning Framework (Department of Health, 2003a) is continuing to have a significant effect on the shape and nature of Child and Adolescent Mental Health Services across England. The forthcoming Children's National Service Framework, whilst it does not specify ADHD as of particular concern over and above other conditions, will shape all local services (Department of Health, 2003b). This, alongside the Green Paper, Every Child Matters: Next Steps (Department for Education and Skills, 2004), forms the key strategic planning framework for child and adolescent mental health within the context of all children's services.

Government policy now states clearly that localities must develop a comprehensive CAMHS, of which the constituents may be summarised as equity of access to and provision of: health promotion, early intervention and effective treatment to age 18. A comprehensive CAMHS will involve networked working both across disciplines and agencies, but also across age transitions, the aim being to provide a seamless service that is meaningful and responsive to the service user, creating a more coherent service experience (Department of Health, 2003b). In many areas developing a comprehensive service will involve re-conceptualising CAMHS, which has often been seen as a specialist service exclusively based in a health setting. Developments in Tiers 1 and 2 are already changing old practices in CAMHS and specialist workers may now operate from a number of non-NHS settings, such as social services departments that include dedicated Looked After Children teams and at community level, where Primary Mental Health Workers, for example, offer liaison and support to primary care, voluntary agencies and school settings.

Another significant national development has been the government's setting across all services of waiting time targets, following the commitment to a prompt and timely service stated in the NHS Plan (Department of Health, 2000). In CAMHS this has had a considerable impact upon the out-patient services offered at Tiers 2-3. Whilst there is little published reportage about this impact, there is a wealth of anecdotal evidence, including exchanges between CAMHS practitioners on the internet and with this author; about the changes that have been made to practice in order to meet the targets. In short, the targets have necessitated that many teams address their, often long standing, concerns about large waiting lists and waiting times of up to a year for a first appointment (Department of Health, 2003c). There are various methods that may be used to reduce waiting times but in CAMHS there are specific developments that are significant in their potential effect upon responses to ADHD.

Some CAMH out-patient services are in the process of changing the ways in which referrals and allocation are managed. Moving away from the established practice of prioritising cases and effectively producing several queues in the system, these services are operating new systems in which all cases are seen and dealt with as routine, unless in rare cases they fit stringent criteria for being seen as emergency. This is a proven, effective way to achieve greater throughput and ensure lower waits, based on the Pareto Principle (Koch, 2000)². Additionally an increasing number of out patient teams are adopting the practice of offering shorter interventions that usually include one assessment followed by a set number of treatment sessions, known as 1+3/4/5 etc. (York et al, 2004). Whilst these developments may help teams in managing their case loads more efficiently, they raise questions about the most effective way to develop provision for children and families where more pervasive and enduring disorders, such as ADHD, are present and require longer term interventions and monitoring.

Specialist provision

Where guidelines agree is that the assessment, diagnosis and treatment of ADHD should be undertaken by a clinician with appropriate skill and knowledge, generally inferred to be a child and adolescent psychiatrist or a paediatrician (National Institute for Clinical Excellence; 2000, Scottish Intercollegiate Guidelines Network, 2001). It is clear however that the different specialist training required for each of these types of practitioner, combined with the effects of their practising in quite different settings, means that the service received from each is likely to vary. Furthermore a recent study, investigating the apparent under-diagnosis in the UK, identified as the main barrier to effective diagnosis and treatment the belief (85% respondents) that there are too few child and adolescent psychiatrists and paediatricians with an interest in this area (ADDISS, 2003).

Footnote 2: Dr. Joseph Juran, working in the US in the 1930s and 40s recognised a universal principle he called the "vital few and trivial many", but the principle was attributed to a mathematician, Pareto, who has observed a similar phenomenon in 1906. The 80/20 rule means that in anything a few (20%) are vital and many (80%) are trivial. Put simply, of the things you do during the day, only 20% really matter. Those 20% produce 80% of your results, whilst you may spend 80% of your time to yield only 20% of your results.

In the NHS, CAMHS are organised separately from community paediatric services, yet both treat children with ADHD. As one consultant child and adolescent psychiatrist has pointed out, it is arbitrary whether families go to a paediatrician and/or a psychiatrist and consequently, "we need to co-ordinate the referral procedure," (Hollis cited in O'Connell, 2003). Little has been published about this aspect of care for ADHD, although one reported study involved a survey of consultant child and adolescent psychiatrists and consultant hospital and community paediatricians in Wales (Salmon, 2002). The aim of the study was to identify key differences and similarities between the approach of each group to the management of ADHD. It was found that paediatricians would be more likely than psychiatrists to conduct a thorough physical examination, including hearing tests, whilst psychiatrists had greater access to a range of treatment options from the multidisciplinary team and were more likely to detect co-morbid conditions through the mental health assessment. Consistency between the two groups was identified in prescribing, where both psychiatrists and paediatricians were found to recommend medication in 100% of appropriate cases. The potential for both duplication and disparity of service is clear and points to the need for greater joint planning and working.

The potential for distance between services, to date, beats the British Rail and London Underground's earnest announcements to 'mind the gap'


(O'Flynn, 2001)

In the USA, the Consensus Developmental Conference Statement issued jointly by the American Medical Association Council on Scientific Affairs and the National Institutes of Health concluded that a major public health problem had been caused by inconsistencies in the diagnosis, treatment, and follow-up of children with ADHD (Magyary and Brandt, 2002).

Assessment and diagnosis

ADHD is pervasive, persistent and multi-faceted and therefore no one profession or discipline will be able identify, assess and treat alone. Whilst medication will not be the inevitable choice of treatment, its proven effectiveness means it will nonetheless be considered routinely within the treatment programme. For as long as this remains the case diagnosis will remain within the remit of medical practitioners (British Psychological Society, 2000).

There is consensus among leading authors and contained within national guidelines that assessment for ADHD must be wide ranging and cannot be achieved in a single consultation. Reports need to be obtained from the child, parents and carers, school (and pre-school in some cases) and from other health or social care services, such as health visitors or social workers. The purpose of the reports is to build a picture of the child's behaviour across a range of settings and over time, so that the process takes account of context and temporality in assessing whether the criteria for diagnosis have been met (Hill and Taylor, 2001; Taylor, et al, 1998; Williams et al, 1999).



The responsibility placed upon the assessing/diagnosing clinician is significant: diagnosis is a powerful phenomenon, turning doubt into certainty and fear of the unknown into the safety of the known. The clinician may also be under pressure from the family to solve the problem. In the absence of validated tests for ADHD, reliance must be placed upon the interpretation of information. The potential for misdiagnosis of ADHD has been described by Halasz and includes the unlikely possibility of purposeful error, such as acting with financial interests over and above clinical concerns. More probable is non purposeful error caused by “the inherent limitations of DSM-IV”. A third possibility is misdiagnosis through poor information or inaccurate interpretation of the information (Halasz, 2002:473) .

Given the varying levels of knowledge prevailing among the different professions involved the value and reliability of reports will vary. Additionally, the contentious nature of public debate about ADHD means that among the multi-professional group contributing to assessment there might also be competing ideologies about the nature and causes of ADHD and this may not always be explicit. One answer would seem to be the use of standardised, validated questionnaires to elicit information from the range of sources. Those commonly used are the Conners Parent and Teacher Rating Scales and the Achenbach Child Behaviour Checklist, though there are many alternatives (Williams, et al, 1999). Expert reviews including the European Child and Adolescent Psychiatry Guidelines, provide comprehensive guides to reliable instruments (Taylor, et al, 1998, Hill and Taylor, 2001).

A caution must be sounded however against over-reliance upon checklists since questionnaire or checklist completion alone leads to higher than expected prevalence rates (up to 14%) of ADHD and:

The proper use of a checklist approach to diagnosis requires training in judgement of severity, consideration of alternative causes or conditions, evaluation of pervasiveness and impact, and direct clinical evaluation of the child.

(Hill, 1998:381)

In addition to assessing behavioural indications, a thorough physical evaluation should be conducted and a clinical history taken. Physical evaluation will assess underlying medical problems and establish height and weight baseline, previous health problems and current medications. Further tests such as for hearing may be arranged with specialists. The history and examination are essential in determining co-morbid conditions and other complications and may indicate the need for further assessment so as to exclude other diagnoses. It may be necessary to involve specialists such as clinical and educational psychologists, occupational and speech and language therapists (Scottish Intercollegiate Guidelines Network, 2001; Hill and Taylor, 2001).

It is evident that where cases have high levels of complexity, complications and co-morbidity, the demands upon specialist services will be great and it can only be concluded that timely

and competent identification and screening in primary care is the key to services that are effective, both in terms of clinical outcomes and in efficient use of limited resources.

Clinical interventions

Medication

There is consistency between the major studies, stating that, provided a thorough assessment and accurate diagnosis has taken place, the most effective treatment will normally be medication in combination with other interventions, which may include individual behaviour management programmes and advice and support to parents (National Institute for Clinical Excellence, 2000; Scottish Intercollegiate Guidelines Network, 2001; MTA Cooperative Group, 1999). It is important to recognise that all the current guidelines focus on the use of psychostimulant medications, specifically methylphenidate, commonly known under the proprietary names of Ritalin, Equasym and Concerta. Psychostimulants are the only drugs currently licensed for use with ADHD in the UK and thus have been the most commonly prescribed and evaluated medications here, although antidepressants may be indicated in some cases (National Institute for Clinical Excellence, 2000; Scottish Intercollegiate Guidelines Network, 2001).

The NICE guidance states

Methylphenidate is recommended for use as part of a comprehensive treatment programme for children with a diagnosis of severe Attention Deficit/Hyperactivity Disorder.

(National Institute for Clinical Excellence, 2000)

The NICE guidance advises careful titration to establish the optimal dosage and timing and states the need for regular monitoring to identify and manage side effects. The SIGN guidelines go further in suggesting that the effectiveness of medication should be evaluated by involving parents and children in the assessment of effects (Scottish Intercollegiate Guidelines Network, 2001).

Two developments that will have an impact upon treatments for ADHD will be the second set of NICE guidance, due for publication in 2005 and the introduction in the UK, in July 2004, of a new, non-stimulant medication, atomoxetine (Strattera).

The largest study of its kind to date has been the Multimodal Treatment Study of Children with ADHD, which demonstrated the effectiveness of treatment by medication alone. Some benefit was shown for medication combined with behavioural treatment, but the positive effects were confined to non-ADHD symptoms (MTA Cooperative Group, 1999). Importantly, however, the combined treatment led to lowered doses of medication being required. This is important for two reasons, the first being that many parents would welcome a reduced dosage of the medicine as a matter of principle and the second is that side-effects

are correlated positively with dose. When evaluating the outcomes a primary consideration is that the MTA study only investigated combined type ADHD, whereas the authors state specifically that results may well have been different for predominantly inattentive type and predominantly hyperactive/impulsive type, had these been included (MTA Cooperative Group 1999). A final caution is highlighted in the report regarding the danger of a "one size fits all" approach: children with ADHD often also present a range of other symptoms and will have varying levels of resource and support both at home and in school. Each case must be assessed and treated on its own merit and within its context.

Whilst the evidence for the efficacy of medication is substantial, there will always be those whose parents are opposed to pharmacotherapy, or for whom the side-effects are intolerable. Additionally some sub-groups of ADHD, for example those with co-existing anxiety, may respond less well to medication. In these cases psychosocial interventions will be the main treatments (Froelich, et al, 2002). Cooper suggests that the orthodoxy of multimodal treatment reflects an underlying concept of ADHD as

a problem that is in part a dysfunction of the individual, and in part a problem that is exacerbated by the environment in which the individual operates.

(Cooper 2001:393)

It may be that parents and teachers (mis)construct the behaviour of children with ADHD as based on motivation and volition, rather than as an involuntary phenomenon. Medication can be viewed as a "window of opportunity" in which the child can be enabled to develop ways of responding to an environment that require a "contrasting cognitive style" (Cooper, 2001:393). Children receiving stimulant medication are able to "learn better, provoke their parents less, and be better tolerated by their peers." (Hill, 1998:383).

Detailed protocols for medical practitioners about selection, titration, dose and general monitoring are necessarily technical and less pertinent to this review; they are however widely available (National Institute for Clinical Excellence, 2000; Scottish Intercollegiate Guidelines Network, 2001; Hill and Taylor, 2001; Taylor, et al, 1998).

Psychosocial interventions

There are several psychosocial interventions which have been shown to have benefits for children with ADHD. These include behavioural techniques such as positive reinforcement, reprimands and redirection, response costs and parent training (Williams et al, 1999). Educational interventions, change in diet, and social skills training may also be employed to positive outcomes, but studies are inconsistent and benefits are often short-term or fail to improve the core symptoms associated with ADHD (Williams et al, 1999). This may be explained partly by the heterogeneity presented by the DSM-IV diagnosis: Hill (1998) asserts that up to half of those with the DSM diagnosis can be managed by behavioural or dietary methods alone, though for the more stringent diagnosis of HKD, most children will require medication.

Individual psychological treatment for ADHD aims to promote appropriate self-regulatory and reflective behaviours in children who experience difficulty in developing these skills. According to the Scottish guidelines, the outcome results for cognitive training are disappointing, even with the adjunct of stimulant medication, whereas skills training with children alone has shown some success in improving children's social skills, whether administered by therapists or parents. Generalisation of these skills to the school setting has been shown to be limited (Scottish Intercollegiate Guidelines Network, 2001). Cognitive behavioural treatment (CBT) with an emphasis on treatment components which facilitate generalisation into the natural environment has been shown to produce a significant reduction in ADHD core symptoms (Froelich, et al, 2002). A study of CBT tested the efficacy of a cognitive-behavioural self-control therapy on children with ADHD. The results showed improvements on several measures and the improvements of children with aggressiveness were slightly better, according to the parents, when training in self-control was accompanied by anger management techniques (Miranda and Presentacion, 1999).

There is an intuitive appeal in offering structured interventions to parents in the treatment of ADHD. Children with ADHD present challenging behaviour that is difficult to manage and there is evidence to suggest that ADHD evokes a more negative parenting style (Taylor, et al, 1991). In addition the co-existence of other disorders, commonly oppositional defiant disorder (ODD) and conduct disorder (CD), serve to exacerbate cycles of negative interaction. Where parent training with a social skills programme is used alongside stimulant medication the transfer of benefits to a non-clinical environment has been reported (Scottish Intercollegiate Guidelines Network, 2001).

Parental management training is recommended for cases where ADHD is co-morbid with other behavioural disorders. (MTA Cooperative Group, 1999). It has also been found to improve parental acceptance of treatment packages and to enhance parents' well being. Anger management training has been successful in helping generally with self-control and the development of specific coping strategies in the clinical setting, but again generalisation to the natural environment remains doubtful. Systematic evaluation of behaviour management training has been conducted for children with oppositional behaviours and shows that, although significant improvements can be achieved, there is significant variation between individuals (Scottish Inter-collegiate Guidelines Network, 2000).

Other therapies

Hill and Taylor state

Although medication is the most powerful treatment in terms of effect size, not all cases will need it, not all families will accept it, and not all children will be suitable for it.

(Hill and Taylor, 2000:405)

Many parents are interested in the potential benefits of dietary methods and there is evidence for the effectiveness of an individually constructed elimination diet, or "few foods" diet, based on the principle of cutting out all foods apart from a very small number; testing for the effects and adding further foods gradually and one by one (Hill and Taylor, 2000). A few foods or elimination diet however requires very careful monitoring and observation, sometimes over a prolonged period. There has been a great deal of interest from parents and professionals, reflected in the extensive media coverage, of the potential benefits of fish oil supplements. Unlike some other dietary methods, which may actually cause harm, using the correct dosage of fish oil supplements is unlikely to be harmful and may be beneficial, though there are no large scale trials yet completed and published.

Partnership working

Shared care

Following the publication of the NICE guidance, more services are now working toward shared care protocols between primary and secondary care. The guidance states

Treatment with methylphenidate should only be initiated by child and adolescent psychiatrists or paediatricians with expertise in ADHD, but continued prescribing and monitoring may be performed by general practitioners, under shared care arrangements with specialists. Trusts and Primary Care organisations should ensure that appropriate shared care arrangements are in place.

(National Institute for Clinical Excellence, 2000)

On average, GPs have between two and four ADHD children receiving treatment on their patient lists and given the frequent contact between GPs and children and families, GPs are well placed to be active in continuing treatment and monitoring (Thapar and Thapar, 2002). Many GPs however are reluctant to manage ADHD, largely because of a lack of expertise. Child and adolescent mental health plays a minor part in GP and nurse education and thus primary care staff lack confidence in taking on the shared care role (Thapar, 2002; Thapar and Thapar, 2003; Sayal, et al 2002). One commentator has observed that, given the pressures on secondary services to maintain throughput by seeing and assessing promptly, GPs should continue and monitor care initiated by the specialist, leaving more time in secondary care for specialised provision, and

everywhere should be working towards shared care arrangements, and the more GPs get involved, the more comfortable they will feel dealing with ADHD

(Spender, cited in O'Connell, 2003)

This is echoed in a survey of psychiatrists and paediatricians, finding that 72% of respondents

felt GPs should have the key role in screening for ADHD and 88% who believed accurate referral would be improved by increasing GP training in this area (ADDISS, 2003).

It is a truism that GPs have competing priorities and numerous calls upon their time. ADHD will not be the most significant aspect of GPs' role and it is arguable therefore that they do not have the time to undertake the necessary training in ADHD. Barbaresi (1996) suggests instead that specific guidelines and a practical plan are required to promote the ability of GPs to provide shared care. In a local study of GPs (150 sample) it was found that 64% would change their views on prescribing if they received more training and 67% suggesting a clear protocol would be required (Ball, 2001).

Shared care is only part of the picture however and a growing number of commentators have been calling for a comprehensive service for ADHD, in which all agencies involved with children and families need to work in partnership to provide care that is seamless and meaningful to the service user.

The contribution of schools

A ten year study by the American Psychiatric Association showed that there was a significant expansion in access to treatment of children with ADHD, but a decline in intensity of treatment, seen in fewer visits. Part of the explanation for these trends is that there was increased public acceptance of psychotropic medication, but also that access to services such as special education had improved, leading to less reliance on specialist health provision (Olfson, 2003).

Of all pupils with ADHD, approximately 25% will be excluded from secondary school because of serious misconduct and about 80% will be behind in at least one academic subject (Tannock, 1999). Children spend the majority of their waking time in school and it is crucial that the environment is one in which those with ADHD have equal opportunity to their peers that enables them to flourish.

Because of the behavioural difficulties associated with ADHD and the conflict between those and the expectations and norms of schools, children with ADHD, especially when severe and pronounced, will be considered to have special educational needs under the provisions of the Special Education and Disabilities Act (Department for Education and Skills, 2001). The requirements of the Act are operationalised for schools through the Special Educational Needs Code of Practice (2002), which uses a graduated approach to children experiencing educational difficulties. Following prescribed steps in developing an individual education plan (IEP), which is the basis of information gathering and low key management strategies, the class teacher will agree with the Special Educational Needs Coordinator (SENCO) to move to the stage of School Action or then to School Action Plus.

The SENCO and class teacher decide together on the action needed to help the child to progress, consulting the head teacher if extra resources will be involved. Intervention

strategies can include:

deployment of extra staff to enable one-to-one tuition (this will depend on financial resources and staff availability); provision of different learning materials or special equipment; staff development and training; SENCO time spent on devising the nature of planned intervention; one-off or occasional advice from the LEA support services.

(Department for Education and Skills, 2002)

Some children with special educational needs are required to have a "Statement" and the process of "statementing" was also a feature of the former Education Act (1981). The duty of the Local Education Authority is first to establish that the child's needs cannot be met adequately within the resources available in mainstream schooling, then

Where an LEA are of the opinion that a child has SEN and that it is necessary for the authority to determine the special educational provision which any learning difficulty he may have calls for, the LEA will make an assessment of the child, to decide whether a statement of SEN should be made for the child (s.323).

(Department for Education and Skills, 2001)

The expectation is that around 20% of children will have some form of special educational need at some time and that most of those will have their needs met within the school, but around 3% will require a statement. Therefore most children with ADHD will not require a statement of SEN.

ADHD has not been specified in the Code of Practice, so the generic special needs procedures have to apply equally. O'Regan, who has also produced a practical book for teachers on managing ADHD, states

The lack of understanding around ADHD means that teachers would benefit from policies that provide more clear and definitive guidance regarding ADHD in the classroom. Only then will the joined up thinking the DfES promotes be translated into effective joined up working.

(cited in ADDISS, 2003:b)

The general guidelines for behavioural management of children with ADHD can be applied by the children themselves, their parents and carers and the professionals working with them, including teachers. But because of the educational culture and configuration children with the disorder often find school the most difficult setting in which to manage and control their behaviour (Cooper, 2001). School staff and teachers in particular, require specific guidance in this area. Much of the effectiveness of treatment in the classroom relies upon the individual teacher, who should ensure that children with ADHD have structure to their

day, including plenty of repetition and reminders. It is recommended that tasks should be broken into small achievable segments, punctuated with breaks for feedback and praise. The child should be seated near the teacher and away from other distracting or distractible pupils (O'Regan, 2003; Cooper and O'Regan, 2001, Newman College, 2003).

Whilst it is necessary to equip the class teacher and assistants with tools to help with behaviour management in ADHD, there is also a responsibility of the whole school, including the head teacher and the board of governors, to provide an environment of inclusivity and an ethos of tolerating difference and diversity and creating opportunity. The growth area of emotional literacy and health promoting schools is not directly linked to ADHD, but may have a significant influence on the school setting in which the child with the disorder is located. A whole school approach to mental, emotional and social health can improve morale and well-being, whilst also raising academic achievement. It involves supportive relationships, a high level of engagement by staff and pupils, the encouragement of autonomy and clear and transparent rules, boundaries and expectations (Weare, 2003). Thus the context and framework for specific classroom strategies is created and maintained.

Transition and continuity of care

ADHD may be thought of as a chronic, long-term disability in the same way as other disorders starting in childhood, such as diabetes or asthma. Follow up studies from adolescence into adult life show that where symptoms persist people have problems with employment, driving offences, substance use and anti-social activities (Barkley, 1998, Farrington et al, 1990). Notwithstanding the mounting evidence of the continuity of ADHD into adulthood and validated studies into persistence throughout adolescence, Danckaerts et al (1999:81) caution that studies into adult ADHD have relied upon self-report, stating "there still is a need for the development of reliable and valid assessment procedures in adolescence and adulthood".

This view has been supported in a recent analysis of the evidence, which concludes that

The diagnostic validity of ADHD poses more of a challenge in adults than it does in children, given the need for retrospective information, the extent of comorbidity with other disorders (Shaffer, 1994) and the fact that DSM IV criteria have been validated only in children and adolescents, not in adults (Weiss et al, 2002).

(Zwi and York, 2004:252)

Danckaerts, et al (2000) report a study in which a sample of 6-7 year old boys was followed up at age 16-18 to assess outcomes of ADHD. The authors provide a breakdown of the confounding factors that have influenced the validity of previous similar studies and, given the high co-morbidity of conduct disorder with diagnosed ADHD, perform a differential analysis that allows the outcomes of hyperactivity and conduct disorder to be separated out. Social adjustment was found to be worse in the adolescents with a hyperactivity disorder



and these young people had significant relationship difficulties, which

demonstrated that the main risk factor for poor peer-relationships was hyperactivity per se rather than associated conduct problems.

and

Peer rejection itself is known to be a strong predictor of later personal adjustment in relevant domains such as school achievement, delinquency and psychopathology.

Danckaerts et al (2000:35)

One of the features of a comprehensive CAMHS outlined in the Children's National Service Framework is to provide a service for young people up to the age of eighteen. Notwithstanding the resource implications for many services that currently offer a service only to age sixteen, this will be taking effect in the near future (Department of Health, 2003b,). Moreover CAMHS will be required to work with their colleagues in adult mental health to develop transition protocols. This will not be without its problems for young people with ADHD. Adult psychiatry and mental health nursing have focused on a range of disorders and conditions that are characterised by their later onset, such as psychosis and bipolar disorder. There are of course exceptions to this and examples of early onset of these disorders, but in the main adult mental health practitioners have not been trained in the management and treatment of disorders, such as ADHD, that were formerly thought to be conditions exclusive to childhood.

Much still needs to be understood about ADHD, particularly in adulthood. Its core symptoms of inattention, hyperactivity and impulsivity, as well as other ADHD-related behaviours, personality traits and disabilities, need thorough developmental observation and study across the life span.

(Zwi and York, 2004:254)

Examples from practice

Among the few published case studies widely available it seems that there is little local information on prevalence and treatment rates for ADHD and even less about unmet need. Where reports of local practice are available they show a range of approaches to the care and management of ADHD.



One region has identified a need for better information to be collected by health services on the number of children being assessed, diagnosed and awaiting assessment for ADHD, to inform clear care pathways for the diagnosis and management of ADHD across three health economies in conjunction with education services (Bickler, 2001).



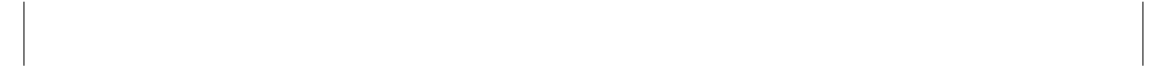


This is likely to be a commonly experienced problem: a key recommendation of Children in Mind (Audit Commission, 1999) was to improve the information for monitoring problems, interventions and outcomes to help support clinicians. The national CAMHS mapping exercise established in 2002 is a partial and welcome response to the recommendation, but problems around information persist at the local level and impede effective commissioning (Lester and Sorohan, 2002; Lee et al, 2002). Problems with information do not apply exclusively to ADHD, but are part of the wider context of rapid expansion and change in local commissioning of both mental health and children's services.

- Multi Agency Working Group**
In West Suffolk a hyperactivity nurse has been appointed who works jointly with a nurse colleague and consultant psychiatrist to develop criteria for referral to local Tier 3 services and to harmonise variations in practice. A working party includes psychiatric and paediatric medical and nursing practitioners, as well as an educational psychologist and co-opted members. Regular monitoring of demand and provision is achieved through consultation across agencies and groups and has revealed that, contrary to concerns that GPs would be exploited and overwhelmed, the flow of cases has been steady and manageable. Following the guidelines for shared care in the NICE guidance, the service now operates whereby the consultant psychiatrist or paediatrician initiates medication and in straightforward cases passes the continuing monitoring and management to the GP (O'Flynn, 2001).
- Shared Care**
East Sussex CAMHS is reported as evolving in response to the increased demands on its service. A multi professional working group has been established to develop standards for involving school in the assessment and monitoring of children with ADHD. An aim of the group is to develop shared care for children with uncomplicated ADHD between school doctors and GPs, in accordance with NICE recommendations (Bickler, 2001).
- Involvement Of Schools**
East Sussex CAMHS is reported as evolving in response to the increased demands on its service. A multi professional working group has been established to develop standards for involving school in the assessment and monitoring of children with ADHD. An aim of the group is to develop shared care for children with uncomplicated ADHD between school doctors and GPs, in accordance with NICE recommendations (Bickler, 2001).

The first consultant nurse post for ADHD in the UK was appointed in Eastbourne and County Health Care NHS Trust, following a health needs assessment of children with ADHD and their families. The role includes coordinating multi agency provision and liaison, developing training programmes and working with the adult mental health service regarding meeting the needs of the young people on reaching adulthood. The nurse consultant is also pivotal in developing a care pathway (Bickler, 2001).

- The Specialist Nurse**
It has been found in a study of practice based in Ipswich that the role of the specialist ADHD nurse has become increasingly specialised following the growing knowledge and evidence about ADHD and heightened demand for services (Osman, 2003).



The diverse and valuable role of nurses in ADHD has also been explored through a project in Southampton, where the particular contribution nurses can make has been outlined, including:

Assessment of the child and family
Liaison with schools to facilitate diagnosis
Parent education
Parenting strategies
Child education
Facilitation of further interventions

(Laver-Bradbury, 2003:78)

Elsewhere, implementation of an ADHD pathway has reportedly

Enhanced cooperation between the different professional disciplines, particularly community paediatrics, CAMHS and education, and given a better understanding of the role that each can play in the management not only of ADHD but also of the comorbid conditions commonly encountered.

(Burgess, 2002)

Examples of effective practice need to be audited and evaluated in the mid to long term. Initial results are promising, but more evidence is required to establish whether clinical and organisational outcomes improve and importantly, whether the outlook for children with ADHD is enhanced. Cooper, concluding a critical review of the literature on understanding ADHD, has argued for a holistic understanding gained through multidisciplinary research, stating

As yet there is very little published research of this kind, enquiring empirically into the social reality of this medical condition. The indication of this study, however, is that the children themselves need to be much more closely involved in the dialogues and debates about ADHD

(Cooper, 2001:393)



This is perhaps echoed in the following extract from a poem by Sharon Kilday (1999);

*Forgive me if this is way off line, but would it not be easier to take the time, for all those
adults to speak to me
After all
It is me who lives with ADD.
They are the ones who argue all day!
They are the ones who wonder every day!
They are the ones who spend thousands of pounds!
They are the ones who walk the grounds!
We are the ones who play all day!
We are the ones who get by every day!
We are the ones who live with ADD!
"please don't avoid me"
"Just ask me"*

Summary

- Assessment and diagnosis should be carried out by child and adolescent psychiatrists or suitably qualified paediatricians, but the care offered by these two groups may not be consistent.
- Assessment should take account of the child's history and should include reports from family, school and other settings.
- Diagnosis should include a physical examination and medical history.
- New national developments in CAMHS that will affect ADHD services state that there must be equal access to care and a service up to age 18 that includes mental health promotion and early intervention.
- Treatment should be multi-modal, which means there will be a range of interventions, including various behaviour management programmes and where indicated, medication.
- Psychostimulant medication is found to be the most beneficial treatment, particularly when combined with behavioural interventions.
- Multimodal treatment requires joined up working from a multidisciplinary team.
- Children with ADHD will often have special educational needs and a minority will require a Statement under the Special Education and Disabilities Act.
- Schools are required to provide for all special educational needs, including but not specifically ADHD; this will involve close liaison with health services so that care is coordinated and integrated.
- Teachers need to organise the classroom and their teaching so that children with the disorder can be enabled to succeed; this will include structuring the day, segmenting tasks, giving praise and encouragement.
- In some people ADHD symptoms endure into adult life and for these young people at age 18 there needs to be an agreed protocol for moving into adult services.
- There are some published examples of innovative work to improve services for ADHD. These always include formalised arrangements for multi agency working, often through the development of a care pathway.

4. Care Pathways

A service planning tool

The purpose of this review of the literature is to enable the commissioners and providers of services for people with ADHD to develop care pathways for best practice. A care pathway should aim to have:

*the right people
doing the right things
in the right order
at the right time
in the right place
with the right outcome
all with attention to the patient experience
and to compare planned care with care actually given.*

(National Electronic Library for Health, 2004)

Given these requisites the foregoing analysis of literature has been broad in its range, encompassing a multi agency and service user perspective as well as reviewing the evidence base. Within the published literature, evidence based clinical guidelines (National Institute for Clinical Excellence, 2000), protocols (Hill and Taylor, 2001) and decision trees (Magyary and Brandt, 2002) are supported by a small but growing number of reports on local initiatives seeking to reconcile the different strands into coherent packages. Guidelines and protocols tend to address one aspect of the service that may be offered to a child and family and there are to date no national standards for the comprehensive care of children with the disorder. Neither the Children's National Service Framework: Emerging Findings nor the Special Education and Disabilities Act, specifies ADHD. Healthcare and allied professionals, clinical, managerial and administrative, face the challenge to provide timely, effective and responsive services, whilst making the best use of limited resources. One way in which to maximise the skills and knowledge of a range of professionals, avoid duplication and provide high quality care is the development of a care pathway that is

both a tool and a concept that embed guidelines, protocols and locally agreed, evidence-based, patient-centred, best practice, into everyday use for the individual patient.

(National Electronic Library for Health, 2004)

Magyary and Brandt offer four client outcomes that will result from the introduction of (ADHD) care pathways. The outcomes will enhance:

the comprehensive and systematic nature of the assessment process, thereby increasing the probability of an accurate diagnosis

the comprehensive and multimodal nature of the intervention plan and the matching of the plan with the individual child and family, thereby increasing the probability of adherence and efficacy

collaboration among the various providers of care, the child and parents, thereby enhancing coordination, relevance, and successful outcomes

cultural sensitivity of care, thereby incorporating health beliefs and practices into the assessment and intervention plan.

(Magyary and Brandt, 2002:556-7)

Terminology

There are many interchangeable terms used in this area and much of the literature focuses upon Integrated Care Pathways (ICP). The ICP is a specific concept that may be defined as "a document that describes a process within health and social care, and that collects variations between planned and actual care." (National Electronic Library for Health, 2004). In the tightly defined ICP the salient feature is the commitment to comparing planned with actual care and tracking the variance. The development of ICPs in health began in critical and acute care and the majority of published examples are for medical and surgical conditions and procedures (Campbell et al, 1998) although since 1992 the application of ICPs has extended across all care groups, including mental health (National Electronic Library for Health, 2004). In adult mental health ICPs have been developed partly in response to the requirements of the Mental Health National Service Framework and the term integrated here reflects the requirement for the amalgamation of health and social care teams alongside the pooling of budgets. Because of its specific usage in adult mental health and for purposes of clarity the term ICP will not be adopted here.

There is more potential for confusion: the following terms tend to be used interchangeably, whilst there are subtle differences between them:

- Anticipated Recovery Pathways (ARPs)
- Multidisciplinary Pathways of Care (MPCs)
- Care Protocols
- Critical Care Pathways
- Pathways of Care
- Care Packages
- Collaborative Care Pathways
- CareMaps®
- Care Profiles

(National Electronic Library for Health, 2004)

A care pathway is not, “a protocol, a flow chart of events, a care map, a process map, a decision tree, a guideline, a care plan” (National Electronic Library for Health, 2004). A care pathway (including ICP) may contain protocols and guidelines and these may have originated in care mapping, process mapping, or decision trees. A care plan may be a way of recording the proposed treatment and outcomes for a client, but will again be only a part of the pathway. Definitions for these terms are offered below.

Specific and related terms

- Protocol
A protocol establishes the provision of care by using the best available evidence if national standards are not available, such as in the case of ADHD. It will normally include specific information on who is responsible for carrying out key parts of the treatment. Commonly in CAMHS local protocols are drawn up for referral, for instance.
- Flow chart
A flow chart shows the sequence of steps to be followed in planning an episode of care.
- Care map
A care map, which may also be called a service map, identifies and describes all the services and resources that offer care to a particular group of individuals, say with ADHD.
- Process map
Within a care system, which might be a CAMHS outpatient service, the patient or client journey through one part of the system is broken down into steps that are arranged sequentially. The process map should highlight areas for improvement.
- Decision tree
A decision tree identifies the critical components of care and shows the outcomes at each juncture of decision A, B, or C. An ADHD decision tree has been produced by Magyary and Brandt, 2002.
- Guideline
Clinical guidelines synthesise best evidence and make specific recommendations for practice (eg National Institute for Clinical Excellence, 2000)
- Care plan
Care plans in mental health may form part of the Care Programme Approach (NSF Mental Health), although many CAMHS use their own, locally designed proformas. The plan states a simple summary of the assessment and/or diagnosis, proposed

intervention and anticipated outcomes or goals. It is usually agreed with the client.

The National Pathways Association (2004) addresses the question “What is a care pathway?” by asserting that it:

determines locally agreed, multidisciplinary health practice, based on guidelines and evidence where available, for a specific user group.

Design and Implementation

The pathway of care should be designed by a multi disciplinary, multi agency group, for local use. It is the application to local practice of national standards, or where they are absent, evidence of best practice. It is suggested that designing a pathway of care will take between 8-10 meetings of the multi-agency group. It is possible to use existing pathways, but these must be amended carefully, both to reflect local conditions, but also to ensure local ownership (National Pathways Association, 2004) .

A care pathway will be documented, but must not be seen as a paper exercise; the documentation should be a clear reflection of the concept of best practice.

Checklist for designing a care pathway

The pathway should have the service user at its heart, ensuring that the best possible service is available at each step of the way. At each stage of the process, from recognition to being discharged from the children's services, there are specific questions to be addressed by commissioners and providers. Finding answers to these questions requires that data are collected about what happens currently. In some cases audits and evaluations will already have been conducted and professional staff will have local knowledge that can be used. In many cases however it will be necessary to conduct specific audits and surveys.

The information provided by the data collection will, in combination with best practice guidelines, provide the basis for action.

The checklist provided in the following section poses the key questions at each stage of the service user journey or process, suggesting how to obtain information and local evidence and ways to address deficits in the system.

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DEVELOPING A CARE PATHWAY FOR ADHD

The Health and Social Care Advisory Service (HASCAS) has published 'Best Practice in Attention Deficit Hyperactivity Disorder (ADHD), A Review of the Literature and Care Pathway'. This summary provides a list of key recommendations from the report, some questions that you can consider for your local service and where and how to find this information. It also provides suggestions on what to do next to improve care for those with ADHD in your local area. It is suggested that a review of ADHD care is performed by a multi-agency multi-disciplinary team.

RECOGNITION

- All individuals and groups within the family and community, professional or otherwise, require awareness, education and training about ADHD.
- Parents are the most likely people to be alerted first to possible ADHD, although lack of awareness and adverse media coverage may prevent or delay their seeking help from the GP.
- ADHD is an early onset disorder and may also be observed by pre-school professionals such as nursery staff and health visitors.
- Concerns are usually more pronounced when the child starts school so teachers and other school staff have an important role to play in contributing to the assessment of suspected ADHD.

Questions to address	Finding answers	Taking action
What is the local prevalence of ADHD?	Expected prevalence can be calculated using national data.	Information and awareness raising for parents, pre-school, primary school staff and primary care staff. Events, publicity, information (e.g. ADDISS brochure)
Is there an unmet need?	Audit service usage numbers and the combined number of cases seen by community paediatrics and Specialist CAMHS. Compare these figures with your prevalence estimates.	
Are cases being detected early?	Audit: average age at referral.	
Do primary care staff e.g. health visitors, teachers, nurses and assistants in nursery and primary school settings know what to do if ADHD is suspected?	Conduct a survey or focus groups for parent feedback.	

RECOGNITION



REFERRAL

- The main gateway to families in gaining access to specialist services is often through the GP, however, this varies and others may be involved.

Questions to address	Finding answers	Taking action
Who can refer to specialist care services and what are the referral criteria?	Audit	Referral protocols for GPs and others covering screening, filtering, differentiating and where/how to refer.
Are GPs and others referring expected numbers to specialist care?	Audit: GP and other referrals compared with expected prevalence to determine whether rates of referral are as expected.	
How is the decision made to refer to Paediatrics or Specialist CAMHS?	Audit: referrals to Paediatrics and CAMHS - how do they differ?	
What is the waiting time for assessment and diagnosis once referral has been made?	Audit: time of referral vs date of first assessment and diagnosis. Identify the bottleneck through process mapping.	Consider innovative ways to improve capacity of service to reduce waiting times e.g. use of nurses and community paediatric services.

REFERRAL TO SPECIALIST SERVICES

DIAGNOSIS

- Assessment and diagnosis should be carried out by a child and adolescent psychiatrist or a suitably qualified paediatrician. Diagnosis should include a physical examination and medical history.
- Assessment should take account of the child's history and should include reports from family, school and other settings.

Questions to address	Finding answers	Taking action
Is there parity between paediatricians and Specialist CAMHS on diagnosis?	Audit	Consider how common assessment tools can be used as part of diagnosis. Deliver joint training.

DIAGNOSIS

TREATMENT

- The care offered by psychiatrists and paediatricians may not be consistent.
- Treatment should be multi-modal, which means there will be a range of interventions, including various behaviour management programmes and medication.

Questions to address	Finding answers	Taking action
Do patients receive parity of service between Paediatrics and Specialist CAMHS?	Audit: comparison of treatment duration and outcomes between the two.	Joint training for joint working.
Are patients offered a range of treatment options that are backed by evidence?	Map the different organisations providing care for children with ADHD. Conduct a survey or focus groups for parent feedback.	Ensure clinicians understand and are following national guidelines. Hold refresher courses / discussion events.

TREATMENT

MULTIAGENCY WORKING SHARED CARE AND LIAISON WITH EDUCATION

- Multi-modal treatment requires joined up working from a multi-disciplinary team.
- GPs are encouraged to get involved in shared care arrangements with specialists.
- Children with ADHD will often have special educational needs and a minority will require a Statement under the Special Education and Disabilities Act.
- Schools are required to provide for all special educational needs including, but not specifically, ADHD; this will involve close liaison with health services so that care is coordinated and integrated.
- Teachers need to organise the classroom and their teaching so that children with the disorder can be enabled to succeed; this will include structuring the day, segmenting tasks, giving praise and encouragement.

Questions to address	Finding answers	Taking action
Is there multi-agency partnership?	Check that education in particular is involved and informed fully - by surveying schools and/or using a survey or focus groups for parent feedback.	
Is there shared care between specialist services and primary care?	Conduct a survey of specialist providers and/or GPs, or analysis of case files.	Training for GPs. Develop protocols for risk assessment and management and shared care.

MULTIAGENCY WORKING

ONGOING CARE

- In some people ADHD symptoms persist into adult life and for these young people at age 18 there needs to be an agreed protocol for moving into adult services

Questions to address	Finding answers	Taking action
What do young people and families need to feel supported through the discharge process?	Conduct a survey or focus groups for parent feedback.	
How many young people will need to move into adult services?	Telephone survey of specialist providers. Audit: compare number of adults receiving care for ADHD with expected prevalence.	Develop a CAMHS to Adult transition protocol for ADHD, or general protocol of which ADHD is a discrete component. Provide joint training between child and adult mental health staff.
How will the transition be managed?	Ask specialist providers what the experience has been to date.	

DISCHARGE & ONGOING CARE