



Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Autistic Spectrum Disorders
- ◆ The Effects of Chemotherapy and Radiotherapy

If DM's have any questions on these issues, please contact us.

## **DLAAB NEWS AND UPDATE**

Hello Everyone,

Even though it is holiday time Issue 3 2004 of DLAAB Update and News is ready to circulate. Since the last issue the Board organised a Seminar attended by 18 Decision Makers. It proved to be a great success with plenty of discussion and problem solving.

This issue continues to build on the discussions which we had at the seminar and I do hope you find it helpful.

Anne Spaight  
Chair DLAAB

## **ATTENTION DEFICIT HYPERACTIVITY DISORDER**

### **1. Diagnosis**

ADHD is a complex disorder that should be assessed through a combination of structured questionnaires and direct interview and assessment. There is no absolute standard for diagnosis, and 'acceptable' behaviour may depend as much on the context and tolerance of the beholder as any specific operational criteria.

There is a genetic linkage, and children with ADHD may well experience family difficulties as a result of parental behaviour itself suggestive of ADHD, even if undiagnosed.

Boys present more commonly than girls in a ratio of approximately 3:1.

### **2. Assessment**

In order to make the diagnosis, practitioners have to have a clear view of expected normal behaviour in a range of age groups from young child to teenager. One needs both the time and the expertise to take a detailed family history, history of the child's personal development and establish a detailed account of the difficulties in the home and school environment supplemented by clinical observations.

Diagnosis is a lengthy business requiring a range of information from a number of sources, particularly focussing on education. Other agencies may be involved, especially if the child is already being assessed by a Speech/Language Therapist or Physiotherapist. Social Services may have comments particularly in relation to parenting if the family are already well known to their service and if a Support Worker is involved.

One would expect the diagnosis to be made by a Specialist, either a Consultant Community Paediatrician or a Consultant Child Psychiatrist. Community Paediatrics largely takes the lead in the diagnosis of treatment of uncomplicated ADHD involving CAMHS (Child & Adolescent Mental Health Services) in situations where children are either presenting with increasingly complex difficulties or failing to respond to standard interventions.

Children with ADHD often present with additional problems, such as learning difficulties, dyslexia or DCD/dyspraxia. In older children and adolescents, conduct disorder (including delinquent behaviour), depression and obsessive compulsive disorders with a range of tics or habits are by no means uncommon, requiring additional support and treatment involving a multi-agency response.

Information presented with DLA claims may indicate that children with ADHD have problems from settling to sleep, to waking in the early hours of the morning. In severe cases they may require supervision in the house, e.g. if awake early in the morning and tempted to go downstairs unattended by a parent to make breakfast or watch television. Some may require a greater degree of oversight than children normally require in order to play out safely with friends because they may be easily led into trouble by their friends, e.g. by throwing stones, entering derelict property or setting fires. If provoked, young people tend to behave impulsively, rarely thinking through the consequences of their action. People with ADHD often suffer from low self-esteem and in order to distract the teacher and peers from academic difficulties, some children will act as the 'class clown', resulting in the young person acquiring secondary labels, e.g. 'disruptive behaviour' or 'conduct disorder'.

### **3. Treatment**

Treatment of ADHD has two core components. Firstly, behaviour modification techniques appropriately tailored to effective use at home and at school and secondly the addition of medication, primarily in the form of stimulant medication, Methylphenidate (generic name Ritalin).

Ritalin in its various forms is the most commonly used medication for the treatment of ADHD. It is available in both quick release and slow release preparations. New preparations available on the market such as Atomoxetine may be promising. The range of drugs tried to treat ADHD include Clonidine, Imipramine and Risperidone. These drugs may be helpful for young people who for various reasons cannot be prescribed Ritalin because of coincidental problems such as tics,

epilepsy, or intolerance of side effects. Such alternative medications are of variable efficacy.

Unfortunately, even with the longer-acting preparations, the medication wears off after approximately eight hours and therefore usually by the time the child comes home from school on weekdays there is no longer a positive medication effect. Indeed, there may be a 'kick-back' effect often described by parents with the child being particularly restless and inattentive for the first half hour or so after coming home from school, a phenomenon which parents often struggle to contain, particularly if the child then has to settle down to doing any homework.

#### **4. Parenting skills**

Effectively, parents with children with ADHD need the same skills as all other parents, but they need to apply their skills more persistently and more rigorously in the context of clear boundaries. The child benefits from clear instructions given step-by-step, e.g. the task 'brush your hair' being completed before the next task is given, e.g. 'wash your face'. Parents need to be vigilant as to their child's whereabouts, and need to take measures to protect the child's safety. There are a number of strategies for teaching parenting skills such as the Webster Stratton parent groups or the parent/child game', which uses a more individual approach. There are also models of family therapy. The extent to which these therapeutic resources are available or taken up effectively by parents varies widely across the country.

Whilst aggression is not a primary feature of the condition many children often develop secondary conduct disorder because of their reckless, impulsive behaviour. Some teenagers may unfortunately move on to develop more classically delinquent behaviour such as stealing or joy riding. Attention Deficit Disorder uncomplicated for instance by autism, epilepsy or significant learning difficulties, does not affect the young person's responsibility in the face of the law if arrested and charged with any criminal activity.

#### **5. Fluctuations in the condition**

Shifts in the child's behaviour between home and school rely not so much on fluctuations in the child's underlying condition as the support, care and attention available to the child in the home and school setting. Differences in behaviour between home and school may be further compounded by the use of medication, which is heavily focused on supporting school-based activities and promoting learning during the day. It is possible for a child who is quite restless and

inattentive at home in the evenings to appear much more settled during the day in school if medication is working properly.

## 6. Sources of information about the condition

Reports might helpfully be obtained from the Special Needs Co-ordinator (SENCO) at school or learning mentor if available and contrasted with parent's report or reports from the Community Paediatrician, Child & Family Services or Social Services, if any of these agencies are involved. If a young person attends a youth group, then the youth leader may be able to comment and if the family is well-known to the General Practitioner or Practice Nurse, again they might provide some helpful knowledge about the child and family's functioning. Finally if the family are engaged with any form of ADHD support group, this too might be a useful source, particularly as workers within that environment may be able to offer some standards of comparison with other young people.

## 7. Prognosis

On the whole, young people tend to show an amelioration in their symptoms as they move into late adolescence. I think this in part is a feature of maturation and in part reflects career choices, e.g. : practically based activities such as working as a motor mechanic or carpenter rather than trying to remain in a more academic work environment.

In the past, relatively few young people, no matter how bright, were able to fulfil their academic potential when suffering from impaired concentration and attention. With the advent of behavioural modification techniques and even more importantly, medication, far more young people are now obtaining appropriate qualifications.

Since ADHD is more common in boys than girls, it is easy to understand how a young, single mother may struggle to care for a very active little boy who finds it hard to contain his behaviour without some boundaries and in the absence of an appropriate male role model. ADHD, its assessment, diagnosis and treatment cannot be divorced from its social and cultural context. Due to its range ADHD is a complex condition. In terms of care and mobility needs these often arise when ADHD is one of a range of presenting conditions.

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## INTRODUCTION

The term dyspraxia (also known as developmental co-ordination disorder) is used to describe difficulties in planning and carrying out skilled motor tasks (tasks involving movement) in the absence of any well-defined neurological deficit or impairment. In addition it may include problems with language, perception and thought.

In February 2004 members of the board met with Dr Amanda Kirby, Medical director of the Dyscovery Centre. We considered it might be helpful to DM's for Dr Kirby to write a 'frequently asked questions' piece for the News and Update.

In common with most conditions DCD ranges from mild to severe with a resulting range in care and mobility needs.

## DEVELOPMENTAL CO-ORDINATION DISORDER (DCD)

**Dr Amanda Kirby, Medical Director, The Dyscovery Centre.**

### **What is Developmental Co-ordination Disorder (also known as Dyspraxia in the UK)?**

This is an umbrella term for children with co-ordination difficulties. In the past children have been given other labels such as clumsy, minimal brain disorder and perceptuo-motor dysfunction. In the UK the term Dyspraxia is often used.

### **What is the incidence?**

DCD is a common condition that is present in about 5% of children who are school-aged. Boys present more commonly than girls in a ratio of approximately 4:1. Children are usually of average or above average intelligence, and their co-ordination difficulties are out of line with their other abilities.

### **What are the signs and symptoms?**

The most typical difficulties in the home setting are dressing and undressing, managing buttons and fastenings, messy eating, with difficulty using a knife and fork, and a tendency to spill drinks or food. There is often difficulty doing activities under time pressure. Young children may have difficulty with some self care tasks such as managing the toilet and cleaning teeth. Most motor tasks take longer than other children of a similar age and intelligence.

In the school setting, the child may have difficulties with writing, using scissors, puzzle activities, changing for PE, ball skills, and team games. Children often have associated difficulties sustaining friendships.

### **At what age are children usually recognised as having the disorder?**

Usually children are identified once they are in school unless they have marked developmental delay in speech, walking, crawling, although parents often identify difficulties early on with self-care tasks and the child being clumsier than siblings or peers. Some individuals are not identified until later when the environment changes and expectations increase such as in the teen years. It is at this stage when organisation and planning can be very difficult for individuals with DCD.

### **Does DCD overlap with other developmental disorders?**

Overlapping of DCD with other disorders is common. As many as 55% of those identified as having dyslexia may also have motor difficulties, and 32% may have ADHD (attention deficit hyperactivity disorder). They may also have social and communication difficulties as well as dyslexia.

### **Do children grow out of it?**

Individuals with DCD can vary in the degree to which they are affected. However there is evidence that most children identified at ages five or six years as having motor co-ordination problems still exhibit motor difficulties 10 years later.

Other children given appropriate support and making reasonable adjustments, can manage to be integrated fully into school and home life.

Some individuals continue into adult hood with difficulties with self-care tasks, organisation, and food preparation as well as difficulties managing transport and being able to undertake DIY tasks in the home. At work they may have difficulties with organisation, specific motor tasks and commonly continue to have difficulty with recording tasks.

### **Who assesses the individual with DCD?**

The child may be first identified as having difficulties by the school and will usually be referred to an Educational Psychologist and onto children's services. The alternative route for assessment is to a local children's centre where a paediatrician may ask for an evaluation by

an Occupational Therapist or Physiotherapist after other causes of motor difficulties have been ruled out.

### **What is the treatment?**

There is strong empirical evidence that the motor problems of children with DCD persist at least into adolescence and lead to the development of secondary physical health, mental health and educational issues including poor physical fitness, poor social competence, academic problems, behavioural problems, and low self-esteem. Treatment is usually undertaken by Occupational Therapy or within the educational curriculum as well as guidance for parents. However there are few services supporting adults with DCD in the UK at the present time, which can lead to a small number of adults not being able to access work opportunities.

Much of the support for individuals with DCD lies in adapting the environment such as providing alternative means for recording information, adaptations in the kitchen, allowing extra time for tasks.

### **What assistance may the children or adults require?**

Parents of children with DCD may need to assist them with dressing and self care tasks for longer. They may need additional supervision when out playing. Some children may have associated sleep disturbance. As adults the individual may need help with organising and planning their day or with manual tasks in the home. Most activities will take the individual longer. However, there is a range of difficulties from mild , where the child usually has declining difficulties with age, to the more severe difficulties where the child is likely to continue to have difficulties into adulthood.

### **Useful organisations:**

#### **The Dyscovery Trust**

**4A Church Rd , Cardiff CF14 2DZ 02920 628222**

[www.dyscoverytrust.org.uk](http://www.dyscoverytrust.org.uk)

#### **The Dyspraxia Foundation**

**West Alley Hitchin Herts. SG5 1EG**

**01462 454986**

[www.dyspraxiafoundation.org.uk](http://www.dyspraxiafoundation.org.uk)

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# DLAAB NEWS

## MEETINGS WITH OUTSIDE ORGANISATIONS

The Board meets regularly with outside organisations. At these meetings Board Members with relevant skills, expertise or interest have discussions with representatives of various groups.

The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board.

We use the News and Update as a means of directly informing DM's of changes that are new or brought to the Board's attention. This is in addition to the information already available in the Disability Handbook.

Updates to the Disability Handbook are being made via ICT where appropriate. Meeting with the Board gives access to representatives of outside organisations to inform us of issues needing clarification.

Since the last issue of Update the Board has run a workshop for Decision Makers, addressing the subjects of Multiple Sclerosis, Mental Health- Psychosis and ADHD.

## THE BOARD

### **Chair:**

~Mrs Anne Spaight MBE

### **Vice-Chair**

~Dr Ian McGill

### **Co-Ordinators:**

~Dr David Cohen (Research)

~Mrs Marion Westacott (Organisation)

~Mrs Clair Poole (Education)

### **Members**

~Mrs Simone Baker

~Mrs Jean Cooper

### **Members (cont)**

~Mrs Judith Holt

~Ms Marilyn Howard

~Dr Lee Illis

~Mrs Christine Whitehead

~Dr Ben Ko

~Prof. David Scott

~Dr Audrey Oppenheim

~Ms Sarah Playforth

~Mr Douglas Ross

~Prof. Tom Sensky

~Mrs Sarah Vines

### THE REMIT

The Board has three main functions:

- To give advice to the Secretary of State on matters referred by him/her.
- To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.
- To present an Annual Report on its activities over the year to the Secretary of State.

### INVITATION TO DM'S

If you have any specific questions or general queries please contact us via the Secretariat.

We wish to use the News & Update as a forum for discussion.

### HEALTH WARNING

Please note- the articles contained in this news- sheet are written for the benefit of Decision Makers, to help them with their job.

The articles are **not to be quoted** in any decision or communication with members of the public or their representatives.

### GETTING IN TOUCH

DLAAB at The Adelphi  
1-11 John Adam Street,  
London, WC2N 6HT

0207 962 8056  
0207 962 8982  
0207 962 8053

Or on the web at:  
[www.dlaab.org.uk](http://www.dlaab.org.uk)