

An overview of the NICE Guidelines on ADHD published in September 2008.

By Professor Eric Taylor

What is NICE?

NICE is the National Institute for Health and Clinical Excellence. It produces both “technology assessments” – which say what drugs or procedures represent good value for the NHS and should be provided - and “guidelines”, which are fuller sets of advice about how the NHS should go about providing good services for particular conditions. The technology assessments have statutory force; and in 2006 one was produced about drugs for ADHD, saying that methylphenidate, dexamfetamine and atomoxetine were all recommended. This is helpful to families, and means that all three should be available. An assessment like this, however, does not say when or how or for whom the treatment should be given. These important details are the business of the guidelines recently published.

NICE Guidelines are advisory and do not have legal force – but they are very influential about how health technologies should be provided and what the priorities should be in service planning and delivery.

The Process of NICE

The process of drawing up guidelines is long and complex. Impartial reviewers search the scientific literature for all the relevant papers, criticise them all, and put them together to see what conclusions can be made on the basis of the science. A panel of clinicians from different disciplines, service users and carers then interpret the research to make recommendations about what should be done.

Independent economists work out how much different sorts of treatment cost and from that, and the trial evidence about their effectiveness, what represents a good buy for the health service. There is then a process of consultation. There were hundreds of comments from many shades of opinion and they were all considered. Finally the guideline is published, on paper and on the web.

No health service can afford every possible treatment for every condition, so priorities have to be set out. NICE has to work out not just what is ideal but what is realistic. This can be a painful process, but as far as possible, the NICE process tries to remove bias and personal opinion and to base recommendations on public and verifiable knowledge.

The first question NICE asked was: “Is ADHD a valid diagnosis?”

The answer will seem totally obvious to many families - but there is a great deal of public controversy, because of the fear that ordinary childhood naughtiness is being medicalised into a sickness and worries that psychotropic drugs are anyway a wrong way of dealing with children’s problems. So the NICE process applied the criteria used scientifically to determine whether a mental state really is a disorder – and the result was clear. ADHD is real and the health service should treat it. This was a

considerable step forward, and makes it much harder for a service to say that there is no such thing or that it is all a matter of bad parenting.

What the guidelines say about treatments for children

Severe ADHD

The first-line treatment for school-age children and young people with *severe* ADHD and *severe* impairment is drug treatment. If the child or young person and/or the parents or carers reject this, a psychological intervention may be tried but drug treatment has more benefits and is superior to other treatments for this group.

The first choice of drug is usually methylphenidate - either an immediate-release version, Ritalin or Equasym; or an extended-release version, Concerta XL, Equasym XL or Medikinet. There may be a preference for atomoxetine when tics, Tourette's syndrome, anxiety disorder, stimulant misuse or risk of stimulant diversion are present as well – the choice is rather evenly poised. Atomoxetine will probably be the best choice if methylphenidate has been tried and has been ineffective or unacceptable. Dexamfetamine has much less evidence about it, and we do not know as much about its safety, so it is usually kept in reserve for when other treatments do not work.

The decision to go on to medication is a big one, because the therapy is likely to go on for years, and no medication is totally free of side-effects. A definite diagnosis, and a decision to recommend medication, should therefore only come after a full assessment. This needs to be full enough to uncover other problems if they are present. Sometimes what looks like ADHD can come about because there is a different kind of learning problem at school, or the child is feeling very insecure, or there is another physical illness. All these problems need to be found and helped, if they are there. The guidelines also say that medication should not be the only intervention given – there should be information for all concerned, including teachers. There should also be the offer of psychological interventions – especially, parent-training programmes, and CBT and/or social skills training for children of school age.

Moderate ADHD

Fortunately, not all cases of ADHD are severe. Indeed, some young people find they can manage their lives satisfactorily even with the condition.

When the impairment is only moderate, or less, NICE puts the treatments in a different order. It reviewed the trials of psychological ways of helping and found some of them to be useful and cost-effective. The recommendation was therefore that “Group-based parent-training/education programmes are usually the first-line treatment for parents and carers of school-age children and young people with ADHD and moderate impairment.” Medication then has a secondary place – it should be provided if and when the psychological interventions have not worked well enough after a reasonable try - ideally, 8-12 sessions. Some families, of course, will not want to take up the offer of a training programme; and some will find that it is not available yet. Medication is then the treatment of choice for school- age children, even for those

whose severity is “only” moderate. But medication is not usually recommended before school age – the adverse effects appear to be worse and the safety is unclear.

What about education?

NICE has indeed provided evidence and suggestions about how important it is for schools to recognise ADHD as a problem and how effective it can be to apply understanding to management in the classroom. This was unusual for NICE, because its key purpose is to set the agenda for what the NHS does and it is not part of the education system. The recommendations, therefore, may not carry much clout, and school systems vary greatly in the extent to which they regard ADHD as their business.

What the guidelines say about treatments for adults

NICE recommended that adults with ADHD should also have the benefit of assessment and treatment. This is a far-reaching conclusion, and should lead to a radical change in mental health practice, with adult psychiatry taking on ADHD as part of its remit.

The precise recommendations were tentative, because there is much less research to draw on about adults – and one NICE conclusion was indeed that more research was needed about treatments for adults. In particular, there is little trial evidence about psychological treatments. This does not necessarily mean that they are ineffective – simply that we cannot be sure that they work, so cannot yet give them priority for the NHS to provide.

The key conclusion is therefore that drug treatment is the first-line treatment for adults with ADHD with either moderate or severe levels of impairment, unless they would prefer a psychological approach.

Transition to adult services

It will take some time before adult services have moved to take on these recommendations, but there is active training in place and a great deal more interest than was shown before the guidelines appeared. In the meantime, there are many teenagers who have been helped by treatment, who are moving outside the ambit of child services, and are quite unclear about where to turn for guidance and prescription. In many places they are dependent on the good sense of their general practitioner, without much in the way of specialist backup.

The NICE guidance is clear that transitional arrangements need to be developed. It also recognises that the exact details will vary from place to place in the light of what has already developed. In some parts of the country adult psychiatrists are already comfortable with treating ADHD. The transition from child to adult services will then need the child and adolescent service to plan ahead, alert the adult service before the age of transition - usually the eighteenth birthday - and draw up a care programme jointly.

In other parts of the country there is little expertise in treating adult ADHD. Those services may well decide to set up a specialist ADHD clinic so that expertise can be developed and diffused into general mental health services. In other areas again the paediatric or child mental health services are already continuing to treat their patients even after the age of 18 years.

NICE is therefore recommending that each region should set up a planning group to make the best use of the local resources and skills and make sure there is a continuing care pathway into adult life for people who need it.

What has the response to NICE guidance been?

The implementation process is just starting, but many NHS Trusts have already started to audit their provision for children against the guidelines and train adult mental health services.

Education does not seem to have reacted so far; but the guidelines group did make it clear that there would be benefits in training teachers about ADHD.

The media response has been rather paradoxical. Journalists picked up the message of limiting the first-line use of medication to the more severely affected – but amplified it into a warning against using drugs at all – and stimulants in particular. This has, in general, been in a tone approving the advice - which is a welcome change for NICE - and expecting a reduction in medication to follow – though in fact the effect of the recommendations is likely to be to increase the availability of medication.

Indeed, where there has been dissent it has been on the grounds that NICE did not go far enough and should have banned the use of medication entirely. This anti-medical view has been linked to the allegation that a large-scale trial in the US - the Multimodal Treatment Study of Children with ADHD (MTA) - has shown no long-term benefit attributable to stimulant treatment. It is an allegation that is not actually true but came with the backing of the BBC's powerful Panorama programme.

By contrast, the other message from NICE - that ADHD needed more, not less, recognition and treatment - did not feature in most journalists' responses. It is therefore likely that those who get their information from the mass media will have received an unbalanced account.

What the NICE Guidelines mean for families

The implications for families will be gradual, as the recommendations are introduced into practice. Families should be able to expect a planned pathway of care. Primary care will have a role in detecting that there is a problem, and referring on to paediatrics or child/ adolescent mental health. Without waiting for the specialists to make a full assessment and diagnosis, there should be access right away to parent training programmes. These will not necessarily be specialised for ADHD, but will include the ADHD symptoms as well as the other behaviour problems for which families seek help.

The next level of specialist care, will diagnose, assess for other problems and start specific treatment - usually behaviour therapy or medication. When medication is established and the dose is right, then the clinic will usually refer back to the general practitioner for continued prescribing, and monitoring of growth and blood pressure, with periodic review at the clinic to check on physical health and psychological progress.

There is now a great deal of work to do in getting the recommendations of the guidelines to be adopted in practice. The guidelines are not a dramatic innovation: what they describe is already being provided in many parts of the country, and this is as it should be. But they should be very helpful for extending good practice more widely – and the development of services for adults should be their most novel contribution.

How to access the NICE Guidelines on ADHD

The NICE Guidelines on ADHD CG72 are available in a number of formats.

How to order

- You can download them from the NICE website www.nice.org.uk
- Order printed copies of the quick reference guide by calling NICE Publications on 0845 003 7783 or email publications@nice.org.uk – quote reference N1684
- They are also available as a slide presentation at: <http://www.nice.org.uk/Guidance/CG72/slideset/ppt/English>

