



**The British
Psychological Society**
Promoting excellence in psychology

British Psychological Society response to NICE

Attention deficit hyperactivity disorder (update)

About the Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of just over 50,000.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for NICE to contact us in the future in relation to this inquiry.

Please direct all queries to:-

Joe Liardet, Policy Advice Administrator (Consultations)
The British Psychological Society, 48 Princess Road East, Leicester, LE1 7DR
Email: consult@bps.org.uk Tel: 0116 252 9936

About this Response

This response was led on behalf of the Society by:

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We hope you find our comments useful.

Alison Clarke

Chair, BPS Professional Practice Board

Please return to: ADHDstandardUpdate@nice.org.uk

Consultation on draft guideline – deadline for comments 5pm on 18/10/17 email: ADHDstandardUpdate@nice.org.uk

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"> 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) <p>See section 3.9 of <u>Developing NICE guidance: how to get involved</u> for suggestions of general points to think about when commenting.</p>
<p>Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>The British Psychological Society</p>
<p>Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.</p>	<p>[None]</p>

Name of commentator person completing form:				
Type		[office use only]		
Comment number	Document (Short version, chapter (number only), or the Appendices)	Page number Or 'General' for comments on the whole document	Line number Or 'General' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
	Short version + appendices	General	General	<p>The Society would recommend the following points in relation to the 2017 updated NICE guidance on ADHD and its treatment:</p> <ol style="list-style-type: none"> 1. We are concerned that the guidance is now recommending that stimulus-medication can be used as the first-line treatment for ADHD above the age of 5 years prior to psychological interventions prior to parent-training, CBT, behaviour management and systemic multi-agency work have been properly planned, executed and the outcomes measured. 2. There is implication that more females – children and adults - require an ADHD diagnosis and treatment because they are 'missed' by clinicians. We believe that this is a statistically spurious argument and ethically questionable in terms of the safeguarding agenda. 3. The Society is concerned that the guidelines state that under-5s can be more routinely diagnosed as having ADHD and prescribed stimulant-medication such as methylphenidate (Ritalin) contrary to manufacturer's licences and guidance. We believe that psychological interventions such as parent-training, CBT, behaviour management and systemic multi-agency work should always be used first. This will better safeguard the under-5 child population. 4. The Society is concerned that ethical considerations of ADHD diagnosis and treatment have not been discussed in this guidance. The symptoms of ADHD are behavioural (hyperactive behaviour, impulsive behaviour, inattentive behaviour). The use of medication to control, change and/or manage the autonomous social-behaviour of children and young people – particularly when the behaviour is not causing the medicated person distress – is ethically contentious and can be viewed as impinging on children's and young people's basic human rights. What constitutes properly informed consent and involvement in decision-making is also ethically contentious and particularly impinges on the safe-guarding of children and young people.
	Short version + versions	General	General	The Society welcomed the Autism guidelines from 2013, in respect of promoting a multi-agency care-pathway for the diagnosis and systemic treatment of people with an autism spectrum condition and believes that this should not have

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				been omitted in the current guidelines.
	Short + appendices	General + p.45 p. 46	General + ll. 27-28 + ll. 6 - 9	The guidance was critically undermined: diagnosis criteria for ADHD depend on core behavioural symptoms of 'hyperactivity', 'impulsivity', and 'inattention'. No differential baseline is provided for 'normal activity', 'normal impulsivity' and 'normal concentration' in any of the guidance, evidence reviews or other appendices for any or all age ranges. This means that 'improvement over baseline' by any treatment can never be scientifically established in any age group in any context, e.g. home, clinic or educational setting.
	Appendices C, E, and F: Evidence review(s) for efficacy of non-pharmacological treatment	General	General	Evidence reviews were critically undermined: diagnosis criteria for ADHD depend on core behavioural symptoms of 'hyperactivity', 'impulsivity', and 'inattention'. No differential quantitative baselines were provided for 'normal activity', 'normal impulsivity' and 'normal concentration' in any of the guidance, evidence reviews or other appendices. This means that 'improvement over baseline' by any treatment can never be scientifically established in any age group in any context, e.g. home or education, in any study. This is a significant methodological limitation in all studies cited.
	+ pharmacological treatments	General	General	Evidence reviews were critically undermined: very few long-term studies cited by the guidance. Majority of pharmacological and non-pharmacological studies are very short in duration – with an approximate mean average of 15 weeks, for age groups under-5, over-5 and adult.
		C., E., F.	General	Evidence reviews were critically undermined: there are no long term (2 years plus) follow-up studies cited, for age groups under-5, over-5 and adult.
		C. p.6	ll.21-23	Evidence reviews were critically undermined. To quote the committee: "Despite a large treatment literature supporting the short-term benefits of stimulant medication in children with ADHD, uncertainty still surrounds the quality of evidence and the balance of risks and benefits of long-term drug treatment for ADHD in children and young people."
		E. p.117	ll.30-31	Evidence reviews were critically undermined. To quote the committee: "The committee noted that the majority of evidence for this review was generally low or very low quality."
		F. p. 107	ll.14-17	Evidence reviews were critically undermined. To quote the committee: "The committee noted that the body of evidence for this review was typically low or very low quality. There was no evidence in children under the age of 5 for this review. There was larger body of evidence for children aged 5 to 18 than for adults over the age of 18. While there were a large number of studies meeting the criteria for the review, in general they were small studies providing imprecise results and only single studies per outcome."

	NICE guideline: short version, 2017: 1	p. 2	I. 26	The Society believes that reference should be made to co-occurring (comorbid) conditions here since evidence suggests that receiving more than one neurodevelopmental diagnosis is the norm. (Gillberg, C. et al, 2004)
	1	p. 6	I. 19	The Society believes that this implies trainee teachers are most in need of training in this area. More balance should be applied and that indeed the training of a variety of new professionals entering public sector jobs including those in health and education may benefit from evidence-based and policy informed training regarding ADHD within their training. (E.g. SALT, OT, Physio, School nurse, Portage...)
	1	p. 7	I. 9	We believe that this should read 'children and young people diagnosed with oppositional defiant disorder or conduct disorder'; the terms 'oppositional defiant disorder' and 'conduct disorder' are labels applied to children and young people, not things that they 'have'. The language used in line 13 ('a close family member diagnosed with ADHD') should be used as the model throughout when talking about diagnoses.
	1	p. 7	I. 21	The Society welcomes the inclusion of 'people with acquired brain injury' and of children with identified 'attachment disorders', as the evidence for these groups being at increased risk of receiving a diagnosis of ADHD is growing, and represents clinical experience.
	1	p. 34	II. 18-19	The guidance reports: "No evidence was found on the increased risk of missing a diagnosis of ADHD in girls." The Society acknowledges that girls are less likely to be diagnosed with ADHD, However, we are concerned about the conclusion of the guidance. The fact that females are under-represented in diagnosed ADHD group is not a reason to diagnose more. This is a statistically spurious argument and not born out by the experience of mental health professionals including psychologists.
	1	p. 7	II. 22-27	Teachers and parents have been aware that as a general rule girls are much more behaviourally compliant than boys in both educational and home settings but to suggest that girls are more likely to be of the 'inattentive' type means that the guidance would contradict DSM-5 and ICD-11 in suggesting that there are sub-categories of ADHD. This is a complex issue and we believe the different socialisation process for girls in our society, differences in biological make up such as the role of male hormones etc may well be part of the explanation and we should not be seeking to address a perceived imbalance in prescribing rates when there may indeed be other possible hypotheses to explain the current differential diagnosis rates.
	1	p. 10	II. 20-24	The Society believes that cognitive or neuropsychological assessment might clarify co-occurring conditions that may

				give rise to attentional difficulties for other reasons (e.g., dyslexia, dyspraxia, autism spectrum disorder or sensory processing disorder. It would also differentiate out the possibility of brain injury. This may then identify dysexecutive function, manifesting as ADHD.
	1	p.11	l. 9	The Society is concerned that the guidance from adults is being applied downwards to children, young people and their families. The ways in which children, young people and their families access healthcare is different and the issues are different. For example the 'Patient experience' document specifies that practitioners should, for example, 'develop an understanding of the patient as an individual, ask the patient about and take into account factors such as domestic, social and work situation...' etc. For children and young people their presentation and care needs need to be in the context of their family, school and wider social systems. Children and young people are not simply little adults.
	1	p. 11	l. 21	"Following a diagnosis of ADHD it is important to have a structured discussion with people (and their families or carers as appropriate)". The Society believes that it needs to be recognised that for children and young people, a discussion with parents is required, as parents are generally the carers for their children; similarly, it is important for the discussion not just to be with parents when the child in question is very young, since all children have the right to know about any health conditions they may have, in an age appropriate format.
	1	p. 11	l. 21	The Society welcomes the recognition that family and carers are a crucial part of the support process for children and young people, but we would like to see this extended to young people over 16 if this is what the young person would like. We have some concern that there should be an expectation that young people aged over 16 are able to, or may want to be solely responsible for their healthcare. This is certainly not the case for young people aged over 16 with complex presentations of neuro-developmental disorders, such as ADHD, where co-occurrence of neuro-developmental conditions is the norm (Gillberg, C., 2010; Lundstrom, S., et al, 2015) or where the young person has intellectual difficulties. We would also argue that young people over 16 should be explicitly asked if they want their parents or carers to continue to be involved in their healthcare management as they navigate the transition to adult mental health services, rather than it being assumed that they do not; this is especially the case for young people with any degree of vulnerability.
	1	p.12	l. 24	The Society welcomes the reference of positive aspects of having a diagnosis and the need for people receiving a diagnosis being given appropriate information, and the requirement for this to be at an age / development appropriate level.
	1	p. 14	l. 13	The Society believes that reference needs to be made to the need for continuity at the point of transition from child to adult services. We would strongly welcome more clarity or guidance in the document about how this should happen. It is all too familiar to hear from young people of a complete breakdown in provision as they move from paediatric

				focused services with a philosophy of care that involves the young person and their family, to adult services where provision is focused only on the individual.
	1	p. 15	I. 4	The Society welcomes the need to encourage children and young people to give their own account of how they feel. We do have some concerns about the lack of self-report measures of 'ADHD symptoms'; evidence suggests that young people can feel detached from the management of ADHD with important implications for treatment compliance. It is important young people are able to give their account to give a fuller picture of the distress and difficulty experienced by children and young people who have a diagnosis of ADHD. (Brinkman, et al, 2012).
	1	p.15	II. 11	We welcome the inclusion of: "the benefits of a healthy lifestyle, including exercise". There is significant evidence not cited that supports the systematic use of physical activity prior to a decision to medicate a child to assess a beneficial effect on the presenting pattern of behaviours. In France, for example, doctors use 'social prescribing' - the state pays for the membership of a sports club for a year to measure if this has any beneficial impact on non-compliant behaviour.
	1	p.16	I. 3	The Society welcomes the inclusion of offering an ADHD focussed Parent Training Programme at this stage for children under 5 years of age, providing that it is informed by evidenced psychological principles, e.g. CBT.
	1	p.16-17	II. 2-10	The Society recommends that consideration be given to forbidding the prescribing of stimulant-medication to children under the age of 6 years unless there is significant distress caused to the child by their own presenting behaviours, and that medication is supported by a second opinion from parent(s) and a tertiary service. We believe that psychological and psycho-educational programmes are advantageous to children of this age and that psychotropic medications are unnecessarily risky, unethical and of limited efficacy. This is therefore a safeguarding issue. In other European countries such as France medication is not recommended under the age of 7 years.
	1	p. 16	II. 18-21	The Society welcomes the recommendation that group based ADHD parent-training should be offered first, however, we have concerns that medication should then be offered 'if ADHD symptoms are having a persistent significant impact in at least one domain of their everyday life after environmental modification'. There is a step missing here, since environmental modifications should be explicitly trialled, their impact monitored and reviewed as a distinct and definitive step. Clinical experience is that parents may be asked if environmental changes have been tried, but because children with ADHD can be challenging, parents very often say these things have been tried when, in reality they have not been implemented in any systematic way, and have not been subject to any review. Medication may be helpful for children and young people, but so might properly implemented environmental interventions (including at school), but these are often not given a chance to work before medication is tried. No change of medication should be considered until medication has been stopped for a period of time and a systemic psychological intervention tried instead in school or in the home.

	1	p. 17	I. 7	The Society welcomes the recommendation to include the use of evidence based CBT treatment for children and would urge that consideration is given to it being used to reduce anxiety etc. prior to medication being offered.
	1	p. 17	I. 16	We welcome the inclusion of the option of individual parent training interventions for parents who cannot attend group based approaches. Clinical experience is that parents are often lost to services when they cannot access the one size fits all service that is on offer.
	1	p. 18	I. 2	The Society would welcome non-pharmacological treatment offered to children and young people on the same basis as they are offered to adults, e.g. when they have made an informed choice not to have medication. Competent children and young people are able to make this choice and should, therefore, be offered it. Similarly, some children and young people are unable to tolerate the side effects of medication.
	1	p. 18	II. 21-23	The Society believes that reference to bespoke plans needs to be made for children and young people around responsibility for taking their own medication, since it would not be appropriate for a very young child to be in charge of taking stimulant medication. This point is mentioned further in the document, but it would be helpful if the document did not read like a document for adults, with children and young people as an afterthought.
	1	p. 21	I. 6	The Society is concerned about the removal of psychological interventions from the 2008 Guidelines as the first line of intervention for children and young people and the replacement with methylphenidate, a stimulant-medication as the first-line intervention. We have concerns that in children where the drug does not have a calming effect that it acts as it is designed to stimulate the central nervous system causing major sleep disturbance and other well evidenced side effects such as growth retardation and weight / appetite loss which cannot be beneficial to the children affected. We have great concerns that this change could lead to a dramatic increase in false positives and overprescribing; and attendant economic risks to the public purse.
	1	p. 27	I. 18	All side effects, for example tics, weight loss and height retardation, should be viewed as serious and the prescribing doctor should always consider cessation of stimulant medication as a first response.
	1	p. 29	II. 17	We welcome the development of the patient's autonomy and decision-making so that the person diagnosed with ADHD makes a significant contribution to their own treatment plan, including the cessation of their treatment / medication as part of their own informed decision making.

	1	p. 29	I. 26	The Society believes that a patient taking medication should be encouraged to identify, measure, record and monitor their side effects in order that they can properly contribute to the regular twice-yearly review of their treatment plan and this needs to be reflected in the guidance.
	1	p.31	II. 3	The Society would recommend that if a patient has been prescribed stimulant medication, the review period should be a minimum of twice yearly because of the seriousness of side-effects, and the importance of patient empowerment and informed decision-making.
	1	p. 34	II. 12-21	The rates of neurodisability disorders are typically much higher in offenders than non-offender groups, (Hughes, N, Williams, W.H. et al, 2012) This was also described in the British Psychological Society publication 'Children and Young People with Neurodisabilities in the Criminal System' (2015).
	1	p. 35	II. 11-15	The Society believes that Schools and colleges should be encouraged to continually scrutinise and challenge diagnoses of ADHD in the fullest consideration of their safeguarding procedures.
	1	p. 36	I. 12	We welcome the notion of 'holistic' but note that throughout the guidance, a medical 'within-child' model as opposed to a 'systemic' model is used to understand a patient and their ADHD.
	1	p.37	II. 12	Under 5s, note: "There was limited evidence on the efficacy of medication and because of concerns about medication in very young children, the committee agreed to recommend a group-based parent training programme as first line treatment." The Society welcomes this guidance and recommends that it would be a significant safeguarding-risk to vulnerable young children to offer medication in the light of this note. We also feel that better safeguarding of children under the age of 5 may provide a significant cost-saving outcome by reducing prescriptions where a significant amount of money saved could be spent on other clinical interventions for children with medical needs.
	1	p. 37-38	II.16-22	The Society believes that it is potentially dangerous to proffer stimulant-medication to the under-5 age group because of the scant evidence of efficacy. Stimulant medication used with under 5s is therefore antithetical to safeguarding them. We would recommend a stronger recommendation on not offering medication to the under 5's unless there are extreme circumstances and a consensus of more than one medical opinion. There is a large body of professional opinion in the child mental health field and amongst some parents that has concerns about the risk of serious side effects such as sudden heart failure due to overstimulation and are aware of reported cases where children have collapsed in school and been hospitalised as a result. These are rare cases but still clearly significant in safeguarding terms.

	1	p.37-38	ll. 11-18	We value elements of the safeguarding agenda and the clarification of the significant impact in at least one domain of their everyday life but do still have concerns that the proposed changes to first-line intervention may result in an increase of inappropriate prescribing of psychostimulants and anti-psychotic medications.
	1	p.37-38	General	The Society is concerned that the change from 'Drug treatment is not recommended for the under-5s' in the 2008 guidelines to the first-line use of ADHD-focussed group parent training programmes whilst laudable as a first step may inadvertently and unintentionally lead to an increase in prescribing medications to pre-school children to the lack of availability of such training packages in some regions of the country and the potential post-code lottery effect in fairly delivering such a response. This in turn we believe may well result in an increased rate of prescribing to pre-school children in those disadvantaged areas due to the resource limitations.
	1	p. 52	ll. 1 - 10	The Society is concerned that the box from the 2008 guidance, noting the precedence of the Mental Health Act (2007) and the Children Act (2007) has been deleted from the 2017 guidance.
				<p><u>References</u></p> <p>Brinkman, W.B., Sherman, S.N., Zmitrovich, A.R., Visscher, M.O., Crosby, L.E., Phelan, K.J. & Donovan, E.F. (2012). In their own words: Adolescent views on ADHD and their evolving role managing medication. <i>Academic Pediatrics</i>, 12(1), 53–61</p> <p>'Children and Young People with Neurodisabilities in the Criminal System' (2015).</p> <p>Gillberg, C. (2010) 'The essence in child psychiatry: Early symptomatic syndromes eliciting neurodevelopment' <i>Research in Developmental Disabilities</i>, 31, 1543–1551;</p> <p>Gillberg, C., Gillber, I.C., Rasmussen, P., Kadesjo, B., Soderstom, H., Rastam, M. Johnson, M., Rothenberger, A., & Niklasson, L., (2004) 'Co-existing disorders in ADHD – implications for diagnosis and intervention' <i>European Child and Adolescent Psychiatry</i>, 1(1). 180-192</p> <p>Gillberg, C., 2010; Lundstrom, S., et al, 2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. <i>Journal of Child Psychology and Psychiatry</i>, 56(6), 702–710</p> <p>Hughes, N, Williams, W.H. et al (2012) 'Nobody made the connection. The prevalence of neurodisability in young people who offend'</p> <p>Lundstrom, S., Reichenberg, A., Melke, J., Rastam, M., Kerekes, N., Lichtenstein, P. Gillberg, C. & Anckarsater, H.</p>

				(2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. <i>Journal of Child Psychology and Psychiatry</i> , 56(6) , 702–710.
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Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Where commenting on one of the 9 guideline chapters, please enter the number only in the document column (**essential** so we know which document you are commenting on), and the page and line numbers.
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons). We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](#).

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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