

National Institute for Health and Care Excellence

Surveillance Review of CG170 Autism spectrum disorder in under 19s: support and management

Stakeholder Comments Form

Please enter the name of your registered stakeholder organisation below.	
NICE is unable to accept comments from non-registered organisations. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.	
Stakeholder Organisation:	BrainTrainUK
Name of commentator:	Stuart Black

Please note an overview of the process for reviewing NICE published clinical guidelines can be found [here](#)

Contents:

- Comments on proposal not to update the guideline – page 2
- Comments on the proposal to remove research recommendations from the NICE version of the guideline and the NICE research recommendations database – page 2
- Comments on equality issues or areas excluded from the guideline scope – page 3

Proposal not to update the guideline

In order to guide your comments, please refer to the following questions:

1. Do you agree that the guidance should not be updated?
2. Do you agree with our proposal to remove the listed research recommendations from the NICE version of the guideline and the NICE research recommendation database?

If a stakeholder wishes to draw our attention to published literature, please supply the full reference. Please add extra rows as needed

1. Do you agree the guideline should not be updated?	Comments If you disagree, please explain why
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1. Do you agree the guideline should not be updated?	Comments If you disagree, please explain why
Disagree	<p>We disagree that the guidelines should not be updated because we see no evidence that neurofeedback has been properly assessed as an intervention.</p> <p>There is also evidence contrary to the statement in the current guidelines “Do not use neurofeedback to manage speech and language problems in children and young people with autism”.</p> <p>There is a strong body of evidence that demonstrates the ability of Neurofeedback (NF) to use the brain’s inherent plasticity to change the electrical patterns in the brain in response to feedback. There is also strong evidence that differences in the electrical patterns in the brain correlate with differences in cognitive and behavioral function, including many of the symptoms associated with ASD. We can supply copies of relevant literature if the Committee is not familiar with this research. We believe this evidence alone, together with growing clinical evidence of NF being applied to ASD, merits Neurofeedback being available for ASD. In addition to this, below we have summarised some key research in this area specific to subjects who have a diagnosis of ASD.</p> <p>A 2010 literature review¹ assessed 5 separate studies which in total reported 180 ASD individuals receiving NF training. The authors concluded “We view neurofeedback as an intervention that may prove to be efficacious in the treatment of symptoms of autism. Presently, it should be viewed as possibly efficacious with potential and would then be in the same category as most interventions used with this challenging population.”</p> <p>A 2010 RCT² involved 20 children age 8-12 diagnosed with autism were randomly assigned to a neurofeedback group and a control group. The neurofeedback group had 40 x 21min sessions of neurofeedback. Parents of the NF group reported significant improvements in reciprocal social interactions and communication skills. EEG analysis showed 60% of those receiving neurofeedback reduced Theta waves in anterior cingulate cortex (ACC) known to be involved in social & executive dysfunctions in autism. Journal of Neurotherapy.</p> <p>A 2013 study³ compared brain connectivity network analysis derived from the EEG (electroencephalogram) of 11 ASD and 12 control group children under fear, neutral and happy face stimuli. They found Children with autism have a different modularity of such networks from typical children.</p> <p>A 2007 controlled trial⁴ conducted 20 sessions of Neurofeedback for 37 patients with ASD. The experimental and control groups were matched for age, gender, race, handedness, other treatments, and severity of ASD. The NF group had 89% success rate improving ASD symptoms, 40% reduction in core ASD symptomology (ATEC scores), 76% reduction in hyper-connectivity.</p> <p>In a 2002 controlled trial⁵ twenty-four autistic children were divided into two groups, matched by sex, age, and disorder severity. One group received neurofeedback training and the second acted as a control group. The NF group had an ATEC score reduction of 26% on average compared with 3% in control group. Parents reported improvements in all behavioral categories assessed.</p> <p>In a 2009 trial⁶ parents reported improvements in social interaction & communication skills after a group of seven autistic children diagnosed with autism spectrum disorders (ASD) received a neurofeedback treatment that aimed to improve their level of executive control. The NF group showed significant improvements in attentional control, cognitive flexibility & goal setting. This study was followed up⁷ 12 months later and the authors found maintenance of improvement of executive functions and social behavior after 12 months.</p> <p>In a 15-year clinical outcome study⁸ published in 2010, between 40–60 sessions of neurofeedback, combined with training in metacognitive strategies and, for most older adolescent and adult clients, biofeedback, resulted in an average 9 points IQ score increase, decrease in difficulties with attention, anxiety, social functioning plus improved academic and intellectual functioning.</p> <ol style="list-style-type: none"> 1. Coben, R., & Myers, T. E. (2010). The relative efficacy of connectivity guided and symptom based EEG biofeedback for autistic disorders. <i>Applied psychophysiology and biofeedback</i>, 35(1), 13-23. 2. Kouijzer, M. E., van Schie, H. T., de Moor, J. M., Gerrits, B. J., & Buitelaar, J. K. (2010). Neurofeedback treatment in autism. Preliminary findings in behavioral, cognitive, and neurophysiological functioning. <i>Research in Autism Spectrum Disorders</i>, 4(3), 386-399. 3. Jamal, W. et al (2013) Using brain connectivity measure of EEG synchrostates for discriminating typical and Autism Spectrum Disorder. 6th International IEEE/EMBS Conference in Neural Engineering (pp. 1402-1405). 4. Coben, R., & Padolsky, I. (2007). Assessment-guided neurofeedback for autistic spectrum disorder. <i>Journal of Neurotherapy</i>, 11(1), 5-23 5. Jarusiewicz, B. (2002). Efficacy of neurofeedback for children in the autistic spectrum: A pilot study. <i>Journal of Neurotherapy</i>, 6(4), 39-49. 6. Kouijzer, M. E., de Moor, J. M., Gerrits, B. J., Congedo, M., & van Schie, H. T. (2009). Neurofeedback improves executive functioning in children with autism spectrum disorders. <i>Research in Autism Spectrum Disorders</i>, 3(1), 145-162. 7. Kouijzer, M. E., de Moor, J. M., Gerrits, B. J., Buitelaar, J. K., & van Schie, H. T. (2009). Long-term effects of neurofeedback treatment in autism. <i>Research in Autism Spectrum Disorders</i>, 3(2), 496-501. 8. Thompson, L., Thompson, M., & Reid, A. (2010). Neurofeedback outcomes in clients with Asperger’s syndrome. <i>Applied psychophysiology and biofeedback</i>, 35(1), 63-81.

1. Do you agree the guideline should not be updated?	Comments If you disagree, please explain why

2. Do you agree with the proposal to remove these research recommendations from the NICE version and research database?	Comments If you disagree, please explain why
What is the value of a key worker approach (defined by protocol and delivered in addition to usual care) for children and young people with autism in terms of parental satisfaction, functioning and stress and child psychopathology?	Agree / Disagree (please delete as appropriate) Comments on proposal to remove these research recommendations from the NICE version and research database
Is a sleep hygiene intervention or melatonin clinically and cost effective in the management of sleep onset, night waking and reduced total sleep in children (aged 4–10 years) with autism?	
What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?	

<p>Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences – an Alternative Program for Preschoolers and their Parents [LEAP] model) effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in pre-school children?</p>		
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Do you have any comments on equality issues or areas excluded from the original scope?

<p>See above comments on Neurofeedback.</p>

Please email this form to: surveillance@nice.org.uk

Closing date: 5:00pm 1 June 2016

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.