

## 4-year surveillance 2016 – Autism spectrum disorder in adults (2012) NICE guideline CG142

### Appendix B: stakeholder consultation comments table

Consultation dates: 11/5/2016-24/5/2016

Stakeholder	Do you agree with the proposal not to update the guideline?	Comments Insert each new comment on a new row	NICE response
Royal College of Psychiatrists	Agree (with caveats, please see comments)	<p>The RCPsych Autism Spectrum Disorder Group would wish to make the point that, at the time the guideline was published, the evidence available in some areas was very limited and the GDG had to draw on their experience perhaps rather more than was usual in NICE reviews.</p> <p>The field is developing and changing so that fresh evidence will emerge. However, at the present, there is not sufficient change to warrant revising the Guideline.</p> <p>There was concern that five years was a long time and we would suggest that NICE go through a similar consultation in, say, three years to determine whether CG142 should be revised.</p>	<p>Thank you for your comments.</p> <p>In the light of information highlighted through the consultation process, we propose not to transfer this topic to the static list, and the guideline will continue to undergo regular surveillance.</p>
Social Policy Research Unit, University of York		See text below re evidence available from two on-going studies, some of which also applies to this question.	Thank you for your response. The two ongoing studies will be monitored in our trial tracker and the results will be considered when available.

			In the light of information highlighted through the consultation process, we propose not to transfer this topic to the static list, and the guideline will continue to undergo regular surveillance.
Research Autism	Agree		Thank you
Cheshire Area for Cheshire Action	Disagree	<p>Guideline urgently needs to be updated to ensure that during Transition those with both autism and complex learning difficulties are not catapulted willy-nilly into Adult Services, long before they are ready. In stochport (about which I have current information) those reaching 18 years of age but who have both autism and a mental age of 3-4, and who are known to have been both harmed and deprived of adequate formal education, are being pushed into adult services. That might be to their benefit, if it were to be done sensitively, since Stockport's Children and Young People's Disability Services is abysmal, but such children need the steady push towards the age of 25 before such transition actually takes place.</p> <p>Placing the whole overview on hold does no service to such children or to their families.. so I do not agree with the proposal.</p>	<p>Thank you for your comment. We did not find sufficiently robust evidence in the surveillance review to justify updating the area of organisation of care.</p> <p>The recently published NICE guideline <a href="#">Transition from children's to adults' services for young people using health or social care services</a> is relevant to this area and will be included in the <a href="#">Autism pathway</a>.</p> <p>The recently published NICE guideline <a href="#">Challenging behaviour and learning disabilities</a> is also relevant to this area, with recommendations on organisation of care, including transition between services, adapted from the NICE guideline on <a href="#">Common mental health problems</a>. This will also be included in the <a href="#">Autism pathway</a></p> <p>Additionally recommendation 1.8.2 of CG142 states that autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include supporting the smooth transition to adult services for young people</p>

			going through the pathway.
Lincolnshire County Council	Agree		Thank you.

Stakeholder	Do you agree with the proposal to put the guideline on the static list?	Comments	NICE response
Social Policy Research Unit, University of York	Disagree	<p>Insert each new comment on a new row</p> <p>I am PI for an NIHR funded study (The SHAPE project) which is evaluating Specialist Autism Teams (<a href="http://www.nets.nihr.ac.uk/projects/hsdr/131086">http://www.nets.nihr.ac.uk/projects/hsdr/131086</a>). The rationale for this study drew substantially on a recommendation for research on Specialist Autism Teams made in the NICE guidance.</p> <p><b>Stage 1</b> of the study is complete, and we can make available evidence to NICE on the ways different localities have implemented the NICE guidance on Specialist Autism Teams and practices regarding diagnostic pathways, the management of presenting health or social need, supporting self-management, supporting carers and advising/up-skilling other professionals.</p> <p>We have just embarked on <b>Stage 2</b>: an outcomes and costs evaluation of different Specialist Autism Teams with a nested qualitative evaluation. The project is scheduled to be completed in 2018.</p> <p>I would be more than happy to share further</p>	<p>Thank you for your response. The two ongoing studies will be monitored in our trial tracker and the results will be considered when available.</p> <p>In the light of information highlighted through the consultation process, we propose not to transfer this topic to the static list, and the guideline will continue to undergo regular surveillance.</p>

		<p>information regarding this study.</p> <p>-----</p> <p>I am also leading a workstream within an NIHR Programme Grant on 'Improving Outcomes for People with Autism Spectrum Disorders by reducing mental health problems' (Programme lead: Professor Emily Simonoff, Institute of Psychiatry, Kings College London). Using qualitative research methods, this workstream will generate evidence on young adults (and their parents) experiences of mental health difficulties, the factors and processes which appear to affect seeking help with emotional, cognitive and behavioural difficulties which are impacting on their mental well-being or have led to mental health difficulties. This piece of work will be completed mid 2017. Again, more than happy to share further information.</p>	
Research Autism	Agree		Thank you.
Cheshire Area for Cheshire Action	Disagree	See comment above.	Thank you for your comment. See response above.
Lincolnshire County Council	Agree		Thank you.

<b>Stakeholder</b>	<b>Do you agree with the removal of the research recommendations; What is the clinical and cost effectiveness of facilitated self-help for the treatment of mild</b>	<b>Comments</b> Insert each new comment on a new row	<b>NICE response</b>
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	anxiety and depressive disorders in adults with autism?		
Research Autism	Disagree	I am aware that work is under way with biofeedback devices that might come under this heading and which seem promising interventions.	<p>Thank you for your comment. Evidence identified in the surveillance review on biofeedback was insufficient to justify updating the review question on psychosocial interventions for autism.</p> <p>However, in view of the fact that biofeedback can be considered a form of facilitated self-help and is the subject of new and ongoing research, we propose not to remove this research recommendation from the NICE version of the guideline and the NICE research recommendations database.</p>
Cheshire Area for Cheshire Action	??	What 'facilitated self-help'?	<p>Thank you for your comment. In adults without autism facilitated self-help is an effective intervention for mild to moderate depression and anxiety. The development of novel methods for the delivery of facilitated self-help could make effective interventions available to a wider group of people than is currently the case.</p> <p>The suggested programme of research would need to: (a) develop current methods for the delivery of self-help measures to take into account the impact of the autism and possibly include developments in the nature of the materials, the methods for their delivery</p>

			<p>and the nature, duration and extent of their facilitation; (b) test the feasibility of the novel methods in a series of pilot studies; and (c) formally evaluate the outcome (including symptoms, satisfaction and quality of life) in a large-scale randomised trial.</p> <p>In view of the fact that biofeedback can be considered a form of facilitated self-help and is the subject of new and ongoing research, we propose not to remove this research recommendation from the NICE version of the guideline and the NICE research recommendations database.</p>
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<b>Stakeholder</b>	<b>Do you agree with the removal of the research recommendations;</b> What is the clinical and cost effectiveness of cognitive behavioural therapy (CBT) for the treatment of moderate and severe anxiety disorders in adults with autism?	<b>Comments</b> Insert each new comment on a new row	<b>NICE response</b>
Research	Disagree	I am not sure if work is ongoing in this area. From clinical contacts I suspect it is. It may be	Thank you for your comment. No new information was identified at any

Autism		good to find out	<p>surveillance review to answer this research recommendation. Any new evidence will be considered at a future review.</p> <p>The research recommendation will still be retained in the full version of the NICE guideline and on the NICE website.</p>
Cheshire Area for Cheshire Action	??	What CBT?	<p>Thank you for your comment.</p> <p>In adults without autism, CBT is an effective intervention for moderate to severe anxiety disorders. The adaptation of CBT for adults with autism and a coexisting anxiety disorder could make effective interventions more widely available.</p> <p>The suggested programme of research would need to: (a) develop current methods for the delivery of CBT to take into account the impact of autism and the nature and duration of the intervention; (b) test the feasibility of the novel treatments in a series of pilot studies (for the commonly experienced anxiety disorders in autism); and (c) formally evaluate the outcomes (including symptoms, satisfaction and quality of life) in a large-scale randomised controlled trial.</p> <p>No new information was identified in this area at any surveillance review. Any new evidence will be considered at a future review.</p> <p>This research recommendation will still be retained in the full version of the NICE guideline and on the NICE website.</p>

Lincolnshire County Council	Agree		Thank you.
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<b>Stakeholder</b>	<b>Do you agree with the removal of the research recommendations;</b> What is the clinical and cost effectiveness of selective serotonin reuptake inhibitors (SSRIs) for the treatment of moderate and severe depression in adults with autism?	<b>Comments</b> Insert each new comment on a new row	<b>NICE response</b>
Research Autism	Agree		Thank you.
Cheshire Area for Cheshire Action	I disagree	<b>Autism is the way someone sees the world. Drugging them u. for no better reason that 'that they are different' is disgraceful. If they have health needs, over and above their autistic view of the world. That might be a different matter.. but 'because they are autistic'? No!</b>	Depression commonly coexists with autism and is associated with poorer health outcomes and quality of life. This may occur because of the direct impact of the depression but also because of a negative interaction with the core symptoms of autism. There is poor recognition and consequently suboptimal treatment for depression in adults with autism. However, it is probable that when depression is recognised the most commonly used treatment is antidepressant medication as it is an effective intervention for moderate to severe depression. Little is known about

			<p>the extent of the use of antidepressant medication, adherence to prescribed medication and its effectiveness in adults with autism. Moreover, concerns have also been raised about the increased sensitivity of people with autism to the side effects of SSRIs and other antidepressant drugs.</p> <p>The suggested programme of research would need to: (a) describe the current use of SSRIs in adults with depression and autism; (b) review the potential impact of increased sensitivity of adults with autism to the side effects of medication; and (c) formally evaluate the outcomes (including symptoms, satisfaction and quality of life) of SSRIs in a series of randomised controlled trials.</p> <p>No new information was identified in this area at any surveillance review. Any new evidence will be considered at a future review.</p> <p>This research recommendation will still be retained in the full version of the NICE guideline and on the NICE website.</p>
Lincolnshire County Council	Agree		Thank you.

<b>Stakeholder</b>	<b>Do you have any comments on equality issues or exclusions?</b>	<b>Comments</b> Insert each new comment on a new row	<b>NICE response</b>
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<p>Cheshire Area for Cheshire Action</p>		<p>This must take full account of the transitional period, which I understand should take several years – between the ages of 14 and 25 – but is being hurried unnecessarily by Local Authorities m, who are more concerned with costs than aid..as seems to be the case in Stockport.</p>	<p>Thank you for your comment. The issue of transition to adult services is not considered to represent an inequality. We did not identify sufficient evidence in the surveillance review to update the area of organisation of care.</p> <p>The recently published NICE guideline <a href="#">Transition from children’s to adults’ services for young people using health or social care services</a> is relevant to this area and will be included in the <a href="#">Autism pathway</a>.</p>
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