

National Institute for Health and Clinical Excellence

Autism spectrum disorders in children and young people Stakeholder Comments

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Stakeholder Organisation:	Royal College of Psychiatrists: Child & Adolescent Faculty			
Name of commentator:	Dr Helen Fitzpatrick & Dr Clare Lamb			
Order number <i>(For internal use only)</i>	Document	Section Number	Page Number	Comments
	Indicate if you are referring to the Full version of the NICE version or the Appendices	Indicate number or 'general' if your comment relates to the whole document	Indicate number or 'general' if your comment relates to the whole document	<p>Please insert each new comment in a new row.</p> <p>Please do not paste other tables into this table, as your comments could get lost – type directly into this table.</p>

Example	Full	3.4.6	45	Our comments are as follows
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PROFORMAS THAT ARE NOT CORRECTLY SUBMITTED AS DETAILED ABOVE MAY BE RETURNED TO YOU

1	Full	general	general	This is a very comprehensive document which at least attempts to recognise the variety of service contexts within which ASD assessments occur.
2	Full	general	general	There is a need to consider the child and family's language needs in assessment. In Wales, offering a monolingual English medium assessment to a child whose family is bilingual (Welsh/English) is inequitable, and may lead to misdiagnosis, which is the most important consideration. There is currently a lack of staff who have specialist ASD assessment skills and the appropriate linguistic skills. We would recommend that in areas where there is a large bilingual population (such as Wales) that there is a need to have professionals involved in the ASD assessment process who are able to speak the language of the family. This is also important that if the child is bilingual that any assessments done are conducted by professionals who are also bilingual, in order to make an accurate assessment of that child's abilities.
3	Full	general	general	The document assumes a degree of integration of LD/CAMHS and pre-school services and the existence of "ASD teams" when specialist CAMHS services are not necessarily organised in this way. It does not mention fragmentation of services and a potential task of integration of services and streamlining of transitions between services; for example, pre-school to school age.

4	Full	General	General	Overall it is a good read and helpful. The group have thoroughly reviewed what evidence base there is about recognition, referral, diagnosis and given, on the whole, very sensible consensus recommendations where there is limited evidence base.
5	Full	General	1 and 22	Where it says, "...families and carers who may have always known there was something wrong", the wording could be changed from "wrong" to "different" as some people (parents or people with ASD's in particular) may find this more acceptable.
6	Full	1.3	3	Recommendation 1: Agree with the priorities for implementation regarding local pathway for recognition, referral and diagnostic assessment, however, how do we define "local". In North West Wales CAHMS is not involved in this group locally. Too many groups can fragment the service.
7	Full	1.3	4	Recommendation 5: does the document mean to say a "single point of entry" or "single case management system" as multiple access points make a system more accessible? Presumably each member of the ASD MDT would be able to bring cases on behalf of their organisations/services. A single point of entry needs dedicated admin and you can't access it unless you use the single entry point.
8	Full	1.3	4	Recommendation 6: There is a risk of this being only applicable to large centres where an adequate skills base is present.
9	Full	1.3	6	Recommendation 20: The word urgent in a health context implies a high level of risk if something isn't done promptly, often hours or days. It would seem that the meaning is "should always refer without undue delay".
10	Full	1.3	7	Recommendation 29: Would benefit from emphasising the need to involve family/carers/patient in process so "commencing assessment process in a timely manner to a timescale agreed with the family/carer/user" rather than the more directive "without delay."
11	Full	1.3	7	Recommendation 30: Having the three lists is very helpful. However, the section attempts to lower the threshold of recognising possible ASD, which will lead to increased referrals. This has a negative outcome for the child where waiting times for generic assessments are shorter than ASD assessments. The need to rule out other factors needs to be stressed – the drift of the section will allow a significant number of referrals to fit under the ASD pathway.
12	Full	1.3	12	Recommendation 63: Those who diagnose a child may lack knowledge of types of service provision available. Ideally, the person who diagnoses and the person who provides services sit together and have a discussion with the family.
13	Full	General	General	With regard to assessment of older children and young people, the guideline gives limited consideration to the young person's informed

				consent to diagnostic assessment and the implications of diagnosis of ASD, which can cause young people to be excluded from particular courses or occupations; for example, the Armed Forces or police force, as well as suffering stigma.
14	Full	Table Following assessment	21	The resource implications of recommendations are recognised. But there is an emphasis on the role of the teams in monitoring and re-assessment of cases if diagnosis is uncertain, which may be unrealistic with hard pressed specialist CAMHS services where there is an emphasis on throughput of cases eg re-assessing within 6 months. It may be prudent with some cases to draw a line under further assessment and live with uncertainty.
15	Full	Section 2	22-34	Methodology seemed very thorough and investigation extensive
16	Full	Section 3.1.6	40-48	Too much emphasis placed on the benefits of a diagnosis of ASD, to the extent that they seem to recommend erring on the side of giving a diagnosis rather than not where grounds for diagnosis may be marginal. GDG seems to assume that a diagnosis improves the outcome for the child or young person. The benefits of diagnosis may vary from one area of the country to another depending on levels of awareness and knowledge in general public and professionals, what resources are available to support the child, young person and their family, and how accessible services are.
17	Full	general	general	May cause families to have unreasonably high expectations of services that may not be able to provide solutions to ASD or secondary or co morbid behavioural difficulties once diagnosis is given. Giving a label of ASD may reduce compliance of families with interventions which are not directly focussed on or specific to ASD, eg adapted parenting approaches.
18	Full	general	general	In an ideal situation, where professionals in other agencies are well informed, resourced and supported with the management of children and YP with ASD, there are benefits to diagnosis. In some circumstances the diagnosis causes professionals to disagree to an unhelpful extent, leaving families and children caught between professionals in disagreement about whether the child has a developmental disorder. Occasionally diagnosis challenges attributions made by professionals and others about the reasons for children displaying problematic behaviour, eg it is caused by "poor parenting" or "naughtiness".
19	Full	3	35-54	Really helpful that GDG have attempted to identify and describe signs and symptoms that could trigger referral to specialist teams for assessment. This will encourage and help shape referrals to specialist teams for assessment and may reduce the amount of information gathering required for developmental assessment.
20	Full	5		There should be a greater emphasis on broader developmental assessments from the beginning,

				rather than focussing on ASD assessment. This would allow assessment to be broader and formulation more comprehensive rather than whether the child has or does not have a diagnosis of ASD, eg encompass effects of neglect/trauma/abnormal attachments and underlying tendencies to autistic phenotype which become evident in stressed situations. This will help to guide recommendations re intervention Not all children with autistic traits warrant ASD diagnosis or benefit from ASD specific interventions.
21	Full	3.1.6	44	Another common way in which children and young people present is with severe emotional and behavioural difficulties and disorders of conduct.
22	Full	4	48	Recommendations regarding information needed when referring to ASD team will require that the person referring is able and qualified to gather those aspects of information in the written report, eg medical history, developmental milestones etc. This may mean that teams will need to reconsider from whom they accept referrals regarding ASD diagnosis eg may not accept referrals direct from certain agencies, eg Social Worker or SENCO but maybe from primary health care services. Implies that referrals need to be through a professional able to gather this information, eg Community Paediatrician, GP, specialist CAMHS clinician. These matters presumably need to be considered by the individuals developing multi-agency pathways and incorporating medical screening to pathway.
23	Full	5.5	85-88	It is of note that the general agreement of an individual clinician and the MDT is moderate. The argument that an MDT provides a more thorough assessment is undeniable and clearly the individual needs to be appropriately skilled and linked to any ASD MDT but would be interested in others views as many families may be happy with this and it would appear to be a more rational use of a limited resource. The discussion regarding this point was not compelling!
24	Full	7	129	When asking "which are the common coexisting conditions that should be considered as part of assessment?", PTSD, attachment driven behaviours and epilepsy need to be mentioned.
25	Full	10.1 table	185	Really helpful that the GDG looked at the time spent carrying out ASD assessments, as this may help guide capacity and demand calculations. This summary helpfully describes the various facets of assessment and the resources required to make assessments valid. It will be helpful to clinicians on teams assessing ASD as a rough guide to average length of assessment. However, it would be helpful to calculate from the estimates, in table 10.1 to 10.5, the average hours of clinicians' time to conduct an ASD assessment.
26	Full	10.1	185	The average time for assessment may be affected by the experience of the teams, their level of

				integration and access to facets of assessment eg SALT, as well as their thresholds for diagnosis. This is worth a mention somewhere.
27	Full	Appendix K	238 onwards	Good idea to attempt to tease out factors that may assist in differentiating other conditions from ASD, however, there is considerable overlap and many grey areas which call for clinical judgement of overall presentation, history etc. Section on Conduct Disorder over simplifies the distinction between Conduct Disorder and Autistic Spectrum Disorder, ie think that sometimes young person with ASD can be antisocial with behaviours and not concerned regarding other emotions. May not be distressed by the impact of their behaviour on others emotions.
28	Full	Appendix K	245	Section on OCD. In ASD, a young person can be distressed by OCD symptoms.
29	Full	Appendix K	243	Section on attachment disorders. Children with attachment disorders can show delay in social development including non verbal aspects in communication and may not necessarily be avoidant in nature. Children with attachment disorder can have delayed development of play, intense interest in objects, may not show rapid progress in a more nurturing environment. Also may not be able to place the child in a more nurturing environment to see how they change.
30	Full	Appendix K	244	A possible omission from this section is that children with ASD and children with attachment difficulties and Oppositional Defiant Disorder can show emotional outbursts/emotional dysregulation. In Oppositional Defiant Disorder, outbursts can be caused by feeling overwhelmed by angry /upset feelings related to being thwarted or disciplined. In ASD, triggers may relate primarily to ASD type difficulties, such as insistence on sameness, sensory sensitivity, and high anxiety in relation to a social difficulty.

Please add extra rows as needed

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

Closing date: 5pm on 25 March 2011

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