National Institute for Health and Clinical Excellence

Autism in children
Guideline Consultation Comments Table
28 January - 25 March 2011

Comment No	Type	Stakeholder	Order No	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1.	SH	Association for Family Therapy and Systemic Practice (AFT)	4	NICE	6	34	Suggest including these NICE guideline: Looked After Children	Thank you for your comment; we have now added a reference to this guideline to the introduction to the full guideline and the 'Related NICE guidance' section of the NICE version.
2.	SH	RCN	2	NICE		5	**Patient-centred care** - we support the view that information patients are given about recognition, referral and diagnosis of ASD should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or intellectual disabilities, and to people who do not speak or read English. Families and carers should also be given the information and	Thank you for your comment. We have also highlighted this important point to the translation of the evidence to recommendations in chapter 9.

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							support they need. This is important!	
3.	SH	SCIE	2	NICE		5	Good communication – written information may not always be the best option for a child or young person or for people with additional needs. Please allow for age and needs appropriate as well as culturally appropriate information	The GDG agrees with this view. Section 2.1.7 of the full guideline explains the ethos of the GDG which is that: "Treatment and care should take into account the needs and preferences of children, young people and those who care for them." It is the GDG's view that the taking into account the child or young person's age is embedded within the concept of need and preferences since these are determined by a child or young person's ability to understand and respond to information.
4.	SH	Association of Child Psychotherapists	1	NICE	Intro	3	We are in agreement that "a diagnosis of ASD can bring a sense of relief to some young people, families and carers who may have always known there was something wrong". However, the guidance also needs to acknowledge the potential for families to find a diagnosis deeply distressing. Parents of a child under five, for example, may be shocked by a diagnosis of ASD when they had thought their child faced only a difficulty with language development. Additionally, while	Thank you for comment. The GDG agree with your point and the introduction has been expanded to make this explicit.

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							there may be a sense of relief for some families at the initial diagnosis, the subsequent realisation of the implications of the diagnosis may be distressing. The shock of diagnosis can lead parents to disengage with therapeutic and other kinds of interventions, and to a distancing from the child, at a time when parents' active engagement is desirable. It would be valuable for the guidance to take into account the potential for the diagnosis to be traumatic so that the diagnostic process can be adjusted in order to help parents to take in and understand what is being said. Families from some ethnic minority backgrounds may have no word in their first language for autism and the concept may in some cases be alien.	
5.	SH	Association of Child Psychothera	2	NICE	Intro	3	In our view, the importance of feeding back sensitively to parents the results of the	Thank you for your comment. The GDG agree with your view and have added to their recommendation about discussing the diagnosis that this should be done 'sensitively'.

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		pists					diagnostic assessment cannot be stressed enough. This cannot be viewed as a tick box exercise, but a tumultuous acknowledgement that their child is on a developmental pathway that is likely to draw on every resource within the family. It would be helpful for the guidance to recommend that work be undertaken to ensure that the diagnostic process helps parents to take in the facts and to process the emotional impact of the diagnosis in order that children and families can make the best use of services offered to them (we welcome the acknowledgement of some of these points in 1.2.11 and 1.2.12).	
6.	SH	Royal College of Paediatrics and Child Health	12	NICE	Introduction	3	Regarding the statement, "A diagnosis of ASD can bring a sense of relief to some young people, families and carers who may have always known there was something wrong". We note that "relief" is true, but also sadness and mixed emotions.	Thank you for comment. The GDG agree with your point and the introduction has been expanded to make this explicit.

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7.	SH	SCIE	1	NICE	Intro-duction	3	Para 1 Please include social services as a source of support	Thank you for your comment. The introduction to the full guideline paragraph 1 has now been amended to include reference to social care.
8.	SH	Association of Child Psychotherapists	3	NICE	Patient-centred care	5	We welcome the statement that treatment and care should take into account the needs and preferences of children, young people and carers. One of the most frequently stated wishes of carers, according to research undertaken by the staff of the Children's Commissioner, is more ready access to CAMHS provision.	Thank you for your comment.
9.	SH	Association of Child Psychotherapists	4	NICE	Patient-centred care	5-6	We welcome the recommendation that transition from child to adult services should be planned and managed according to best practice guidance. This transition can be profoundly difficult both for young people and for carers.	Thank you for your comment
10.	SH	Association of Child Psychotherapists	14	NICE	2.0	30	Accepting the limits of the intentions of the guidelines and that its scope does not include guidance on ongoing management, it would be helpful	We recognised the importance of outcome and continuity. While this guideline is intended to focus strictly on diagnostic assessment various recommendations do consider this aspect. The importance of including profiling in the assessment is a central recommendation, and is intended to facilitate individual support following the diagnostic

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							to have some recommendations for good practice with respect to ongoing care for what is defined as a lifelong condition. Otherwise the diagnostic model advocated (separated as it is from a treatment/intervention process) could come across as making a massive disruption into families' lives, with no clear cut outcome or recommendation for continuity.	assessment. There is a recommendation on offering a follow-up appointment 6 weeks after assessment to address concerns. There is a recommendation to provide information on the support available locally. There is a recommendation that information be provided to help prepare for the future.
11.	SH	Peach	2	NICE	4 Research		Just a comment to say we agree and are currently in talks with Dr *Christos* K. Nikopoulos at Brunel University about researching the long term cost effectiveness of Applied Behaviour Analysis for children with ASD in the UK. A similar piece of research in the US showed that at least $2million could be saved in child and adult costs combined if ABA was used. Jacobson, Mulick and Green 1998 http://cchs.org/pdf/contentmgmt/DOCUMENT.PDF	Thank you for your comment. Although the scope of this guideline did not include therapeutic management, this may be covered in the upcoming guideline on the management of ASD in children and young people.
12.	SH	Optical Confederatio	1	NICE	General		The Optical Confederation works closely with charities such	Thank you for all your comments.

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		n/ LOC Support Unit			al		as SeeAbility who provide specialist services for people with learning disabilities, acquired brain injury, cerebral palsy, and epilepsy. The vast majority of the people they support also have a visual impairment and, although more prevalent in certain groups e.g. people with learning disabilities, this has often been previously undetected in such people, adding to their sense of isolation and frustration. It is crucial that staff working with people with sight loss and autism, are able to use effective and individualised strategies. SeeAbility also regularly host training and awareness courses to enable staff to have a better understanding about autism and sight loss to equip them with the necessary knowledge and tools to support individuals. The Local Optical Committee Support Unit (LOCSU) is currently developing a pathway	

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							for a specialist sight testing service for people with autism. This will ensure that people with autism have good vision, do not suffer from refractive error and that any sight-threatening problems are detected and treated early. Many people with autism may require longer appointment times, several visits to the optical practice to become familiar with the environment and may need longer with the optometrist so that the results of the eye examination can be explained. We are willing to work with NICE, the Department of Health and the NHS Commissioning Board to commend to GP commissioning consortia the early adoption of the LOC Support Unit pathway for people with autism. We recognise that people with an ASD face challenges with: • Communication • Invasion of personal	

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							space • Disruption of routine • Introduction of strangers • Introduction of equipment All of these challenges will cause difficulties with normal communication and exam routines. However, with time, patience and training, they can all be overcome. At present, there is no provision for any of these examinations in the General Ophthalmic Services contract. People with ASD, or any other disability for that matter, have an equal right to regular and comprehensive eye care as any other (Disability Discrimination Act and the Equality Act 2010). As recommended by the National Autistic Society, a person with autism should plan an informal trip prior to their optical practice before the actual	

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							examination occurs. The involvement of the health professional at these times is extremely useful, in order that the person with an ASD can get to the optician, become accustomed to the room and any equipment, e.g. special chair, eye glasses. Another option might be to allow a child with an ASD to watch while a sibling is being treated so that subsequent appointments will not be such a shock. The advice of the patient's carer will help to inform this approach. As with injections, a doll could be given 'treatment' e.g. a quick eye test, dental check. It is also a good idea to book a double appointment so that things can be taken at the patient's pace. More information is available	

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							here: http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx	

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13.	SH	Optical Confederation/ LOC Support Unit	6	NICE	General		Statistics suggest 30% of people with learning disabilities have visual impairment and 40% have hearing impairment. Therefore both vision and hearing should be investigated. Perhaps stating that "there should be tests of sensory function, such as vision and hearing".	Thank you for your comment. The GDG agree with this point. The GDG have now amended their recommendations to make it clear that if vision and hearing assessments have already been carried out, then the results should be sought by the ASD team prior to the diagnostic assessment. Severe vision and hearing impairments are also included in the recommendation that lists important differential diagnosis to prompt clinicians to carry out assessments if they have not already been undertaken.

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14.	SH	Royal College of Paediatrics and Child Health	1	NICE	General		We note that a consultant paediatrician working in mental health and complex care regularly sees children referred by general paediatric colleagues with 'odd' behaviour. About one-third of these have ASD. Most of those have gone unrecognised for some years. The tables of behaviours listed would help colleagues identify this group of children and young people much earlier and make an appropriate referral. The College thinks this guideline, if properly implemented, will improve recognition, referral and diagnosis of ASD.	Thank you for your comment.
15.	SH	Royal College of Paediatrics and Child Health	2	NICE	General		In general this guideline appears very useful and to have been well-researched. While we note you were not specifically asking for comments on the feasibility for implementation, we believe that the services described are particularly well-resourced and are unlikely to reflect the usual	Thank you for this comment. The service descriptions included for illustration only. In order to deliver the guideline recommendation for an integrated multidisciplinary assessment of ASD, services will need to offer a similar level of service.

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							NHS service in most districts. We think this may have implications on workforce.	
16.	SH	Royal College of Paediatrics and Child Health	3	NICE	General		The guideline seems to assume under diagnosis of ASD. Is this one of its intended messages? It is not very clear about the importance of core social difficulties in a list of possible symptoms.	Thank you for your comment. Under diagnosis is not an intended message. However, the GDG consensus is that any child or young person where there is sufficient concern should be considered for referral for ASD and the guideline could identify unmet need for assessment if it exists. The importance of core social difficulties is further emphasised now in the introduction to the full guideline. The table of symptoms and signs is of course intended to be relatively comprehensive and includes many potential pointers including numerous examples of social difficulties. We have revised the tables in light of all stakeholder comments for clarity and usefulness.
17.	SH	Royal College of Paediatrics and Child Health	4	NICE	General		The lists of other conditions to be excluded or considered are repetitive and this does not help.	Thank you for your comment. The list of coexisting conditions differs from the list of differential diagnoses and even though there is overlap. We think it is important to list the separately because health care professionals will use the lists differently.
18.	SH	Royal College of Paediatrics and Child Health	5	NICE	General		We think the guideline covers all the points in the initial scope in a very comprehensive and easy to read manner, particularly with the following:	Thank you for your comment. In relation to your final point the GDG have now clarified in their recommendation that the strategy group should include 'managerial, commissioner and clinical representation'.

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							1. The choice of the term ASD rather then PDD. 2. The recognition that good clinical assessment and judgement are often enough for a diagnosis of ASD. 3. The recognition that it is often necessary to liaise closely with other agencies. 4. The recognition of the need for a local ASD strategy group. These groups, however, need to include the practitioners who are actually running the services. Strategy groups exist already in some places, but they include only top managers and executives who know very little about the reality of service provision at ground level. They often go on	

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							meeting now and then, discussing issues they barely understand in an abstract and detached manner, without any concrete and practical outcomes. Managers and executives are, of course, essential in this process to help with business and administrative matters and to provide financial support. They must be guided, however, by those delivering services, who actually have the knowledge and the expertise to know what is needed and what works better.	
19.	SH	Royal College of Paediatrics and Child Health	6	NICE	General		We feel that organisation of autism services, from detection to intervention, needs to follow a multi-agency approach. This is because: 1. The number of children of all ages needing	Thank you for your comment. The GDG acknowledge that a multi-agency approach central to the care of children and young people with suspected or known ASD. There are recommendations to encourage joint working. Specifically, the GDG have been amended their recommendations to indicate that the local strategy group should be multiagency. The core ASD team could be multidisciplinary as these professionals are located within the NHS.

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							diagnostic and intervention services for ASD is such that no one agency alone can bear the costs singlehanded. Joining expertise and resources makes a lot of sense, both in terms of financial costs, quality standards and speed. 2. Except in very young children, most referrals to health come from nurseries and schools where the problems are often noticed first or become more obvious. In these situations, education services and professionals are involved much before referral to health services. Their initial approach and the quality of information they send when referring these children for medical assessment	We agree that much of the support for those with ASD will come from education and that continued multi agency working is vital. Further consideration of this will we hope be in the management guideline.

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							can play an important role in the quality and speed of diagnosis. We are pleased to see that research into this area has been considered in the guidelines. 3. Regarding intervention, apart from the initial stages after diagnosis, children are mostly supported and managed in educational settings. This can be for the whole of their school life. We are aware that these guidelines do not cover intervention but this is just one more argument for multiagency approach.	
20.	SH	Royal College of Paediatrics and Child Health	7	NICE	General		Large chunks of text are repeated in different sections. We are not clear why this is necessary.	Thank you, we have removed repeated text where this has been identified in the editing phase.

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21.	SH	Royal College of Paediatrics and Child Health	8	NICE	General		We understand that NICE guidelines can only focus on medical services, so, while its advice to the medical diagnosis of ASD is invaluable, it may not be the ideal organisation to advise on a well co-ordinated multiagency approach to ASD services that is desperately needed. The National Autism Plan for Children published in 2003 was extremely useful at the time, but needs revision and update. Following these medical guidelines, we would like to propose that a multiagency group be assembled to discuss and provide recommendations for a truly integrated service model for ASD including detection and pathways for referral, assessment, diagnosis and intervention.	Thank you for your comment. The GDG acknowledge that a multi-agency approach is central to the care of children and young people with suspected or known ASD. There are recommendations to encourage joint working. Specifically, the GDG has amended their recommendation to indicate that the local strategy group should be multiagency. The core ASD team could be multidisciplinary as these professionals are located within the NHS.

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22.	SH	Royal College of Paediatrics and Child Health	9	NICE	General		We think this is a most useful document considering the quality and detail of clinical advice in all three areas of recognition, referral and diagnosis. We are certain that it will be of great help to anyone starting to work in this area. For more established services and paediatricians it is possibly a little disappointing, maybe because our expectations were incorrect to start with. We were hoping for more specific advice in terms of: 1. Best formal assessment tools – We agree that formal assessment is not always required or advisable but, if it is necessary, it would be useful to have some evidence-based advice on which of the existing tools is more adequate (in terms of time,	Thank you for your comment, the GDG considered the accuracy of diagnostic tools in the review of the evidence and concluded that there was insufficient evidence to support any specific recommendations. There is a summary of the tools in appendix J to give professionals guidance about these instruments addressing the aspects you mention including user friendliness and time. The GDG agree with your concern about the needs of children who do not meet the diagnostic criteria but have autistic traits. They have clarified in the Introduction the dimensional nature of the ASD spectrum. They also indicated that there may be children who have features of behaviour in the autism spectrum who do not meet criteria for a diagnosis of ASD but who nevertheless may both find the discussion of those characteristics helpful and may have needs identified during the profiling assessment which will also be helpful for intervention. The GDG has also made a recommendation to ensure that children and young people who fall into this category receive appropriate care. The GDG reconsidered the issue of time frames and where possible have provided guidance about the appropriate intervals between key stages in the pathway. These timeframes are based on parental concerns and clinical consensus about what constitutes a good service. Where timeframes have not been provided it is because there was a specific clinical rational for not doing so, e.g. for completion of assessments as this depends of the individual profile of the child or young person. It was beyond the scope to make specific recommendations about the

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							accuracy, user friendliness). 2. Some clarification or, at least, some discussion around borderline cases and cut-off points - This is one of the most difficult areas at present and many children who fall in this 'no man's land' often suffer the most. This is due to lengthy and repeated assessments which often end up with 'does not fulfil criteria' or receive a diagnosis of PDDNOS, none of which is particularly helpful in terms of future intervention. 3. Time targets and advice on number of professionals required per population – In the NHS and especially in children with disability	number of professionals needed per population as this will depend on local service configuration and individual clinician's expertise and experience. However the introduction has been expanded to include some guidance as follows: "Current prevalence rates in districts suggest between 1.5 and 2% of children are diagnosed with ASD from a referral percentage of approximately 3% of the population. In a district with a birth rate of 5000 per year, this equates to 3 referrals per week for query ASD requiring diagnostic assessment and profiling by the multidisciplinary team."

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							services, it has always been difficult to convince managers and commissioners of the need for more resources. These days it is virtually impossible. They will only respond to mandatory targets or very expert advice. NICE, as an NHS organisation, carries a lot of weight in local organisations, so specific advice on time intervals and numbers of professionals per population would lend strength to the arguments of local clinicians for better services.	
23.	SH	Royal College of Paediatrics and Child Health	10	NICE	General		We think that not enough is made of the important distinction between *diagnosis* of ASD and *assessment* of developmental / emotional / physical needs. The first is quite often quite straightforward- the finding that	Thank you for your comment. The GDG acknowledge that the draft recommendations did not say that arriving at a diagnosis of ASD does not constitute a complete diagnostic assessment. The 'key elements' of the diagnostic assessment now includes a profile of individual strengths, skills, impairments and needs. This would not be complete without input from a multidisciplinary team, the minimum constituency of which has also now been clearly defined in the recommendations.

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							a single experienced clinician **can** make the diagnosis alone should be brought from the full version guideline into the NICE version. It is completely right to insist on a multi-professional *assessment of need,* however. We think that given the complexity of the work involved in the detection and diagnosis of the comorbid conditions listed, it is a mistake to call the team 'the autism team'. This puts the cart before the horse, and diagnosis before assessment. The team should be a broad neurodevelopmental team, capable of diagnosing the co-morbidities just as well as ASD. The role of an autism team should be local leadership on ASD issues/ interventions.	The GDG recognise that the members of the ASD team may also be members of other teams, (neurodevelopmental, CAMHS, community paediatrics, education), and have taken care not to imply otherwise in their recommendations. This has been made explicit in the corresponding translation.
24.	SH	Royal College of Paediatrics and Child Health	11	NICE	General		We would like more guidance on a timeframe from ASD referral to actual assessment & diagnosis.	Thank you for your comment. We have proposed that the diagnostic assessment must be started within three months of referral. Most importantly, we have stated that the child's or young person's and families needs must be met throughout the process of diagnostic assessment. The GDG did not consider that it was appropriate to give a timeframe for the completion of the diagnostic assessment because

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								the length and number of the assessment would vary according to the child or young person's individual profile.
25.	SH	Association of Child Psychotherapists	15	NICE	General		The emotional well-being of the team whose work is to deliver difficult diagnoses may need to be thought about so that ways of avoiding thinking about very painful issues do not become part of its functioning. Team training is important for this, and this may include, alongside training in the diagnostic process itself, a consideration of team dynamics and the effect on team members of delivering 'bad news' without necessarily having the opportunity to follow through with the family.	We agree that this is an important consideration and part of MDT team training for any health service team.
26.	SH	Association of Child Psychotherapists	16	NICE	General		Finally, we are concerned that these guidelines should not appear unduly negative, with corresponding effects on the families who will be affected by them. The focus is on developing fine-tuned diagnostic procedures including the choice of appropriate instruments which inevitably focus on what ASD children and young people	Thank you for your comment. The GDG agree that the diagnostic process can help to identify the child's strengths as well as their needs and have specified that their strengths should be highlighted in a profile that can be used to create a needs based management plan.

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							cannot do and on those things that differentiate them from other children. It might be helpful to include, for example, in the opening paragraphs (p3) a further sentence on the importance of identifying children's strengths, and about how much more ASD children may be able to achieve with appropriate intervention.	
27.	SH	Autism in Mind	1	NICE	General		Autism In Mind (AIM) welcomes guidance on the development of a pathway for the recognition, referral and diagnosis of Autism Spectrum Disorders in children and young people. We agree that a diagnosis can bring relief to families because it confirms that the young person's developmental difficulties are not the result of bad behaviour or poor parenting.	Thank you for your comment. This view is incorporated in the introduction referring to the benefits of diagnosis.

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28.	SH	Autism in Mind	2	NICE	General		The title of the guideline refers to 'Autism Spectrum Disorders' (plural) but throughout the document ASD is referred to as a single disorder. We understand that for the forthcoming fifth edition of the Diagnostic and Statistical Manual (DSM-V), it is proposed that Asperger's Disorder will not be included as a separate diagnosis and we assume this is why Asperger's Disorder is not referred to in the guidance. Parents have told AIM that children and young people diagnosed with Asperger's Disorder are often intelligent and have no obvious language problems, and that prior to diagnosis their autistic characteristics are often	Thank you for your comment. Autism spectrum disorder (ASD) is the term used to describe all the subgroups incorporated in the ICD and DSM PDD definition. The guideline inconsistencies have been removed. The introduction refers to the new ICD and DSM proposals. Asperger syndrome is incorporated in the ASD group. We have also made clear that absence of language delay and high intellectual ability are not exclusions for an ASD diagnosis but may make such diagnosis more difficult.

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							overlooked. AIM is concerned that children and young people at the high-functioning end of the autism spectrum could fail to be referred for diagnosis and that this could mean they miss out on much needed support.	
29.	SH	Ambitious about Autism/Autism Alliance	3	NICE	General		There is mention of sharing information widely to ensure the best educational outcomes for children with ASD. Ambitious about Autism would like the guidelines to reflect more strongly the pivotal link between health professionals and schools and just how vital establishing this relationship is to a child's education. This may be something that NICE would like to reflect in the forthcoming guidelines on management of ASD in children and young people.	The GDG agree that this is an important aspect and advocate sharing information on the diagnostic assessment with key professionals including those in education in their recommendations.
30.	SH	Ambitious	5	NICE	Ge		In order to ensure equal	The guideline is unable to signpost specific sources of information as

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		about Autism/Autism Alliance			neral		opportunities for patients, Ambitious about Autism would like the guidelines to contain signposting for parents to information on available support and advice as well as their legal entitlements once they have a diagnosis.	this may become out of date very quickly. It does recommend that such information is always offered to all young people, families and their carers during diagnostic assessment.
31.	SH	British Psychological Society	1	NICE	General		In general this is a very clear and helpful document that will be useful to clinicians, service managers and people with Autism Spectrum Disorder (ASD) and their families. The implementation of these guidelines will undoubtedly improve the assessment and diagnostic services to children and young people with ASD, and it would be helpful to see this extended along the care pathway to intervention and support.	Thank you for your comment.
32.	SH	British Psychological Society	2	NICE	General		Given the lifelong nature of ASD it seems unfortunate that the guidance did not address assessment and diagnosis in adults with ASD.	Thank you for your comment. The assessment and diagnosis of adults with ASD was beyond the remit of this guideline. NICE is currently developing an ASD guideline for adults in conjunction with the National Collaborating Centre for Mental Health. More details can be found on the NICE website.

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33.	SH	Airedale NHS Foundation Trust	1	NICE	general		We felt the document was extremely comprehensive	Thank you for your comment.
34.	SH	Airedale NHS Foundation Trust	2	NICE	general		We felt the guidelines were robust and appropriate	Thank you for your comment.

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35.	SH	Optical Confederation/ LOC Support Unit	2	NICE	General	3	Mention is made of "severe visual impairment" in paragraph 1, which is good, but paragraph 2 "After the ASD diagnostic assessment" discusses strengths, skills and impairments as well as communication etc. Difficulties in all of these areas may be caused by undetected visual problems and hence, to avoid diagnostic overshadowing, an assessment of visual function should be made before assuming any of these problems relate to ASD.	Thank you for your comment. It was the GDG's view that because routine hearing and vision testing is standard practice in child health services it was unnecessary to write a specific recommendation to say that these should be done as part of an ASD diagnostic assessment. The GDG agree that knowing whether the child or young person had a vision or hearing impairment was essential as it may affect interpretation of signs and symptoms of ASD though so have made it clear in recommendations that if vision and hearing assessments have already been carried out, then the results should be sought by the ASD team prior to the diagnostic assessment. They have also identified severe vision and hearing impairments in the recommendations that lists important differential diagnosis to prompt clinicians to carry out assessments if they have not already been undertaken.

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36.	SH	Autism in Mind	3	NICE	General	3	The meaning of the sentence '*autism is the classical disorder in the autism spectrum'* is unclear. Since a child with Asperger's Disorder has a very different profile and very different needs to a child with low-functioning autism, some clarification of the definitions used in the guidance would be helpful.	Thank you for your comment. The guideline is concerned with ASD, not autism and this phrase has been removed to avoid confusion.

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37.	SH	Autism in Mind	5	NICE	General	3	Many children have autistic traits without meeting the criteria for a formal diagnosis. These children need support for their difficulties too. We are concerned that a focus on diagnosis might detract from the identification of the specific difficulties encountered by individuals.	Thank you for your comment. The GDG agree with your point and have made a new recommendation to highlight that children who do not meet the criteria for diagnosis should be referred to appropriate services by the ASD team if their profile indicates needs.

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38.	SH	Autism in Mind	6	NICE	General	3	The guidance is unclear as to how a diagnosis can help ‘*get support from education, health services and voluntary organisations*’. Help should be available from education and health services according to the child’s needs, regardless of diagnosis. A lack of diagnosis should not act as a barrier to support. This is particularly important in the case of children whose developmental characteristics do not fit clearly into any diagnostic category.	Thank you for your comment. The GDG have now added recommendations to make clear that children referred for an ASD assessment but do not receive a diagnosis of ASD may have needs anyway and should be referred on to appropriate services by the ASD team.

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39.	SH	Autism in Mind	7	NICE	General	3, 11, 29, 33	The guidance acknowledges that autistic traits often appear only when the child starts nursery or school, recommends that the child is observed in an educational setting (eg:1.1.4, 1.8.9) and also recommends research into the effectiveness and cost effectiveness of doing so (4.4). AIM has been contacted by many parents who have chosen to educate their child with an ASD at home, either because they do not feel that the child could learn effectively in a nursery or school environment, or because they have found that their child’s school or nursery has not been able to provide the support their child needs in order to learn. Although the numbers of children with autism being educated at home is difficult to determine, Parsons &	Thank you for your comment. The GDG agree with your concerns about including children who are educated at home. The recommendation about what to do if there are discrepancies during the diagnostic assessment has been amended to include observations at home and the recommendation about what should be included in the ASD diagnostic assessment now includes experiences of home life to emphasise that some children are predominantly cared for in a home environment.

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							Lewis (2010) report that 7% of parents contacted for a survey on parental views on schooling children with SEN reported that they were educating their children at home, and almost 50% of this sample indicated that their children had autistic traits. Parents have reported that their decision to educate their child at home has been seen as: A possible indicator of maltreatment - the parent is trying to hide maltreatment by keeping the child out of school Neglect - school is seen as the only route to access support An attachment issue - the parent is overprotective and does not want the child to become	

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							independent The cause of the child's behavioural issues because too much time is spent with the parent. AIM recommends that the guidance should include a paragraph on home education pointing out that: Home education is an option that is both legal and viable It is often the only setting in which an autistic child can learn effectively Home education can sometimes mask/reduce the severity of a child's autistic characteristics because the child is in a	

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							comfortable and familiar environment Home education should not be a barrier to diagnosis Home education should not be seen as a concern warranting further investigation. Some parents have reported to us that much of their appointment time with health professionals is spent explaining and defending their choice to home educate. Reference: Parsons, S. and Lewis, A. (2010). The home-education of children with special needs or disabilities in the UK: views of parents from an	

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							online survey. *International Journal of Inclusive Education*, 14,1464-5173.	
40.	SH	Autism in Mind	8	NICE	General	3	'*Coordination between health agencies and other key services such as education, social services and the voluntary sector is important'*. AIM agrees wholeheartedly with this statement. Unfortunately, ASDs, and indeed many other developmental disorders are not well understood in many key services, and high quality training will need to be put in place before guidance for health agencies can be effective.	Thank you for your comment. The GDG were unable to make specific recommendations about the competencies of professionals as this was excluded from the scope. However, they have recommended the formation of a local strategy group whose responsibilities include improving early recognition of ASD by raising awareness of signs and symptoms through training
41.	SH	Autism in Mind	9	NICE	General	5	AIM welcomes the recommendations for patient-	Thank you for your comment, the GDG recognises that importance of appropriate communication with children and young people who are undergoing assessment for ASD. They have now amended their

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							centred care. However, in our experience, guidance designed for all patients is not always appropriate for specific groups, such as children with ASDs. *'Children and young people with ASDs and their families and carers should have the opportunity to make informed decisions about their care and treatment in partnership with their healthcare professionals.'* *'Good communication between healthcare professionals and children and young people is essential.'* One parent reported that her 12 year-old son, with a diagnosis of an ASD, has great difficulty answering questions, particularly abstract ones, but health practitioners have frequently	recommendations to make clear that professionals should discuss with parents and carers, and when appropriate children and young people, how best to communicate and always take into account the child's age and ability to understand.

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							asked him how he feels about his life, education and/or developmental condition. This has introduced considerable confusion and distress into what would otherwise have been a straightforward medical assessment. The parent has expressed concern about what will happen when her son is 16 and is expected to manage his healthcare himself. AIM recognizes that not all parents know what is best for their children, but we feel that most parents know their children best. We recommend that the guidance should include a specific requirement for practitioners to ask parents how best to communicate with the	

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							child before the child is assessed.	

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42.	SH	Autism in Mind	10	NICE	General	5	*‘Families and carers should also be given the information and support they need.’* AIM welcomes this statement, but notes that parents have reported significant problems with professionals not having a good understanding of autism and information and support not being available due to lack of personnel or resources. It would be helpful if the guidance could clarify what kind of support families and carers can reasonably expect.	Thank you for your comment, the GDG has made a recommendation that provides guidance on what should be available for every child or young person. It is also part of the case coordinators role that they should ensure the provision of information and support.

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43.	SH	Autism in Mind	11	NICE	General	9, 1.6.4	AIM supports the recommendation that an individual profile and needs-based management plan be developed for each child. Since children with autism spectrum disorders vary so widely, we feel that this is a better use of resources than focusing on a formal diagnosis.	Thank you. This comment reflects the concerns of the GDG. The recommendations on developing a profile of a child or young person's strengths and weaknesses regardless of eventual diagnosis are designed to address this issue.
44.	SH	Autism in Mind	15	NICE	general	general	Autism In Mind welcomes moves toward the identification and support of children and young people with Autism Spectrum Disorders. However, we have concerns that a focus on diagnosis could have some undesirable outcomes, namely: A focus on diagnosis of ASDs as a single disorder could give the	Thank you for your comments. The guideline considers ASD as a range of disorders and this has been clarified in the Introduction. The acronym ASD used throughout the guideline refers to 'disorders' (plural) and this has been made clear in the glossary. The GDG recognise your concern that those who do not receive a diagnosis should not be overlooked and have tried to mitigate against the risk of this occurring by incorporating the development of an individual profile into the key elements of the diagnostic assessment and adding two new recommendations which make explicit that those who do not meet the criteria for ASD may have needs anyway and should be referred on to appropriate services by the ASD team.

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							impression that all children and young people diagnosed with ASDs have the same fundamental characteristics and need for support. This is far from being the case. A focus on diagnosis, as distinct from profiling the developmental and medical problems experienced by the individual, could result in children who do not meet any diagnostic criteria being assumed not to have a developmental disorder. A focus on diagnosis could lead to support being dependent on a diagnosis. Since a diagnosis of ASDs is not conclusive, children and young people could be denied much-needed support as	The guideline includes specific recommendations which are now clearer for the ASD team to produce a written report which, with consent, should be shared with other professionals to develop a needs based management plan. The GDG agree with your concerns about including children who are educated at home, they have amended the recommendations to include observations at home in situations of uncertainty and the recommendation about the components of the diagnostic assessment now includes experiences of home life to emphasise that some children are predominantly cared for in a home environment. The GDG support the idea of joined up working but were limited by the scope of the guideline to making recommendations about diagnosis. A new children's guideline on management is now in preparation which should address these concerns. The GDG acknowledge your final point and have now decided to give more precedence to the profiling process by incorporating into the key elements of the diagnostic assessment recommendation. Also the recommendations now requires the health care professional to consider whether to keep a child under review if the diagnosis is uncertain as continued pursuit of definite diagnosis may not always be of value. As stated above the GDG have also made new recommendations to ensure that needs are met for all children regardless of diagnostic outcome.

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							a consequence. A focus on diagnosis could lead to inadequately resourced health-care providers developing a diagnostic pathway that conforms to the guidance but overlooks children's medical problems and is unable to ensure that appropriate social care and educational support are in place. A diagnostic pathway which includes observation in formal educational settings only will put children being home-educated at a disadvantage. Home education should be included as an alternative setting and recognized as an appropriate learning environment for some	

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							children with ASDs. We recognize that support has to start somewhere, but we are concerned that a pathway only for diagnosis cannot ensure the 'joined-up thinking' and co-operation that are so necessary for the support of all of the child's needs. Although it might be useful to identify the child's developmental difficulties as an autistic spectrum disorder, we do not feel that there is any point expending significant resources on attempting to reach a conclusive diagnosis. We feel that what would be more helpful would be the development of an individual profile for each child	

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							recommended by the guidance.	
45.	SH	NHS Milton Keynes	12	NICE		17	Our comment is that it is full of text and that a flow chart as on page 17 -19 of the full version might make it more user friendly.	Thank you for your comment. NICE publishes several abbreviated versions of the full guideline. Your comment relates to the NICE version that was made available for consultation. The purpose of this document is to present all the recommendations from the 'Summary of recommendations' section [1.3] section of the full guideline and is therefore a text based document. However, when the final guideline is published, NICE will also release another version of the guideline called the Quick Reference Guide, which will both summarise the recommendations and contain a care pathway.
46.	SH	Autism NI	3	Full	General		Overall this is very good guidance.	Thank you for your comment.
47.	SH	RCGP	1	Full	General		This will remain a rather general comment on the guidelines which are welcome. The greatest concern parents have (and which GPs need to support and deal with) are: 1. Does their child have autism 2. What is the support available 3. Can anything be done to improve the quality of life for their child(and the family)	Thank you for your comment.

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							The burden on families is great and carers of children wit autism suffer. The guidelines refer to key age dependent features of autism which should be well received. The importance of the transition from paediatrics to adult services is mentioned in the guidelines and the recognition of the importance of the MDT and multiagency involvement is welcome. Similarly the importance of who the lead clinician. The guidelines are useful and I see no major weakness in them.	
48.	SH	Department for Education	9	Full	General		The high quality information includes a standard set of materials containing information families said they need to know when their child is first diagnosed with a disability. There are information booklets explaining how different services	Thank you for your comment. The GDG considered whether it was possible to make a more focussed recommendation about what type of information should be made available. Published information on recognition and diagnosis of ASD information will now be required to follow the recommendations in this guideline and therefore it was not possible to recommend current published information about ASD which will be out of date. We hope that the materials that you mention will be updated following publication of these guidelines and

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							work as well as information about a range of specific disabilities and conditions including autism. **Since 2004, almost 100,000 copies of the Early Support Information for Parents booklet on autism have been distributed**. All the Early Support materials are available free of charge to families and practitioners and are widely used across a number of different services. The Early Support materials were developed in consultation with families, who wanted information that was factual and easy to understand and would support them to share information about their child with different services as well as with individual professionals working with them.	professionals will use them widely.

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49.	SH	The Royal college of psychiatrists in Wales	3	Full	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.	Thank you for your comment. We are aware of the fragmentation of services and have recommended a multiagency strategy group, an ASD team which has multi-professional membership, a single point of referral for ASD and a clear pathway for all ages up to 19 plus integration with adult diagnostic services for a young person approaching transition age.
50.	SH	The Royal college of psychiatrists in Wales	4	Full	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.	Thank you for your comment.

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51.	SH	The Royal college of psychiatrists in Wales	13	Full	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.	Thank you for your comment, throughout the guideline we have made clear how young people should be included in decision making about their care, in particular we have detailed in a recommendation that information sharing should always be appropriate to their age and ability to understand. This recommendation has been moved up in the pathway to appear before the commencement of the diagnostic assessment to give it more prominence.

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52.	SH	The Royal college of psychiatrists in Wales	17	Full	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.	The GDG believe that the recommendations for an ASD team will lead to a profile and a better understanding of the needs of a child or young person, regardless of the diagnosis. We have recommended a multiagency strategy group, an ASD team which has multi-professional membership, a single point of referral for ASD and a clear pathway for all ages up to 19 plus integration with adult diagnostic services for a young person approaching transition age thereby maximising the likelihood of agreement across professionals. In addition we have tasked the strategy group with multiagency training.

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53.	SH	The Royal college of psychiatrists in Wales	18	Full	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".	Thank you for your comment. The purpose of this guideline is to address some of these considerable problems that you helpfully describe. They have made recommendations about, being critical about one's own expertise, when to seek a second opinion, when to seek more information and what to do when there is uncertainty about a diagnosis.
54.	SH	RCN	1	Full	General		The guideline is comprehensive and welcomed. There is however, a query on how the recommendations would resourced?	Thank you for your comment. The GDG consider that to improve recognition and diagnosis there may be uplift in resources if more children are referred as a result of better recognition. However children with signs and symptoms and impact on function will require some sort of assessment, the guideline recommends that an early decision should be made on the type of assessment required so

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								that not all of these children will be given an ASD diagnostic assessment but should be offered appropriate support earlier on as a result of this guideline. The GDG believe that this is a good use of NHS resources. The rationale underpinning this view can be found in the translations of evidence to recommendations throughout the guideline.
55.	SH	Royal College of Speech and Language therapists	1	Full	General		In general, the RCSLT considers this document is a valuable resource for the recognition, referral, and diagnosis of children and young people with Autism Spectrum Disorders (ASD).	Thank you for your comment
56.	SH	Royal College of Speech and Language therapists	2	Full	General		While we fully endorse the establishment of multidisciplinary ASD assessment teams, we are concerned that given the current financial situation some services (as part of this assessment) may not be commissioned or available equally for children and young people across the country.	Thank you. The GDG view is that the recommendations should bring about a change in the organisation of ASD diagnostic services – the same professionals will be involved but recognised as a dedicated team. The recommendations are sufficiently flexible to allow for variation in ASD teams across commissioning arrangements.
57.	SH	Royal College of Speech and	3	Full	Gener		Following on from point 2, we recommend a clear ASD	Thank you. The guideline recommends a clear diagnostic pathway for all children and young people with signs of ASD. The guideline recommends an ASD team which should consist of a core

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		Language therapists			al		assessment pathway for children and parents where certain services are not commissioned or available in a part of the country. This will reduce the risk of the ASD assessment pathway becoming challenging and complex for parents and children.	membership, but also allows for flexibility in local arrangements. The guideline also recommends referral to tertiary services. These services may not be close to the ASD team. The guideline should reduce the complexity of the pathway for children and young people which should be easier to understand.
58.	SH	Royal College of Speech and Language therapists	4	Full	General		With funding pathways being linked to new commissioning arrangements, for instance GP consortia, we recommend additional guidance be provided to GPs to refer children and young people to ASD assessment teams.	Thank you. The recommendations in the guideline provide guidance to non-experts about when to refer. It also includes a recommendation for non experts to seek advice when they are uncertain of the next step.
59.	SH	Royal College of Speech and Language therapists	5	Full	General		We notice a lack of detail in the consultation document regarding ASD assessment for children from bi-lingual home backgrounds. We recommend that guidance is tailored to meet the assessment needs of these children. Diagnosis and assessment of	Thank you. The GDG considered language where it was pertinent to recognition and diagnosis of ASD. We have emphasised that a bilingual background should not be assumed to be the cause of language delay and that language competence in the native tongue should be assessed. However, the recommendations do not specify generic support for bilingual children as this should always be met by the NHS regardless of the type of assessment, which includes ASD diagnostic assessment.

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							this group can be problematic and further support for assessment will be needed.	
60.	SH	Royal College of Speech and Language therapists	6	Full	General		It is important that the timing of assessment is right so that each member of the ASD assessment team feeds in at the appropriate stage to maximise the effectiveness of each intervention. The sequence of treatment along the pathway enables more effective diagnosis, better joint working and creates efficiencies in the process on the whole.	Thank you, we have set out the core team members and core elements of a diagnostic assessment leading to a diagnosis and profile of needs.
61.	SH	Autism Education Trust	1	Full	General		there is ongoing discussion in many agencies, authorities and schools as to whether to use the term Autism Spectrum Disorder or Autism Spectrum Condition. The use of the term “disorder” is not accepted by some individuals with autism and Asperger syndrome who do not see themselves as disordered or deficient. The use of the term	The term autism spectrum disorders is in the original remit from the Department of Health. The GDG consider that the condition becomes a disorder once there is impact. The guideline is for children and young people for whom their signs and symptoms have an impact on their lives.

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							"autism spectrum" may therefore be more helpful throughout the document	
62.	SH	Autism Education Trust	2	Full	General		there is concern that the guidelines have not built on or referred to the NAPC stages of assessment	Thank you. The NAP-C is referred to in the introduction to the guideline (see chapter 2) in terms of the current clinical context and was also considered by the GDG when planning the evidence review for signs and symptoms (see chapter 3). The GDG have considered the stages of assessment and recommended that not all children require a general developmental assessment. This is a divergence from the NAP-C. In other aspects such as multi-agency and multi-professional working, they have remained in line with the NAP-C.

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63.	SH	Autism Education Trust	3	Full	General		It may be more helpful to use the term assessment rather than diagnosis in the title and document as a whole. Assessment is essential to a diagnosis and as the guidelines point out not all children will eventually be diagnosed.	Thank you, the title was set during the scoping phase and now cannot be changed. The guideline recommends that a diagnostic assessment must include profile of needs. The GDG also expanded their recommendations for children who do not end up with a diagnosis of ASD to ensure their needs are met.
64.	SH	Sheffield Children's Hospital	1	Full	General		General comments - This guideline has been much awaited and is highly welcomed - There are many helpful	Thank you for your comment.

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							recommendations striving at early identification, comprehensive multidisciplinary assessment not only of ASD but of its many comorbidities as well as differential diagnosis. - The style and language of the guideline is not easy to read and does not flow. There are noticeable differences in style, many repetitions and quite a number of grammatical errors. We assume these will be rectified in the final document. - It has been made very clear that the guideline concerns itself with pathway up to the point of diagnosis and the need for a specific remit for the guideline is understandable. Nevertheless there is a sense of disappointment and of 'unfinished business' by the guideline not covering 'what happens	The technical team has significantly edited the guideline for style during this revisions process and it will also be professionally edited prior to publication. The children's guideline on management of ASD is currently underway and should address your concerns about the scope. The introduction has been expanded and key references are added

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							next' - The introduction could be fleshed out more – although this is not meant to be an exercise in the review of the literature per se, more coverage of the literature in the body of the text (not just the references) would be helpful - The clear statements about ASD in Looked After children and in girls are most helpful. We particularly welcome the statements regarding 'previous negative findings not ruling out need for re- assessment' as are the statements about additional assessments to be carried out *selectively* rather than routinely. - There are discrepancies in the style and strength of recommendation of the guidelines e.g. very prescriptive about waiting time for appointments (3 months) and timescale for	but this is not intended to be a comprehensive textbook on ASD. Thank you. The GDG reconsidered their recommendations that give specific timescales and removed these targets where they did not feel that they were not helpful.

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							follow-up appointment (6 weeks) as well as timescale till review appointment in cases where diagnosis is uncertain (6 months), but it is not specific enough with regards to ASD team composition, size of team for whole population, timescales for response for further assessments requested from professionals outside the team etc…(see below)	The GDG have revised their recommendations on the ASD team to make it more specific.

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65.	SH	Sheffield Children's Hospital	2	Full	General		We strongly support the concept of a multi-agency city wide ASD strategy group or even a steering group. Our experience of a similar group for ADHD has proved very positive over the last 10 years and has facilitated a coordinated plan of training and support as well as the development of a shared vision.	Thank you. This is reflected in the recommendations.

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66.	SH	Sheffield Children's Hospital	3	Full	General		Composition of the ASD team: the guideline states that "the multidisciplinary team *'may'* include a paediatrician, child & adolescent psychiatrist, speech and language therapist, clinical or educational psychologist, occupational therapist". The guideline needs to state more strongly the need for all those skills to be available. In particular, it needs to capture the need for close working between paediatric/child development centres and CAMHS. After all, not many C&A psychiatrists would be able to (for e.g.) use a Wood's lamp and not many paediatricians would be able to diagnose the psychiatric disorders so often found in ASD.	Thank you for your comment. The GDG had reconsidered this recommendation and now defined a core membership of professionals who should always be on the team as well as a range of other professionals who should either be on the team or accessible to the team. The new team composition reflects your concerns about close working between clinicians with different skills required to carry out an ASD diagnostic assessment.

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67.	SH	Sheffield Children's Hospital	4	Full	General		The guideline states strongly the need for an ASD team – does this mean that only professionals within the ASD team should be diagnosing ASD? Surely there are many skilled clinicians 'out there' able to diagnose	Thank you for your comment. The guideline defines an ASD team as those involved in the diagnostic assessment. The recommendations leave open the exact make up and skill mix with each team. The purpose of defining themselves as a team is so that non-experts can seek their advice on referral. The members of the ASD team may also be members of other teams, (neurodevelopmental, CAMHS, community paediatrics, education), and the developers have taken care not to imply otherwise in their recommendations. This has been made explicit in the corresponding translation.

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68.	SH	Sheffield Children's Hospital	5	Full	General		There is no clarity about who should 'host' such an ASD team – nor is there any clarity about process when referral will be needed, from ASD team, to another service for assessment/clarification of other diagnoses (at stage of differential diagnosis &/or comorbidity). Whilst we appreciate need for local interpretation, there is a risk that conflicting demands and different commissioning arrangements will mean that children with ASD will not be able to have a holistic assessment at the 'one stop shop' as aspired to in the guideline.	Thank you for your comment. The guideline is intended for healthcare professionals and those responsible for commissioning and planning healthcare (see section 2.3) and it is expected that commissioners will ensure that these services and arrangements are developed. Although the exact composition of the ASD team remains flexible, the GDG have now defined a core membership, which combined with their other recommendation about the key elements of a diagnostic assessment, should ensure a uniform standard of care for all children and young people undergoing the diagnostic assessment, while allowing for some necessary variation in service at a local level.

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69.	SH	Sheffield Children’s Hospital	6	Full	General		There is no comment about the needs of children and young people with severe and profound Learning Disabilities. Would they be assessed by this same ASD team? Is it realistic to have the same team assessing and meeting the needs of children with AS & ASD also assessing and meeting the needs of children with the classic (Kanner’s) autism?	Thank you for your comment. The GDG have revised their recommendations on the ASD team for clarity. The recommendations now state that the team should carry out the diagnostic assessment but also that the ASD team may not have the skills within the team to assess those with complex co-existing conditions, and should have access to the professionals with these competencies.

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70.	SH	Sheffield Children's Hospital	7	Full	General		Single point of entry: we applaud the concept of a single point of entry and welcome the proposed pathways. Nevertheless, there is no consideration of the size of the population that could be served by a single point of entry nor the size of the ASD team for that said population. There is no consideration for a reverse pathway to 'generic' services and there is no consideration for what happens after the diagnosis: after all much of the criticisms of service users is about "being given a diagnosis and a report" but then being "left in the lurch".	Thank you for your comment, this recommendation has been changed to single point of referral for clarity. The population to be served will be determined by the expertise and range of the professional on the team and local commissioning arrangements. This has now been expanded in the introduction. The recommendation on the ASD team has now been changed to clarify that the team is responsible for deciding when referral to another team is required. The GDG consider that the inclusion of the profile in the diagnostic assessment and the recommendation that this should be made available with consent to other services should ensure that the diagnostic assessment leads to informed and appropriate intervention planning.

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71.	SH	Sheffield Children's Hospital	8	Full	General		Needs Based management plan: Is this envisaged to be similar to a CPA, being updated every year? Who will be involved in this?	Thank you for your comment. It is beyond the scope to make recommendations about intervention and management. However, the GDG consider that the inclusion of the profile in the diagnostic assessment and the recommendation that this should be made available with consent to other services should ensure that the diagnostic assessment leads to informed and appropriate intervention planning.
72.	SH	Sheffield Children's Hospital	9	Full	General		Screening /diagnostic tools: the statement "ASD-screening tools *may* be useful but is not essential" is understandable considering the weak body of evidence. We would have nevertheless welcomed a more definite recommendation regarding use of ASD-specific diagnostic tools, particularly with regards to social-communication abilities	Thank you for your comment, the GDG considered the accuracy of diagnostic tools in the review of the evidence and concluded that there was insufficient evidence to support any specific recommendations. There is a summary of the tools in appendix J to give professionals guidance about these instruments.

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73.	SH	Sheffield Children’s Hospital	10	Full	General		Although clinically undisputable, there isn’t a clear and strongly worded statement about assessment needing to be across various contexts	Thank you for your comment. The guideline now includes a recommendation to seek a school report for all children proceeding to a diagnostic assessment. The GDG considered that not all children required an observation in different settings and have specified when this additional assessment should be undertaken.
74.	SH	Sheffield Children’s Hospital	11	Full	General		We were surprised to note that ‘Eating Disorders’ were not listed in the co-morbidities	Thank you for your comment. The evidence is inadequate to justify the inclusion of eating disorders in the list of co-existing conditions. A statement has been added to the translations for coexisting conditions to make clear that the GDG are aware that health care professionals have raised the possibility of eating disorders but at the current time, the evidence is not strong enough and the clinical view within the group was that this should be listed as a coexisting condition that should be systematically looked for.
75.	SH	Sheffield	12	Full	Ge		Finally, although we welcome	Thank you for your comment. The GDG acknowledge these concerns.

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		Children's Hospital			neral		the spirit of the guideline about the 'spectrum' concept and about the 'broader autism phenotype' (which clearly matches our experience as clinicians) we are concerned about the ASD indicators. Whilst the guideline acknowledges the low threshold (to ensure ASD children are not missed), we are concerned about the threshold being too low, about the risk of overwhelming health services that are already stretched and about 'false positives'	The introduction has been expanded to further acknowledge the difficulties of the diagnostic threshold while also acknowledging that many children and young people who are 'below threshold' for ASD may or may not have traits with other conditions, and regardless of whether they have other conditions or not, may have needs for support and management. Also, the recommendations on the ASD team gathering information should prevent many children from being inappropriately assessed. Children and young people with signs and symptoms of ASD are likely to need some sort of assessment and this pathway allows for early exit to more appropriate services if this best suits their needs. The GDG consider that the pathway will improve the organisation of diagnostic services overall and help services cope with a higher level of initial referrals.
76.	SH	GOSH Haringey	10	Full	General		It is important to ensure that the guidelines consider other multi agency routes for service provision like early support panel, CAF. Preschool children can be refd to community paediatricians rather than asd teams as small units have people multi tasking. Locally all school children are refd by schools to the caf panel and this triggers asd assessment and referral to Ed Psychologist if	Thank you for your comment. The guideline sets out a pathway that can be adapted to local commissioning arrangements. Multi-agency working is also a key recommendation.

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							referral indicates that support is needed in school.	
77.	SH	Royal College of Paediatrics and Child Health	34	Full	General		This guideline reflects a massive amount of work, has been thoroughly researched and is well presented in a style that is clear and mostly easy to understand.	Thank you for your comment.
78.	SH	Royal College of Paediatrics and Child Health	35	Full	General		We think that this document is extremely comprehensive and should be commended. We look forward to the NICE guideline on management of autism.	Thank you for your comment.
79.	SH	Royal College of Paediatrics and Child Health	36	Full	General		The guideline clearly recommends establishing specific autism assessment teams, including a specific paediatrician as part of this, in every health district. It recommends appointment of an assessment coordinator for every child to be assessed and states that each assessment is likely to take the paediatrician 3-4 hours. Autism spectrum disorders are thought to affect 1% of the child population, but in order to be	Thank you for your comment. We are aware that in many districts the referral rate has been increasing for query ASD and may now be plateauing. We hope that this guideline by emphasising multi agency planning and working will lead to a re-alignment of existing resources and elimination of duplicated assessments with a fuller appreciation of each professional role. As a model of service, it is the GDG view that if services are 'right for ASD ' they will be 'right for all disability' as the complexity of ASD is as great as any other disability. The GDG acknowledge concerns about resources but believe that the proposed diagnostic pathway should lead to early assessment and support for those children who most require it. For those who do not require it, the initial referral process will also be of benefit as nearly all children with developmental or behavioural problems will probably require some form of assessment, the diagnostic pathway allows these children to be recognised and referred to more appropriate

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							confident in identifying this 1%, more than 1% of children will need to go through the same assessments, some of whom will not have autism spectrum disorders. Thus significant resources will be required in every single district to provide such services that do not currently exist at this level in many districts. When Paediatric Neurodisability was proposed as a separate subspecialty of paediatrics, the target was for there to be one fully trained consultant in paediatric neurodisability for every 100 000 total population. This was to lead on providing paediatric services for children and young people with ALL types of disabilities. We know from manpower surveys that we are a very long way from achieving this goal at this time, although some areas, e.g. Scotland, are nearer to the target than others.	services at an early stage. The GDG agree with your concerns about the risk of inequalities in resource use with the implementation of NICE guidelines, however, our remit was to improve the diagnostic pathway for ASD and justified the organisation of services and resource use to this extent.

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							It is a cause for concern that in these times of financial constraint within the NHS, this guideline for autism spectrum disorders may inadvertently lead to inequalities of service between those who may have an autism spectrum disorder, for whom there will be an expectation that services must reach the standards specified by NICE, and children and young people with other neurodisabling conditions, who will have to manage on what is left of the resources within neurodisability teams, once the autism services have been set up. Why should the child with a potential autism spectrum disorder have an assessment coordinator appointed and not the child with a potential diagnosis of cerebral palsy, learning disability or complex disability, etc.? Why should the child with a potential autism spectrum disorder take up 3-4 hours of a paediatrician’s	

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							time in establishing the diagnosis and not the child with a potential diagnosis of cerebral palsy, learning disability, complex disability, etc.? If we are to have equitable services and thus equitable opportunities for the best outcomes for all disabled children and young people, we must make it clear that service developments for one group of **must not** be at the expense of disadvantaging others. Any resources required to uplift services to the standards specified in the NICE guidance must be **new** resources, not resources 'robbed' from services for other disabled children and young people.	
80.	SH	Royal College of Paediatrics and Child Health	37	Full	General		More so in the past, but still the case in many child development services in the UK, assessment of children presenting with disordered development is dominated by the use of a particular assessment tool, such as the Griffiths assessment. It is	Thank you for your comment. We have emphasised the need for assessments leading to a profile to inform the management plan. We feel such an emphasis strengthens the holistic approach to the child or young person's assessment including within the family context and avoids a 'has he/she got ASD' only approach. We have emphasised that the ASD team should have the competences to consider the differential diagnosis but that referral to another team may be needed

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							very pleasing indeed that the NICE guideline does **not** advocate universal use of autism diagnostic tools such as the ADOS, DISCO or 3Di. However, because the guideline places so much emphasis on the development of autism assessment teams with specific paediatricians taking on most of this work, there is a danger that clinicians will over-focus in the autism-or-not issues and neglect the bigger picture for the individual child. This will be even more the case for those children who are not physically examined. We believe this is a retrograde step and will lead to many children and young people only being considered as having autism or not, rather than the breadth of potential differential and co-morbid diagnoses being equally carefully considered. Many children who reach diagnostic threshold for autism	for confirmation/treatment.

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							spectrum disorders also have other conditions, that may have other implications in terms of potential secondary disabilities or implications for the wider family and it is important that these are not lost because the team is the 'autism assessment team'. If the child also has to be seen by a different disability team in order to think about other diagnostic possibilities, this will definitely lead to duplication of effort and there are insufficient resources in neurodisability teams across the UK for this to be achievable at this time.	

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81.	SH	Royal College of Paediatrics and Child Health	38	Full	General		If assessments are to be undertaken by multidisciplinary teams, then it should not take the paediatrician as long as 3-4 hours to reach a diagnosis. It is recognised that for complex 'grey' cases it may well take longer – review may be necessary over a number of years, especially when the child presents very early.	Thank you. We agree that sometimes diagnosis may be straightforward for the experienced clinician. However it is in those very cases that the profile of needs may be most important and hence best practice is the carry out all elements of the diagnostic assessment making best use of the skills of individual team members.
82.	SH	Humber Foundation NHS Trust	3	Full	General		Our comments are as follows: in general it was felt that the proposed guidelines are good in recommending the establishment of a local ASD strategy group and multi-disciplinary ASD team, with clear guidance regarding membership of the team, what should be included in the diagnostic assessment and what	Thank you know, the GDG acknowledges that the recommendations will lead to a reorganisation of resources in developing an ASD team but that its member will usually already be the same professionals as those already involved by diagnostic assessment. The added value is having a group of multidisciplinary professionals who coordinate their decisions and assessments and our recognised by referrers and families as a team.

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							should happen following diagnosis. The guidelines will have significant implications for services in our area with regards to resources and co-ordination across agencies.	
83.	SH	NHS Direct	1	Full	General		NHS Direct welcome the guideline and have no comments on the content.	Thank you for your comment.
84.	SH	Tees Esk and Wear Valleys NHS Foundation trust	1	Full	General		I think that it is good that they are using autism spectrum disorder rather than autistic spectrum disorder / autism spectrum conditions or pervasive developmental disorder. The guidance fits well with my own experience of having been involved with 7 different ASD diagnostic teams throughout the north of England.	Thank you for your comment.
85.	SH	Tees Esk and Wear Valleys NHS Foundation trust	4	Full	General		What about time scales? NAP-C had them…. NICE has a)see within ASD team by 3 months and b) see after diagnosis by 6 weeks….what about the bits inbetween?	Thank you for your comment. The GDG reconsidered their recommendations that give specific timescales and has not specified these targets where they did not feel that they were not helpful to diagnosis.
86.	SH	Tees Esk and Wear	5	Full	Gener		Post-diagnosis- parent courses eg early Bird, early Bird plus,	The value of parent courses was outside the scope of the guideline. It was not possible to consider post diagnosis support in any detail in

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		Valleys NHS Foundation trust			al		help, help 2, sygnet, ASCEND- why no specific recommendations based upon the evidence base for them? They are referred to in the post-diagnosis section as courses may be available. Could NICE include an evaluation of them?	the guideline as this would normally fall under management after diagnosis. The scope of the upcoming children's guideline on management of ASD may cover courses.
87.	SH	Tees Esk and Wear Valleys NHS Foundation trust	6	Full	General		is it within the scope of the guideline for the creation of a about a post-diagnostic reading list for parents/professionals?	Thank you for your comment. The scope of the guideline extends to the point diagnosis so the GDG have made recommendations about how the diagnosis should be communicated that include recommendations about providing families and carers with information. However, they concluded that any information given to parents/carers and professionals should be tailored to the individual needs of the child or young person who had received the diagnosis of ASD and as such have chosen not to define specific types of resources such as a reading list. The GDG's recommendation on information and support for families and carers also states that parents and carers should be directed to other sources of information such as local and national support groups who may be able to provide reading lists of this kind.
88.	SH	Tees Esk and Wear Valleys NHS Foundation trust	7	Full	General		When multiagency/multidisciplinary assessment teams are created, there is a lot of 're-inventing the wheel'. Can NICE create some example proformas / standard processes for: a) stages of assessment eg a	Thank you. We have emphasised the principles and components of assessment but the detail should be left to localities. The exemplars of services—chapter 10 gives an indication of the variety that is possible and effective.

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							checklist of info requested and received, b) a diagnostic grid for the evidence gathered, c) a proforma for the post diagnosis strengths/skills/impairments profile / diagnostic report and d) standard letters for requests to professionals (psychiatry, educational psychology, paediatrics, speech and language therapy etc) for their opinion/assessment to include the NICE guidance for expected content of assessment and report.- This should improve the quality of information collected and assessments by different professional groups and reduce the national time spent on re-inventing pro-formas.	
89.	SH	Tees Esk and Wear Valleys NHS Foundation trust	8	Full	General		The advising of using semi-structured processes as guidance but without the evidence to back-up which ones to use is confusing and difficult	Thank you for your comment. The evidence on the use of structured tools did not provide the GDG with the evidence that one tool was better than another, or better than not using a structured tool. The GDG consensus was that they have some value in gathering information when used by those with expertise in interpreting the data.

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							to assess at a local level when the national advisors cannot recommend any particular tool	They have provided a summary of the tools in appendix J to provide more information about the tools currently available.
90.	SH	Welsh Assembly Government	1	Full	General		Many of the recommendations are made on consensus agreement by the group and, in particular, the assumption that the demand for diagnostic services will not provide a significant challenge needs to be tested.	Thank you for your comment. We are aware that in some districts, referrals are already at 3% of the population. What we are proposing outlines the principles of ASD assessment. We anticipate that restructuring existing multiagency resources will improve capacity and reduce duplication. The GDG acknowledge concerns about resources but believe that the proposed diagnostic pathway should lead to early assessment and support for those children who most require it. For those who do not require it the initial referral process will also be of benefit as nearly all children with developmental or behavioural problems will probably require some form of assessment, the diagnostic pathway allows these children to be recognised and referred to more appropriate services at an early stage.
91.	SH	CAMHS Wales	1	Full	General		Comprehensive document which at least attempts to recognise the variety of service contexts within which ASD assessments occur. Need to consider child and family's language needs in assessment. In Wales, offering a monolingual English medium assessment to a child whose	Thank you for your comment. The guideline includes specific recommendations for professionals to take into consideration the child's first language where this is relevant to the diagnostic assessment.

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							family is bilingual (Welsh/English) is inequitable, and may lead to misdiagnosis, which is the most important consideration. Lack of staff who have specialist ASD assessment skills and the appropriate linguistic skills,	
92.	SH	CAMHS Wales	2	Full	General		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. Does not mention fragmentation of services and a potential task of integration of services and streamlining of transitions between services e.g. pre-school to school age.	Thank you for your comment. We have amended the recommendation about the constituents of the ASD team to ensure greater integration between agencies dealing with all children/young people with ASD.
93.	SH	CAMHS Wales	3	Full	Gener		Overall it is a good read and helpful, The group have	Thank you for your comment.

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					al		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.	
94.	SH	CAMHS Wales	4	Full	General		Provisional recommendations are sensible and I agree with all of them.	Thank you for your comment.
95.	SH	CAMHS Wales	5	Full	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 eg Armed Forces or police force, as well as suffering stigma.	Thank you for highlighting this. We have now made clear where informed consent is required in the recommendations. We have also added a statement about stigma and further employment prospects to the introduction to this document.

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96.	SH	CAMHS Wales	9	Full	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.	Thank you. This is a valid concern and the GDG have recommended that a complete assessment of needs is carried out which should help facilitate compliance. Enquiry about co-existing conditions, many of which have recognised treatments should help families and young people. It is the GDG's view that with adequate professional training and consideration of parental and carer concerns, as well as the concerns of children and young people themselves, a diagnostic assessment will provide positive benefits overall.

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97.	SH	CAMHS Wales	10	Full	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".	Thank you for your comment. GDG consider that the multi-agency ASD strategy group and ASD team should address this concern. The GDG have also recommended that information be shared with parent/young people and other professionals in a sensitive manner.

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98.	SH	NHS Milton Keynes	14	Full	General		Our comment is that the guideline does not highlight the use of interpreters when working with children and families whose chosen language is not English during consultations.	The GDG view is that the use of interpreters is not specific to ASD but a part of routine practice in the NHS.
99.	SH	NHS Milton Keynes	15	Full	General		Our comment is that whilst best practice is to use interpreters as identified in our previous comment that this can limit the use of some assessments e.g. ADOS assessment	Thank you, we agree that the need for interpreters may make impractical some levels of the ADOS; it is possible to carry out modules 1 and 2 asking the interpreter about any utterances of the children and young people. The situation referred to is rare and it may be possible to access in a specialist location appropriately skilled professional if absolutely necessary.
100.	SH	NHS Milton Keynes	16	Full	General		Our comment is that the guideline does not recognise the impact that race and culture can have regarding assessment and diagnosis of ASD or in respect of acceptance of the diagnosis. For example emphasis on eye contact and variation in play can be viewed differently in different cultures.	The GDG discussed the risk of inequality in assessment and diagnosis at some length. They have provided a recommendation to alert professionals considering the possibility of ASD of what they need to be aware of in terms of equalities to address this issue explicitly.
101.	SH	BACD	1	Full	General		We welcome this guideline. Am aware that the guideline is governed by a weak evidence base. • Positive description of	Thank you for your comments, We have added a statement on audit to the recommendation about the multi-agency strategy group.

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							differential, second opinions, features (not all have all). • Would have possibly anticipated the ASD Strategy group would have a more 'strategic' role e.g. audit, data collection, trends • Very concerned that a speech and language therapist 'may ' be included in the assessment team not 'should' • Some concern (and puzzlement) that the guideline does not appear to believe that all children with potentially a lifelong disabling condition should have a	The GDG agree and have added a speech and language therapist to the core ASD team. The GDG agree and changed the recommendation on physical examination so that all children and young people have physical examinations. The GDG agree and have added a statement on nutrition to the profiling recommendation and amended recommendation on co-existing conditions to highlight to clinicians the need to look for feeding problems including restricted diets. The GDG agree and have added paediatrician to the core membership of the ASD team and a paediatric neurologist to the list of professionals the team should include or have access to.

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							physical examination by a person with a neurodisability competency. Could a consensus view be considered here? • No reference to dietary fads / rigidity potentially causing mineral / vitamin deficiencies? • Community paediatricians and Paed neurologists are not mentioned early on recommendations, though are described by name p 177 .8,9 - believe that the former	

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							is a key player in the diagnosis and on-going care of this group, and that the latter are important in the assessment of the regressing child with seizures.	

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102.	SH	Royal College of Psychiatrists	2	Full	General		Disintegrative psychosis ICD 10 code F84.3 Issues relating to the investigation of children presenting with regression of language and social skills were well covered in the document however there was no specific mention regarding the investigation of children who regress with language, social skills and adaptive functioning. The view from paediatrics historically is to refer for paediatric neurology opinion and usually a battery of investigations. The evidence in 8.1.4 did not appear to look at these children as a separate group and we wondered if they were included within the whole group of autistic regression. What does the evidence indicate for the Disintegrative psychosis group?	Thank you. The introduction, chapters 3 and 4 and corresponding recommendations have all now been changed to reflect the fact that children with regression of language and social skills over 3 years need to be considered differently to those under 3. The review in chapter 8 considered children and young people with regression including CDD, but did not sub-divide by age as the GDG did not feel this was likely to provide useful evidence because of the rarity of CDD.

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103.	SH	Royal College of Psychiatrists	3	Full	General		Sensory Assessment The need for a profile of sensory sensitivities was noted in 1.5.10 and is also mentioned briefly on page 95. It would be helpful to have sensory assessment in the section 1.5.7 if considered appropriate. It may be helpful for the group to be aware that sensory assessments by OT's have been withdrawn in some Trusts and it was hoped that a clear recommendation within this guideline would aid recommissioning this service.	Thank you. The importance of sensory interests and sensitivities as a manifestation of ASD in some children and young people is noted in the introduction. In the signs and symptom tables under- and over-reaction are the terms employed. Hypo and hyper sensitivities are specifically included in the profile. Also we have recommended that an occupational therapist should either be on the ADS team or available to the team.
104.	SH	Royal College of Psychiatrists	6	Full	General		Thank you for requesting comments from the Royal College of Psychiatrists. We are hopeful that this guideline will benefit our patients in the future and it will aid us in discussions regarding commissioning of services.	Thank you for your comment.

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105.	SH	College of Occupational Therapists	1	Full	General		I wonder whether we need clarification on the use of the DSM IV as it is due to change next year (DSM V) and the terminology is changing as well as the triad becoming a dyad. Also differentiation between aspects of the condition such as Aspergers, ASD, autism etc will not be available if this criterion is used. I think this will confuse parents and professionals.	Thank you. The GDG is aware that both ICD and DSM are undergoing revision and that the diagnostic criteria and terminology will be changing. The introduction has been amplified to make this clearer. The current guideline uses ICD 10 and DSM IV-TR, however we have used ASD rather than PDD and ASD includes all the subgroups currently in ICD and DSM. We have placed particular emphasis on the profile which will highlight the differences across the spectrum and between individuals.
106.	SH	Ambitious about Autism/Autism Alliance	6	Full	General		Ambitious about Autism understands that NICE require an extremely high standard of clinical research in order to make recommendations and there is a lack of research into autism and its diagnosis which makes it difficult for the guidelines to be very firm. We appreciate that currently a range of diagnostic approaches and tools are named in the guidance. We would welcome further research into which of these tools and approaches are	Thank you for your comment. The GDG considered a research recommendation on diagnostic tools but the consensus view was that the tools were more useful in collecting information to inform the assessment of needs and that any further studies on the diagnostic accuracy of these tools was not a priority.

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							most effective methods. This could be helpfully informed by parents and young people's views of the diagnostic process, and what experiences were positive for them.	
107.	SH	Department for Education	1	Full	General		Necessarily much of the guideline, focusing as it does on the diagnosis of autism, is beyond the remit of the Department for Education. The Department's main interest is in the composition of the local multidisciplinary groups and strategy groups and the support offered to parents and children following diagnosis. DfE is pleased by the role assigned to educationalists in the recommendations for these groups. We have relatively few comments on that aspect as a result but we think more account might be taken of developments in the arrangements for support for children with special educational needs and disability, particularly in relation to Early Support and support in the	Thank you. The GDG is fully supportive of multiagency working and especially with education colleagues.

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							transition process to adulthood.	
108.	SH	Department for Education	7	Full	General		Early Support is a national programme that's targeted at families with babies or children under five with additional support needs associated with disability or emerging special educational needs. It’s designed to help families access better co-ordinated services for their children, and is particularly relevant where families are in contact with lots of different people. Early Support promotes partnership working with families so that they are at the centre of any discussions or decisions about their child - their views are listened to and respected and their expertise is valued by the professionals working with them.	The GDG agrees that Early Support is a valuable programme and would be an invaluable resource to the ASD strategy group and ASD team. The GDG has recommended that information be obtained from settings outside the home of which Early Support groups would be one.
109.	SH	Department for Education	8	Full	General		Early Support promotes the use of key workers for those families who are in contact with a large number of different services or agencies because families have said that they are spending too much of their valuable time trying to co-ordinate	Thank you for your comment. The GDG were aware of this and an amendment has been added to the translation of evidence to recommendations for the chapter on information and support.

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							appointments or the services they receive. Key workers act as a single point of contact when parents and carers are looking for information and can help to reduce stress by encouraging everyone who is in contact with a family to work better together as a group. Where families are juggling many appointments and meetings, they may also be able to help by co-ordinating visits to hospitals and clinics.	
110.	SH	Autism NI	2	Full	General		The absence of Psychosis under all the 'Neuropsychiatric Conditions' headings is puzzling as it can be misdiagnosed or be a comorbid condition in older adolescent with ASD. See 1 Schizophrenia or Asperger syndrome? David Da Fonseca, Marine Viellard, Eric Fakra, Delphine Bastard-Rosset, Christine Deruelle and François Poinso. La Presse Médicale Volume 37, Issue 9, September 2008, Pages 1268-1273 2 The Autistic Spectrum. Updated edition 2002. Lorna	Thank you. Psychosis was in our original consensus list but was inadvertently omitted in the consultation draft. It has now been reinserted as a differential diagnosis.

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							Wing. The Robinson Press: London. 3 Persecutory beliefs, attributions and theory of mind: comparison of patients with paranoid delusions, Asperger's syndrome and healthy controls. Jaime S. Craig, Christopher Hatton, Fiona B. Craig and Richard P. Bentall. Schizophrenia Research Volume 69, Issue 1, 1 July 2004, Pages 29-33 Also Since the assessment age is up to 19th birthday the differential of Schizotypyal Personality Disorder might also be relevant – see The Relationship of Asperger's Characteristics and Schizotypal Personality Traits in a Non-clinical Adult Sample. Ruth M. Hurst, Rosemery O. Nelson-Gray, John T. Mitchel, Thomas R. Kwapil. J Autism Dev Disord (2007) 37:1711–1720	

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111.	SH	British Psychological Society	1	Full	General & eg 1	p5, 5x2, 47 etc	The Society believes there is a greater need for consideration of the child and family's language needs in considering an ASD assessment. In England, it is a matter respecting diversity, a matter of good practice and in the interests of everyone (child, family, service, public etc) and in the interests of obtaining an accurate diagnosis, that the language needs of the child and family are considered. In Wales, things are different as the legal position of the Welsh language is equal to that of English. Offering a monolingual English medium assessment to a child whose family is bilingual (Welsh/English) in Wales is inequitable, and may affect diagnostic decision-making, which is the most important consideration. We are very short of staff with specialist ASD assessment skills and who have the appropriate linguistic skills, however, those are gaps in	The GDG view is that the use of interpreters is not specific to ASD but a part of routine practice in the NHS.

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							service rather than reasons not to address the issue.	

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112.	SH	British Psychological Society	2	Full	General		Arriving at a firm diagnosis of ASD is a complex and often time-consuming process. Since it provides no information about the causes or outcomes of the putative disorder for individual patients, the value of such a diagnosis is questionable. What might be a better use of resources is a pathway that excludes known causes of autism, identifies the most likely cause of the signs and symptoms as a developmental disorder resulting in autistic (and/or other) characteristics and then, as the consultation document suggests, maps out the medical, cognitive and affective profile of the individual who can then be referred to relevant services that can help. The focus should be on the individual child and his or her profile of needs, rather than on diagnosis of disorders whose nature is essentially speculative.	Thank you for your comment. The GDG, particularly parent representation, describe considerable advantages to diagnosis but the GDG as a whole have emphasised the assessment of the profile which directly leads to an understanding of needs.

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113.	SH	British Psychological Society	3	Full	General		The consultation document contains a large number of typographical errors, making some sentences difficult to understand. In one case, the pooled prevalence of neurodevelopmental conditions was reported to be 776% (7.1.4). The prevalence of typos brings the reliability of the figures into question.	Thank you for noting this error, we have rectified this and have made corrections throughout the document where needed.
114.	SH	British Psychological Society	4	Full	General		The Society recommends that a clear distinction is maintained between a diagnosis in *descriptive* terms and a diagnosis in *causal* terms. If not, there are implications for researchers. Apparently inconclusive and contradictory findings might only be inconclusive and contradictory if there is an assumption implicit in the research design, that autistic research participants form a homogeneous group.	Thank you for your comment. We agree that ASD is a descriptive term for likely heterogeneous causality and we have made this explicit in the Introduction – see section 2.1.
115.	SH	British Psychological Society	5	Full	General		**Lack of provision for services provided to young people and overreliance on the voluntary**	Thank you for your comment. The purpose of this guideline is to improve the organisation of services for children with signs of ASD by defining those who diagnose and profile children with query ASD as

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					9.2.5		**sector.** Currently provision is very limited and is not meeting the needs of these young people and their families. Access to CAMHS is only provided when there is a clear mental health concern. ASD statutory provision is often for a limited period post-diagnosis and there is an overreliance on the voluntary sector. Therefore a large number of these children and young people may not get adequate support.	part of a recognised ASD team, regardless of the other groupings or affiliations. The ASD Strategy Group will have the responsibility of ensuring that local diagnostic services are adequate to meet local need.

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116.	SH	British Psychological Society	6	Full	General		**Provision of services based on a diagnosis of ASD.** This consultation emphasises the need for a diagnosis of ASD to enable those individuals to obtain an adequate provision of services. There are a very large number of young people experiencing significant ASD 'traits' who do not meet the criteria for a diagnosis of ASD, yet would benefit from provision of services. We recommend consideration be given to designing services based on needs (e.g. social / communication/behaviour difficulties) rather than on a diagnosis.	Thank you We agree this point and have clarified this in the introduction. New recommendations have been added to emphasise this important point. We have recommended that each child who is assessed is given a profile of strengths, skills needs and impairments on which to base the needs-based management plan.
117.	SH	British Psychological Society	7	Full	General		Despite the attention to detail throughout it is disappointing that the document is not very specific at the end. It generally reads with a medical bias in the	Thank you for your comment. The GDG was charged with considering the evidence, which was very poor. The guideline is aimed at health care professionals diagnosing ASD, although we recognise that the management of ASD is primary

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							perspective it adopts towards autism. For example, we would question whether the genetic risk to potential siblings should be conveyed to parents at the time of their child's diagnosis. We would also welcome greater stress/mention of the need for post-diagnostic counselling (see p15 and p45 in *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*).	in education and other sectors other than health care. The question of raising the issue of a genetic link with families needs to be handled with great sensitivity. The GDG view was that it should be briefly introduced when face to face feedback on the assessment is given as it may have been forgotten that ASD is a highly heritable condition. Detailed discussion should not take place at this stage as it may be too much to take in all at once for many families facing an ASD diagnosis. The guideline did not cover post diagnosis counselling. The upcoming guideline on the management of ASD in children and young people may address this topic in the scope.
118.	SH	Association for Family Therapy and Systemic Practice (AFT)	1	Full	General		AFT members may work with children and young people with autism, often with other complex problems in the family, in different contexts. Some members are registered Systemic Family & Couple Therapists, most often working in CAMHS, while others will use systemic practice and family therapy within their different roles as social workers, psychiatrists, clinical	Thank you for your comment. It is helpful to have information on how multi-professional teams work across the NHS.

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							psychologists, psychiatric nurses or other roles in voluntary agencies, social care or the NHS.	
119.	SH	Association for Family Therapy and Systemic Practice (AFT)	2	FULL	General		There are many references to the need to involve parents in the process of assessment and diagnosis, and the complex problems that may be present in families, which is helpful. Given the references to the potential for other mental health problems in the family, it would be helpful to use a systemic approach for family interventions after the diagnosis has been made. Examples would be where a parent has mental health problems, or siblings with autism or other mental health problems, so that the systems can be prepared for how to involve families after diagnosis.	Thank you for your comment. Although we recognise the need for specific interventions where problems are complex, the scope of this guideline is limited to the recognition and diagnosis of ASD therefore the GDG cannot make any recommendations regarding interventions following diagnosis. A guideline on the management of ASD in children/young people is currently being developed which will be able to answer this question.
120.	SH	NCCMH	1	Full	General		Since the commissioning of this guideline the National Audit Society consulted with the Department of Health and agreed that all DH documents/policy now refers to	Thank you We have described the autism spectrum in the introduction but focussed on diagnosis of 'disorder', which continues to be the accepted ICD and DSM and WHO term.

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							this as 'Autism Spectrum Conditions' rather than 'disorders'. At NCCMH we have followed the DH lead with the adults' guideline, and will do so with the management in children guideline, which is soon to begin. It might make better sense for all three guidelines being produced by NICE to be consistent with each other and DH policy.	
121.	SH	HTA Ref 1	1	Full	general		**)**I've checked through the scope and consider that the guideline does fulfil the declared intentions, thought they seemed to have been based on the premise that some evidence on effectiveness and cost-effectiveness of different recognition, referral and diagnoses practices would be identified, which was of course not the case.	Thank you for your comment. The GDG looked extensively for evidence on effectiveness and cost-effectiveness but there was only limited evidence for effectiveness.
122.	SH	HTA Ref 1	2	Full	General		I'm assuming that no economic modelling was undertaken for this guideline because there were insufficient data. However	Thank you. The challenge for any model is to relate resource use to any meaningful outcome. Given that there was no agreed health or welfare related quality of life outcome for ASD identified by the GDG, the modelling approach was not adopted throughout the guideline.

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							given as this approach is listed in the Guidelines Manual as appropriate when there is insufficient evidence from trials, it might be appropriate to include a line or two explaining this. There were a couple of examples where I felt that some modelling to support the consensus of the guideline development group on the possible cost-effectiveness of different approaches may have been warranted, and may help to justify the strong opinions professed.	This is discussed in the economics chapter but it has now been reinforced.
123.	SH	HTA Ref 1	11	Full	General		I'm afraid I can't comment on the recommendations that are based on the clinical findings. As no economic evaluations or other relevant evidence was identified these issues were not covered in the recommendations.	Thank you.
124.	SH	HTA Ref 1	12	Full	General		**3.2 Are any important limitations of the evidence clearly described and discussed?**I'm not sure how	Thank you.

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							relevant this section is as there was no evidence to consider.	
125.	SH	HTA Ref 1	13	Full	General		I**4.1 Is the whole report readable and well presented? Please comment on the overall style and whether, for example, it is easy to understand how the recommendations have been reached from the evidence.**t's generally accepted that cost-effective(ness) is hyphenated, and the inclusion of a hyphen is pretty mixed throughout the document.	Thank you for your comment, this amendment has now been made.
126.	SH	HTA Ref 1	19	Full	General		**Section five – additional comments** **Please make any additional comments you want the NICE Guideline Development Group to see, feel free to use as much or as little space as you wish.** The GDG had a very difficult task here, the lack of economic data or evidence in recognition,	Thank you for your comment.

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							referral and diagnosis of autism means that there was very little that could be done in terms of analysis and recommendations. They should be commended for the work they have done.	
127.	SH	HTA Ref 2	1	Full	General		**Are there any important ways in which the work has not fulfilled the declared intentions of the NICE guideline (compared to its scope – attached)**NO – this is a very comprehensive and impressive guide. There are just 5 important areas where I feel more needs to be added, as follows:	Thank you for your comment.
128.	SH	HTA Ref 2	2	Full	General		**Topic 1** The first topic that I would want to add if possible – is some discussion on the fact that some children and young people may meet the criteria for a diagnosis but do not need additional or different support to that usually provided – if they are with a supportive family and in a school which supports learners with	Thank you for this comment. We have emphasised that the profile of strengths, skills, impairments and needs is equally important, regardless of whether there is an eventual diagnosis of ASD. The profile may indicate that there is no additional need for intervention.

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							SEN well – and that in some instances – consideration needs to be given, in discussion with the parents/carers (in the absence of the child) – about the pros and cons of sharing the diagnosis. An edited book by Dinah Murray entitled *Coming Out Asperger* – covers these issues. We all know – for example – that there are many undiagnosed adults with ASD in the general population – who are successful and happy and who do not need services and support (although of course there are many who would benefit from diagnosis and appropriate services). **Reference**: Murray, D (2006*) Coming out Asperger: Diagnosis, disclosure and self-confidence*, London: Jessica Kingsley	
129.	SH	HTA Ref 2	3	Full	General		**Topic 2** Related to this – is the issue of when and how to share the diagnosis with the child and young person – which is also	Thank you for this suggestion. The GDG has moved up a recommendation about how information about the diagnosis should be shared with a child or young person up to give this emphasis at the start of the diagnostic process. The recommendation about sharing the findings of the diagnostic assessment has also been reworded for

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							covered in Dinah Murray's book. I have met parents who were given the diagnosis with their child PRESENT – and the child was very angry and depressed at this knowledge and refuted it. These parents wished they had been able to tell their own child – in their own way at a time they felt it was appropriate – so can we include more on this very important topic.	clarity.
130.	SH	HTA Ref 2	4	Full	General		**Topic 3** I also think that we should add *A parent with ASD* as a risk factor in the various sections in which risk is discussed – we have mentioned siblings – but not parents explicitly. (Table 4 and p. 66)	The GDG considered whether it should be included based on consensus. Although there was some agreement that in children with ASD there is perceived increased likelihood that a parent will have autistic trait, expert opinion within the GDG was that a parent with ASD is not routinely considered a risk factor in clinical practice. Therefore a parent with ASD it was left off the list of risk factors.
131.	SH	HTA Ref 2	5	Full	General		**Topic 4** We need another vignette of a child who is non-verbal with severe learning disabilities (as this is a significant group of children who come for diagnosis) (p. 54)	Thank you. All the vignettes have been removed as there were only a few and as such, did not show a complete range of possible presentations and as such. After further consideration, the GDG agreed they were not useful to non expert clinicians interpreting signs and making the decision whether to refer.

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132.	SH	HTA Ref 2	6	Full	General		**Topic 5** Recommendations on the ASD team – as educational interventions are currently the most useful type of intervention and ALL children with ASD attend school/receive education - (see NAP-C) – it is very important to have a strong educational component in the ASD team – so I would want to have Educational Psychologist as separate from the Clinical Psychologist – and/or – to have a specialist teacher listed in the team. The latter may be more realistic given the resource implications. (p. 97)	Thank you for your comment. The GDG have changed the recommendation on ASD team to say the team should have as a core member a clinical and/or educational psychologist and should also have access to educational or clinical psychologist
133.	SH	HTA Ref 2	7	Full	General		**2.1 Please comment on the validity of the work i.e. the quality of the methods and their application (the methods should comply with NICE's Guidelines Manual available at http://www.nice.org.uk/page.aspx?o=guidelinesmanual).**Ver	Thank you for your comment.

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							y thorough and rigorous and their findings agreed with my own view on the topics researched.	
134.	SH	HTA Ref 2	8	Full	General		**2.2 Please comment on the health economics and/or statistical issues depending on your area of expertise.**Not my area of expertise – except to say that costing services and support is hugely complex.	Thank you for your comment.
135.	SH	HTA Ref 2	9	Full	General		**3.1 How far are the recommendations based on the findings? Are they a) justified i.e. not overstated or understated given the evidence? b) Complete? i.e. are all the important aspects of the evidence reflected?**YES – recommendations reflect the findings very well.	Thank you for your comment.
136.	SH	HTA Ref 2	10	Full	General		**3.2 Are any important limitations of the evidence clearly described and discussed?**YES – very well done.	Thank you for your comment.
137.	SH	HTA Ref 2	11	Full	General		There are still some typos and inconsistencies which I assume will be picked up in the proof	Thank you for your comment. The technical team will make every effort to correct typos as they revise the draft guideline in light of these comments. The document will also be professionally edited by a

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							reading – but I have given some below. There is also a lot of repetition – particularly – in that the initial pages and Tables 1 to 4 seem to be repeated again on pages 49ff. There is a lot to read and so the summary pages on 18ff are very welcome. Can the guide try to show readers what is essential. I like the structure of giving the findings followed by the recommendations for each topic. That works well.	medical editor prior to publication. The repetition of the tables in the relevant chapters is dictated by our house style.
138.	SH	HTA Ref 2	36	Full	General		**4.2 Please comment on whether the research recommendations, if included, are clear and justified.** These are both clear and justified.	Thank you for your comment.
139.	SH	Whitstone Head Educational (Charitable) Trust Limited	1	Full	General		Our comments are as follows: The term "Autism Spectrum Conditions" should be used in general throughout the guideline. The term "Autism Spectrum Disorder" should be used to specifically denote where an "Autism Spectrum Condition" causes <u>significant</u>	Thank you We have used the term autism spectrum disorders as defined in DSM-IV and ICD-10 in which functional impairment is required as these are the diagnostic criteria in current use. Disorder is the ICD/DSM and WHO term. The guideline focuses on children and young people who do have significant impairment to daily function.

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							impairment to daily functioning.	
140.	SH	National Autistic Society	1	Full	General		The National Autistic Society (NAS) warmly welcomes the work that NICE and the Guideline Development Group (GDG) have put into to making this comprehensive guideline for recognition, referral and diagnosis in children and young people. This guideline has the potential to substantially improve clinical knowledge, patient experience and the nature of support offered to children with autism. We are acutely aware of the difficulties faced by the GDG because of the lack of clinical evidence and believe that praise is due for producing such a useful document. As a general point, however, the NAS would argue that this guideline (and the two other autism specific guidelines currently under development) should be used to create a Quality Standard for autism. The NAS would argue that it would be a wasted opportunity to not	Thank you for your comment. The GDG agree that a Quality Standard for ASD would be beneficial but do not consider it was charged to write quality standards.

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							develop such a standard at the same time as the other guidelines. Indeed, the lack of clinical evidence identified by the GDG during the development of this guideline adds weight to this call, not least because many of the recommendations in this guideline read more like some of the Quality Standards that have been developed than classic NICE guidelines. We firmly believe that an autism specific Quality Standard offers a valuable opportunity to bring together a lot of the good, yet patchy, work that currently exists across health and social care. It will also give local commissioners and health practitioners guidance on how best to arrange services in their area in a reformed health and social care environment. We would, therefore, suggest that the GDG recommend the production of a Quality Standard covering diagnosis, post	

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							diagnostic support, and interventions for co-occurring mental health problems for adults and children.	
141.	SH	National Autistic Society	2	Full	General		Across the NHS and local authorities, major reforms are underway. With all of the changes occurring the NAS believes it is vital that some context is given to this guideline or that NICE will commit to reviewing the guideline in a few years to ensure that the recommendations in this document are workable within the new health and social care framework. Throughout this response we have attempted to highlight were more context is required.	Thank you for your comment. The GDG is aware of the current changes to service provision and consider that their recommendation making the ASD strategy group responsible for audit would help monitor the appropriateness of this guideline.
142.	SH	Department for Education	2	Full	General	12 (Recommen-datio	advice given to parents whose child is being assessed under the special educational needs regime and given a statement should not include advice about which school to go to. That	Thank you for your comment. We agree with this point. The GDG intended to emphasise the sharing of information with education and we have taken care not to give advice in the recommendations about which school to go to.

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						n 63	should be the parents' decision.	
143.	SH	British Psychological Society	8	Full	General (eg 7	129	The Society would welcome an increased focus on the nature of autism and autistic development. Without this there seems too great an emphasis on the many varied forms of more heterogeneous milder autism spectrum disorders and particularly on their co-existing conditions (eg Chapter 7, p129) although this does inevitably highlight how infrequently such dual diagnoses are made in clinical settings.	A NICE clinical guideline is not intended to be a textbook on ASD but focuses on the actions that professionals should take when assessing, diagnosing and profiling children and young people with ASD as well as the consideration of co-existing conditions. We have tried to capture the varying age presentations and changes over time. In particular we have focussed on the importance of developing a profile to highlight the range of presentations e.g. severe intellectual disability, extreme anxiety etc.
144.	SH	HTA Ref 2	27	Full	General	162	Table 9.1 – first comment by parent – a typo – realize and in the first column – Professionals' reluctance	Thank you for your comment. These amendments have now been made.
145.	SH	HTA Ref 2	28	Full	General	166	Recommendations – social care	Thank you for your comment. We have now amended this recommendation to include social care.
146.	SH	HTA Ref 2	30	Full	General	173	Trade off – Line 2 – is a priority – not is as a	Thank you for your comment this amendment has now been made.

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147.	SH	HTA Ref 2	31	Full	General	174	Other considerations – add in social care – so health, education and social care	Thank you for your comment this amendment has now been made.
148.	SH	HTA Ref 2	15	Full	General	24	Line 1 – Asperger syndrome - be consistent throughout the guide	Thank you for your comment this amendment has now been made.

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149.	SH	British Psychological Society	9	Full	General (eg 1	4 p4)	Whilst Clinical Psychologists are identified on p4 for possible inclusion in a multi-disciplinary team, along with a Paediatrician and Psychiatrist and Occupational Therapist, the former are listed as "clinical or educational psychologist". We would like to clarify that these roles are not interchangeable and to highlight the importance of early social communication in an interactive context and the relevance of this to Autism. Clinical Psychology benefits from the application of evidence from developmental psychology whilst Educational Psychology inevitably focuses on later development.	Thank you for your comment. The GDG is fully aware of the differences between clinical and educational psychologist and consider psychologist to be a core member of every assessment with both professional roles being available.
150.	SH	Department for Education	4	Full	Gener	94	The GDG might want to consider mentioning in this	Thank you for your comment. The importance of assessing individuals in relation to skills and learning are highlighted in the discussion. We

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					al	(Other considerations, third paragraph)	context the relevance of special educational needs assessments and statements. For the assessment local authorities must seek advice from parents, schools/early years providers, educational psychologists, health and social care. The statement is meant to give an overall picture of the child's strengths and difficulties. The GDG may also want to be aware that in the recently published SEN and disability Green Paper *Support and aspiration: A new approach to special educational needs and disability* (9 March) we proposed replacing SEN assessments and statements with a more integrated assessment and an Education, Health and Care Plan which would be clear about who is responsible across education, health and social care for which services and includes a commitment from all parties to provide their services.	have added the following sentence to the evidence to recommendations section to reflect the value of the information that can be obtained from SEN statements: "If a child has undergone a Special Educational Needs (SEN) assessment, this should be considered as it may be another important source of information"
151.	SH	The Royal	1	Full	Ge	gene	This is a very comprehensive	Thank you for your comment

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		college of psychiatrists in Wales			neral	ral	document which at least attempts to recognise the variety of service contexts within which ASD assessments occur.	
152.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comment. The guideline includes specific recommendations for professionals to take into consideration the child's first language where this is relevant to the diagnostic assessment.

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							professionals who are also bilingual, in order to make an accurate assessment of that child's abilities.	
153.	SH	Autism Education Trust	20	Full	general	general	the guidelines focus on a specialist team which seems to work very much in isolation. This does not tie in with the emphasis on multiagency working in partnership with parents that is steering work in education, social care and health. the guidelines do not refer to Early Support or to the CAF process or even to the SEN Code of practice	Thank you for your comment. Our view is that the ASD specialist team needs to be adequately supported by the local ASD Strategy Group which it has recommended and which is able to signpost support/information/advice from different sources. The guideline recommends multiagency working, parent partnership and good communication.
154.	SH	Royal College of Psychiatrists	1	Full	General	General	Pathological demand avoidance as part of the spectrum of autism. It would be helpful to have a definitive statement within this document regarding the status of this diagnosis. Clearly PDA is not a diagnosis within ICD 10 (favoured in most Trusts as the diagnostic classification system) but this diagnosis is used by some child psychiatrists and psychologists. Parents are referred to CAMHS	Thank you for your comment. PDA as a description is included in the ODD description in appendix K and the glossary. The status of this diagnosis is outlined in the glossary.

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							with the expectation of receiving this diagnosis. This would be an opportunity to clarify the status of this term.	
155.	SH	Royal College of Paediatrics and Child Health	39	Full	1.1	1	Lines 15 and 16 should read, "ASDs are described as abnormal social interaction, social communication and behaviour".	Thank you for your comment. We have now amended this paragraph as follows: The term 'autism spectrum' describes behavioural differences in and difficulties with reciprocal social interaction and social communication combined with restricted interests and rigid/repetitive behaviours in children, young people and adults. An autism spectrum disorder (ASD) is diagnosed when these behaviours meet the criteria defined in the DSM and ICD and have a significant impact on function.
156.	SH	Royal College of Paediatrics and Child Health	40	Full	1.1	1	In line 20, "(less commonly)" should be removed.	Thank you for your comment, this amendment has now been made.
157.	SH	British Association for Art Therapists	1	Full	1.1	1	Health services should also include art therapy with reference to: Art Therapy and Autism: Overview and Recommendations Nicole Martin, Lawrence, KS	Thank you. The GDG agree that art therapy is a valuable intervention for children/young people with ASD. However interventions are outside the scope of this guideline and will be dealt with in a subsequent guideline on the management of ASD in children and young people.

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							Art therapy as an intervention for autism Melinda J. Emery, ATR-BC, LMFT The Arts Therapies are included in the ASD strategic action plan for Wales (Welsh assembly government, April 2008). Section 12 (p.28) lists Arts therapies as one of those being regulated by the HPC and represented on the Welsh assembly advisory committee. Chapter 5 the basis for intervention from theory to practice. Case studies of art therapy with individual autistic children demonstrate the use of the model and the outcomes, art therapy works as an integral part of overall management and treatment approaches to autism Art therapy with children on the autistic spectrum, beyond words, Kathy Evans and Janek Dubowski, Jessica Kingsley,	

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							London, 2001 The Autism Treatment Survey was developed to identify strategies used in education of children with autism spectrum disorders (ASD) in Georgia. Respondents of the web-based survey included a representative sample of 185 teachers across the state, reporting on 226 children with ASD in grades preschool-12th. 11.79% used art therpaies, music therpaies amongst others. Autism treatment survey: services received by children with autism spectrum disorders in public school classrooms. Journal of autism and developmental disorders, May 2008, vol./is. 38/5(961-71), 0162-3257	
158.	SH	British Psychological Society	3	Full	1.1, 2.1	1, 22	A clear distinction needs to be maintained between a diagnosis in *descriptive* terms and a diagnosis in *causal* terms. If not, there are implications for	Thank you for your comment. We agree that ASD is a descriptive term for likely heterogeneous causality and we have made this explicit in the Introduction – see section 2.1.

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							families. If carried out properly a diagnosis will exclude a range of medical conditions known to be associated with autistic traits, and will confirm that one child's behavioural characteristics match those of a group of other children. However, a diagnosis of ASD does not offer 'an understanding of why a child or young person is different from their peers' as the consultation document states (1.1, 2.1), because a diagnosis of ASD is descriptive, and in the absence of information about causal factors, *explains* nothing.	
159.	SH	British Psychological Society	4	Full	1.1, 4.4.7, 9.3.5	1, 75,173	*Liaison with education services*: Often a child's developmental abnormalities are not suspected until the child starts school or nursery. This means that education practitioners can find themselves in the role of gatekeeper with regard to referrals for diagnosis, resulting in some children being referred unnecessarily and others not	Thank you. We agree with these comments. The GDG have made a recommendation describing the multi agency nature of strategic planning in which education is a partner. The ASD team recommendations include a role for an educational psychologist in the diagnostic assessment and they also recommend that a school report is acquired prior to assessment.

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							being referred until their development has been significantly impaired by their disability. Parents report that teachers and even health practitioners working in the education sector (such as speech and language therapists or occupational therapists) are not always familiar with pathways for referral for suspected complex developmental disorders. The recommendation that schools and nurseries be involved in information-gathering (4.4.7) is welcome, as is the encouragement to liaise with educational colleagues (9.3.5). However, we feel that consideration should be given to the resource implications for the education service. Since parental reports indicate that children often fall into the gaps	By publishing this NICE guidance, parents, teachers and health professionals should be more aware that there is a local ASD pathway with a single point of entry for referral. The GDG recognise that a change in resource use will be required. This process of information gathering already happens but it is not always carried out in a way that optimally uses professionals' time or gathers the appropriate information specific to each child or young person. The intention of the guideline is that this process is streamlined so that resources are used more effectively. However, NICE guidelines cannot mandate professionals in other agencies to follow its recommendations. The GDG has been careful not to make recommendations that impose specific actions on professionals outside the NHS. Good liaison is strongly encouraged for effective working partnerships. The GDG hopes that colleagues in education will also find this a useful document and use the pathway to ensure that the right children and young people are recognised and assessed quickly without falling through the gaps between services.

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							between services due to each service implementing its own budgetary constraints, it would be helpful to ensure that the diagnostic pathway is mapped out for education as well as health. The Department of Health's/Department for Education & Skills' *National Service Framework for Children, Young People and Maternity Services: Autistic Spectrum Disorders* (2004), which addressed the issue of liaison between sectors, might be useful in this respect. There are also issues to be addressed with regard to the conceptual models of autism spectrum disorders in use in the education sector. Some educational theorists would question the medical model of disability (diagnosis or no diagnosis) *per se* and it is not uncommon for the behaviour of children with autistic characteristics to be assumed to	In recognition of this specific point, the components of the diagnostic assessment incorporate the medical and needs based models.

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							originate in dysfunctional or inadequate parenting. The Society recommends that the number of mainstream class teachers with SEN training, or training in dealing with complex developmental disorders, be ascertained, so that any significant issues can be addressed before the proposed pathway for recognition, referral and diagnosis is introduced.	The implementation of the guideline will depend on having in place professionals who have the competencies to deal with complex developmental disorders. Mapping who these professionals are and what training they need is outside the remit of a clinical guideline, but the need for training is highlighted in a key recommendation. It is hoped that the implementation of this guideline triggers appropriate training across agencies in order to fully implement the guideline's recommendations.
160.	SH	HTA Ref 2	37	Full	1.1	1	**Section five – additional comments** **Please make any additional comments you want the NICE Guideline Development Group to see, feel free to use as much or as little space as you wish.** Line 8 – rather than something wrong – use the term different or unusual about their child's development– or put 'wrong' in single quotes	Thank you for your comment, this amendment has now been made.
161.	SH	HTA Ref 2	38	Full	1.1	1	Line 12 – include social care	Thank you for your comment this amendment has now been made.

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162.	SH	HTA Ref 2	39	Full	1.1	1	Line 15 – delete abnormal – and use instead – difficulties in social interaction and communication	Thank you for your comment; we have now revised the wording in this section.
163.	SH	HTA Ref 2	40	Full	1.1	1	Line 36 Social care – not services	Thank you for your comment this amendment has now been made.
164.	SH	British Psychological Society	5	Full	1.1	1 line 33	Sentence meaning is not clear.	Thank you for your comment, the sentence has now been reworded to clarify the meaning.
165.	SH	British Psychological Society	6	Full	1.1	2 line 4	We suggest removing the word 'management'.	Thank you for your comment, this amendment has now been made.

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166.	SH	British Psychological Society	7	Full	1.1, 5.76	1, 107	The Society recognises the limited remit of the guideline. However, if there are points in the recommended pathway that are dependent on services other than healthcare, it is essential that those parts of the pathway are addressed. The consultation document assumes that other agencies will be willing and able to facilitate the recognition, diagnosis and support of children with ASD, when there is no guarantee that this will be the case. *Opening doors:* The examples of diagnosis and support pathways developed by various local services were helpful and informative. It is easy to assume (unless one is a service user) that a diagnosis can 'open doors to support and services' (1.1.11). However, a service offer does not mean that the varied needs of autistic children are met, nor that the service is sufficient to meet the need.	Thank you for your comments. The GDG consider that involving different agencies in the ASD strategy group and ASD team would encourage more inter-agency co-operation. The GDG have also recommended that a full assessment of needs is carried out and with consent shared with key professionals in other services. The GDG view is that the assessment of needs will provide a basis for support/information whether a diagnosis of ASD is given or not.

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167.	SH	Royal College of Speech and Language therapists	10	Full	1.2	3	Comment on *70% of individuals with ASDs also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing psychosocial functioning.* This comment suggests that there is a key role for mental health and clinical psychologists in the ASD assessment. SLTs often find that additional services are very difficult to source locally. We are concerned that without the availability of additional services SLTs will be required to carry out the initial ASD assessment without input from other professionals, such as psychologists. We consider that the guidance needs to make allowance for the involvement of other services, such as mental health and clinical psychologists, along the ASD assessment pathway.	Thank you. The recommendations now specify that a speech and language therapist and psychologist should be included in the core ASD team.

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168.	SH	The Royal college of psychiatrists in Wales	5	Full		1 and 22	Where is says, "...families and carers who may have always known there was something wrong", the working could be changed from "wrong" to "different" as some people (parents or people with ASD's in particular) may find this more acceptable.	Thank you for your comment, this section has now been amended.
169.	SH	Autism NI	1	Full		27 , 29	References to Northern Ireland should be deleted as there is a separate DHSSPS process for implementing NICE guidance in NI. (see circular HSS(PPMD)/(NICE)01/06)	Thank you for your comment, this amendment has now been made.
170.	SH	RCN	3	NICE	**recommendation**	8	Should this also include input from those involved in the child or young person's education? Should it also include input from carers in the case of looked after children?	Thank you for your comment. The GDG agree that input from those involved in the child's education and social care can be extremely valuable in expediting and increasing the accuracy of the diagnostic process and made reference to this in several recommendations including their key priority for implementation which states that the ASD specific diagnostic assessment must include assessment of the child or young person's experiences of education and social care. The sharing of information between services features prominently in other recommendations throughout the guideline, albeit within the limits of the scope and the legal requirements surrounding consent. For example, the guideline has now recommended that a school report should be sought about every child who will be having an ASD assessment (with the parent's, carer's and when appropriate the child's or young person's consent) so that behaviour in other contexts

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								is available at the diagnostic assessment. The GDG also made a recommendation that when there is insufficient information to make a decision about referral for an ASD diagnostic assessment, clinicians should consider seeking information from schools. Finally the GDG have, in accordance with NICE style and with advice from PPIP, used the term parent or carer wherever possible to indicate that their recommendations apply to anyone who has legal responsibility for the child, not just blood relatives. When a child is in care, the story of current function needs to include information from the carer.
171.	SH	HTA Ref 2	43	Full	1.3	10	Point 45 – add *average and above average ability* to the bullet points	Thank you for your comment. The GDG view is that the current list of bullet points in the recommendation highlights the children and young people where there more likely to be instability in a diagnosis of ASD. The rationale for this is described in the translation of evidence to recommendations in section 5.20.
172.	SH	Autism Education Trust	5	Full	1.1.38	1	the term "on the spectrum" may be more acceptable than "with ASDs"	Thank you for your comment. The GDG agreed to use the term ASD as the acronym for autism spectrum disorders.

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173.	SH	Royal College of Paediatrics and Child Health	13	NICE	Key priorities for implementation	7	The guideline leaves it unclear whether a multi professional assessment is **usually** appropriate. Experience has told us locally that this is best practice; the value of the separate professional perspectives, especially specialist speech therapist and/or clinical psychiatry may only become apparent after they have made their assessments. This has resource implications. The guideline does not seem to address the limitations of 'diagnosis' by a single professional, e.g. a psychiatrist or paediatrician using reported history without broader assessment and information.	Thank you. The view of the GDG is that an experienced expert in the diagnosis of ASD may make a diagnosis (using ICD-10 or DSM-IV criteria) single handed, but a profile of strengths, skills, impairments and needs is now one of the key elements of the ASD diagnostic assessment. This profile cannot be done by one individual but requires a multidisciplinary team to carry out all the necessary assessments. This is now clarified in chapter 5.

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174.	SH	Airedale NHS Foundation Trust	3	NICE	1.1	10	We support the concept of a local pathway and currently this is the way we operate in our area.	Thank you for your comment
175.	SH	Royal College of Paediatrics and Child Health	14	NICE	Key priorities for implementation	7	The ASD strategy group should include appropriate representation from adult services, as transition to adult services is identified as a goal.	Thank you for your comment. The GDG has now recommended that a child and adolescent psychiatrist be involved in the ASD team to smooth the transition to adult services. We have also identified the need for liaison with adult services for any child approaching transition
176.	SH	SCIE	3	NICE	Key priorities for implementation	7	First bullet point –strongly agree	Thank you for your comment.

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177.	SH	BACD-British Assoc of Childhood Disability	2	Full	1.2	2	**ASD strategy Group** - Good idea but apart from a teaching and training role there is no reference to them being a group who will collect data or audit the local service which would I believe be key to strategy, outcome measurements and relevant for service planning.	Thank you for your comment. The GDG has added that the ASD strategy group is responsible for ensuring data collection and audit of the pathway to their recommendation.
178.	SH	British Association for Art Therapists	2	Full	1.2	2	Local ASD strategy group should also include representation from art therapy services and should be considered separate from the education services Reference as above and including-	Thank you. The GDG agree that art therapy is a valuable intervention for children/young people with ASD. We did not prioritise art therapy in the strategy group or ASD team as these services are not core to ASD diagnostic services and many areas would not be able to provide them.

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							Working with Children in Art Therapy is a collection of papers by ten art therapists, Each paper describes a different theoretical perspective and clinical setting with an emphasis on the language of art in art therapy and ways of understanding non-verbal communication. Contributions cover working with children in psychiatric clinics within the National Health Service, in mainstream and special schools, and in the social services. 'Art versus language (separate development during childhood)' Working with Children in Art Therapy, Dubowski, J (1990) This article examines some of the factors that contribute to the success of art as a therapeutic tool with children with autism. Art and the Child with Autism:	

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							Therapy or education? Early Child Development and Care, 08 2003, vol./is. 173/4(411-423), 0300-4430;1476-8275 (Aug 2003) Osborne, Jan	
179.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment. The GDG considered ‘local’ to be most applicable term as it would vary depending on how services are structured in different areas. It will usually be synonymous with the local authority area.

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180.	SH	Royal College of Paediatrics and Child Health	27	NICE	1.1.1	10	We would like clarification on the evidence that a local 'ASD strategy group' will improve the service, as well as for the composition of the group, especially including parents and voluntary organisations? This is politically correct but we are concerned that such a group will be more politically driven than serving a truly evidence-based purpose. Anecdotal evidence notes a local clinician group which meets regularly. It is reported that this group has been extremely helpful in refining the pathway, and that it has the interests of clients, without the need for service user presence. We note this could itself be giving certain individuals unfair advantage at the expense of others.	Thank you. The guideline has been developed taking into account the Autism Bill and Autism strategy. We have listed the proposed membership for multiagency planning which includes commissioners, clinicians, parents et al. This could be a model for other children's services.

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181.	SH	Airedale NHS Foundation Trust	4	NICE	1.1.1	10	We agree that there should be a local ASD Strategy group – this is the situation for Bradford.	Thank you for your comment.
182.	SH	Ambitious about Autism/Autism Alliance	1	NICE	1.1.1	7	Ambitious about Autism would like to know how the strategy group will be accessible to parents and be held accountable. For example, could a parent representative join the meetings?	The GDG agreed not to be prescriptive about the accountability of every local strategy group as this is beyond the remit of a clinical guideline.

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183.	SH	Ambitious about Autism/Autism Alliance	4	NICE	1.1.1	7	The Autism Act requires local authorities to appoint an autism lead. Ambitious about Autism feels that this officer must be required to maintain a strong relationship with the strategy group and have the knowledge and influence to make a significant input on local practice. Whilst the autism lead will not be involved in diagnosis, it is important that the local authority is aware of the numbers of diagnoses and levels of need in their area, in order to ensure they are able to commission the correct range and level of services.	Thank you The guideline has been developed taking into account the Autism Bill and Autism strategy. We have listed the proposed membership for multiagency planning which includes commissioners, clinicians, parents et al. This could be a model for other children's services.
184.	SH	Association of Child Psychotherapists	5	NICE	1.1.2	10	We welcome the emphasis on improving early recognition of ASD through training. We would welcome a recommendation that professionals should aim for a diagnosis as early as possible, rather than following the present frequent practice of re-assessing	Thank you for your comment. We have recommended that the ASD teams have skills in diagnosis from 0-19 years and have encouraged early recognition and diagnosis at all stages of the pathway. The GDG have noted that there may be uncertainty about diagnosis children under 24 months of age but the entire tenor of the guideline is directed towards early diagnosis.

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							children once they reach the age of 24 or even 30 months.	
185.	SH	British Psychological Society	1	Full	1.2	2 line 25	We suggest adding a bullet point 'advise on the development of a range of flexible resources suitable for people with ASD'.	Thank you for your comment. The provision of resources for people with ASD is outside the scope of this guideline since this implies that a child or young person has already been diagnosed with ASD. The scope of the upcoming children's guideline on the management of ASD may cover this aspect of care.
186.	SH	Royal College of Speech and Language therapists	11	Full	1.3	3	Comment *Improving early recognition of ASD by raising awareness of the signs and symptoms of ASD through training.* We agree with this general statement, but we consider that there must be further information (potentially outside of this guidance) that sets out how this commitment will be achieved (e.g. time scales, outcome measures, and funding commitments). We have concerns that young people and their families visit a number of service providers along the current ASD assessment	Thank you for your comment. We agree with this concern. The GDG have recommended that those responsible for ASD assessment should avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

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							pathway which can be both timely and frustrating.	
187.	SH	Derbyshire Mental Health Trust	6	Nice		7	As comment 1. MDT may include a Specialist Nurse	Thank you for your comment. The GDG have amended this recommendation on the team to clarify the role of specialist nurses.

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188.	SH	Nottinghamshire Healthcare NHS Trust	1	Full	1.1.2 – 7	10 -12	The context of the ASD team needs clarification. Is this a new team or is a "virtual" team or clinic. If this is a new team then where does the funding stream come from (Child health / CAMHS). Where such a team would be based? Guidance needs to be given about whole time equivalent resources that make up this team or should be committed to this effort.	Thank you for your comment. The GDG considers that the ASD team will consist of existing professionals already involved in diagnosing ASD. These professionals may also be affiliated to other organisations and professionals groups and be involved in assessing children with other conditions. The purpose of having an ASD team is for these professionals to recognise that they are a team and for others (referrers) to recognise who is in the team locally. This has now been clarified in chapter 5 with examples of services in chapter 10.
189.	SH	Nottinghamshire Healthcare NHS Trust	2	Full	1.1.3	10	The team composition could also include Clinical Nurse Specialists or other Mental Health Specialists with appropriate training and experience	Thank you for your comment. In recognition of variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.

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190.	SH	Derbyshire Mental Health Trust	1	Full	1.2	2	There should be a multidisciplinary ASD team which may include a Specialist Nurse	Thank you for your comment. In recognition of variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.
191.	SH	British Psychological Society	1	Full	1.2	2 line 26	We suggest replacing 'may' with 'should'.	Thank you. This recommendation has been changed to "should" to reflect the importance of a core membership of the ASD team.
192.	SH	British Psychological Society	1	Full	1.2	2 line 31	We suggest an addition to the last bullet point, 'occupational therapist and other professionals as appropriate'.	Thank you for your comment. In recognition of the variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.
193.	SH	Royal College of Speech and Language therapists	7	Full	1.2.	2	There needs to be stronger wording and certainty around the makeup of the multidisciplinary ASD team. Currently the document states: There *should* be a multidisciplinary ASD team which *may* include: We suggest changing the wording to There ***must*** be a multidisciplinary ASD team which ***must*** include:	Thank you. This recommendation has been changed to "should" to reflect the importance of a core membership of the ASD team.

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							If stronger wording is not used in this section then key team members, such as SLTs, may be excluded.	
194.	SH	Department for Education	5	Full		97, recommendations, 3	suggest that as well as an educational psychologist there should be someone from the local authority's Special Educational Needs team or its Autism Outreach team if it has one.	Thank you. NICE guideline cannot make recommendations for professionals outside the NHS but throughout the guideline we have emphasised the need for a multiagency approach.
195.	SH	Royal College of Paediatrics and Child Health	28	NICE	1.1.3	10	Assessment for possible ASD is now a common cause for referral to Community Child Health Services and it could in some districts cause unacceptable delays in diagnosis if only a dedicated team were to be allowed to carry out assessments. The evidence that a dedicated ASD team is a better model than managing ASD assessment within the general child development team has been queried.	Thank you for your comment. In recognition of the variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals will contribute to the diagnostic process, depending on local commissioning arrangements. This recommendation addresses the need for a recognised group of professionals' expert in the diagnosis of ASD. This will not prevent them from working in other professionals groups and teams and should not ring fence resources.

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							ASD is the commonest developmental syndrome and it has been suggested that all clinicians involved in specialist child development services should have the skill to assess and diagnose the majority of affected individuals. There is concern that to set up a dedicated ASD team could de-skill other members of the child development team, and may disadvantage other client groups by ring-fencing resources away from them, and therefore be inequitable. It is agreed that within this group of clients some are diagnostically challenging and there should be local mechanisms to address these challenges, but this is seen to be different from setting up a dedicated ASD team for everyone referred for ASD assessment.	
196.	SH	Northumberland and Tyne and Wear NHS	1	NICE	1.1.3	10	Although local circumstances will vary, it would be helpful to include some definition of the population area to be covered	Thank you. We have not defined the size of the population to be covered by an ASD team as this will depend on local arrangements and is beyond the scope of a clinical guideline. The GDG has in mind a local authority area which, depending on size, will need variable size

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		Foundation Trust					for a 'local pathway' and multidisciplinary ASD team. Taken literally, the guidance might suggest one team of 5 part time members would be able to provide all ASD diagnostic services for a large local authority area. This is not so, and would lead to very long waiting lists.	of ASD MDT members. We have provided some information in the Introduction on the possible number of new referrals per week for a local area.
197.	SH	Association of Child Psychotherapists	6	NICE	1.1.3	10	We welcome the acknowledgement that the ASD team should be multi-disciplinary. The high incidence of co-morbid mental health problems in ASD children makes the inclusion of mental health professionals particularly important. This section mentions various professional groups. We would add that the multi-disciplinary team may benefit from the inclusion of other mental health professionals who are skilled in observation and communicating with children and families, particularly with children who may have limited verbal skills.	Thank you for your comment. In recognition of the variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.

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							Family Therapists can help families to absorb and reflect on diagnostic information and Child and Adolescent Psychotherapists are especially trained to work with non-verbal children, to contain and process high levels of emotional distress and to work with colleagues in a way which compliments the diagnostic process, for example, in weighting the significance of family history information. Child Psychotherapists are also in a position to assess risk, including thinking about family functioning, the responses of siblings and the distress and emotional state of the child or young person themselves.	
198.	SH	Derbyshire Mental Health Trust	7	Nice	1.1.3	10	As comment 2. MDT may include a Specialist Nurse	Thank you for your comment. In recognition of the variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.
199.	SH	Sheffield PCT	1	NICE	1.1.3	10	We felt strongly that the Multi Disciplinary team should include	Thank you for your comment. The GDG considered that the case coordinator should be a clinician from within the team, but with support

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							an Administrator or an A&C person who can focus on this client group and be a positive source of contact and information for families, as well as a link with relevant professionals who may not always be at the end of a telephone.	from an administrator to gather information and arrange new assessments. This has now been made clear in the translation of evidence to recommendations in chapter 9.
200.	SH	Airedale NHS Foundation Trust	5	NICE	1.1.3	10	We agree with the team members identified but would also add "may include Specialist Autism Support Teachers and Educational Psychologists". To ensure the assessment is not only multidisciplinary but also multi-agency.	Thank you for your comment. The guideline recommends that the ASD strategy group overseeing the local ASD pathway be multiagency, recognising the need for close liaison with other agencies at that strategic level. The ASD team that undertakes the diagnostic assessment should be a multidisciplinary group within the NHS since the skills to diagnose and profile a child or young person can be identified within the NHS. This is different from the management of ASD which should be multiagency.
201.	SH	Royal College of Speech and Language therapists	14	NICE	1.1.3	7	As explored in point 10 above, there needs to be stronger wording and certainty around the makeup of the multidisciplinary ASD team. Currently the document states: There *should* be a multidisciplinary ASD team which *may* include:	Thank you for your comment. In recognition of variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.

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							We suggest changing the wording to There ***must*** be a multidisciplinary ASD team which ***must*** **i**nclude: If stronger wording is not used in this section then key team members, such as speech and language therapists may be excluded.	
202.	SH	Peach	1	NICE	1.1.3	7	We recommend that Behaviour Analysts be listed as key members of the multidisciplinary ABA team. Board Certified Behaviour Analysts are uniquely placed to help all those involved help the child with ASD to increase key skills (such as communication and social skills) and also to train and monitor the reduction of challenging behaviours. Behaviour Analysts are automatically assigned to a child with ASD in other countries such Norway and many states in the US.	Thank you for your comment. In recognition of variability across the NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.

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203.	SH	Autism in Mind	12	NICE	1.13	7, 10	*There should be a multidisciplinary ASD team (the ASD team) which may include a:* *paediatrician* *child and adolescent psychiatrist* *speech and language therapist* *clinical or educational psychologist* *occupational therapist. [1.1.3]'* The wording gives the impression that clinical and educational psychologists have interchangeable roles; they do not. Clinical psychologists	Thank you for your comment. We have clarified in the recommendations the core members of the ASD diagnostic team and made clear that access to a wide range of others is needed for the individual components of the diagnostic assessment. The precise composition is a matter for localities depending upon available expertise. The GDG is strongly supportive of educational, child health and mental health professional being core members. The GDG is well aware that clinical and educational psychologists have differing roles and think both need to be available in the wider team.

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							would have expertise that is highly relevant to the diagnosis and support of children with ASDs and the list should make clear that the two disciplines are distinct.	
204.	SH	Autism in Mind	12	NICE	1.13	7, 10	*There should be a multidisciplinary ASD team (the ASD team) which may include a:* *paediatrician* *child and adolescent psychiatrist* *speech and language therapist* *clinical or educational psychologist* *occupational therapist.*	Thank you for your comment. We have clarified in the recommendations the core members of the ASD diagnostic team and made clear that access to a wide range of others is needed for the individual components of the diagnostic assessment. The precise composition is a matter for localities depending upon available expertise. The GDG is strongly supportive of educational, child health and mental health professional being core members. The GDG is well aware that clinical and educational psychologists have differing roles and think both disciplines need to be available in the wider team.

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							[1.1.3]' The wording gives the impression that clinical and educational psychologists have interchangeable roles; they do not. Clinical psychologists would have expertise that is highly relevant to the diagnosis and support of children with ASDs and the list should make clear that the two disciplines are distinct.	
205.	SH	British Psychological Society	1	Full	1.3	4 Para 3	We suggest replacing 'may with 'should'.	Thank you. This recommendation has been changed to "should" to reflect the importance of a core membership of the ASD team.
206.	SH	Autism Education Trust	4	Full	1.3.3	4	where there is an educational psychologist involved, the team will be multiagency rather than multidisciplinary	Thank you for your comment. The GDG view is that multi disciplinary is the appropriate term for the ASD team with a minimum constituency. The recommendation has been modified to reflect that the team may have access to educational psychologist and social worker but these may not be core members of the team.
207.	SH	Derbyshire	2	Full	1.3.	4	The multidisciplinary ASD team	Thank you for your comment. In recognition of variability across the

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		Mental Health Trust			3		may also include a Specialist Nurse	NHS, we have recommended that the ASD team should have a core component of specific clinicians who must be on the team, and access to a wider group of professionals who contribute to the diagnostic process, depending on local commissioning arrangements.
208.	SH	Whetstone Head Educational (Charitable) Trust Limited	3	Full	1.3.3	4	Our comments are as follows: The replacement of "clinical or educational psychologist" with "clinical and/or educational psychologist" to denote that, dependent on needs, both strands of practise may be involved rather than just one. It is important that the guideline clearly makes reference possible joint working, so that 'commissioning' takes it into account.	Thank you for your comment. We recognise that these are distinct roles, but that in diagnostic assessment, different localities have different arrangements for access to psychology services. The amended recommendation now indicates that the ASD team could include either an educational psychologist or a clinical psychologist as core members and have access to the other professional group if they are not part of that core team.
209.	SH	British Psychological Society	1	Full	1	2	We particularly welcome the vision of a multidisciplinary ASD team (p2, lines 26 & 33)…with access through a single point of entry and an appointed case coordinator appointed from within an ASD team (line 35).	Thank you for your comment.
210.	SH	British Psychological Society	1	NICE	1.1.4	11	We recommend wording specifically reflects that - *The Team should provide diagnostic*	Thank you for your comment. The recommendations now state that the ASD team should have the skills and competences to carry out the ASD diagnostic assessment.

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							assessment of ASD for children and young people.	
211.	SH	Royal College of Speech and Language therapists	16	NICE	1.1.4	18	Section 1.4 provides a very valuable summary of risk factors from ASD	Thank you for your comment.
212.	SH	SCIE	7	NICE	1.1 4	11	Give information – again, sw contribution to ASD team	The GDG recognises the contribution of a wide group of professionals to the team and recognises the variation in local arrangements for assessment in their recommendations. There is no one model of a team which will work well in all localities across England and Wales.
213.	SH	National Autistic Society	3	Full	1.2.33	2	"Access to the ASD team should be through a single point of entry." This sentence has the potential to confuse and be misconstrued to be only a single point of referral to the ASD team.	Thank you for your comment. The recommendation has now been changed to single point of referral for clarity.
214.	SH	Nottinghamshire Healthcare NHS Trust	3	Full	1.1.5	11	The idea of a single point of access for ASD diagnosis is incredibly useful and may make better use of scarce resources.	Thank you for your comment
215.	SH	Sheffield PCT	2	NICE	1.1.5	11	Re "Access to the ASD team should be through a single point of entry" we felt that, depending on a local service's structure, single point of entry can be used as a barrier. We would be keen	Thank you for your comment. The recommendation has now been changed to single point of referral for clarity. Local arrangements may vary as to how entry to the ASD pathway is managed, but the recommendation about the ASD Strategy group makes clear that it is their responsibility to ensure that relevant professionals are aware of how to access the pathway.

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							that the guidelines make provision for referral pathways to be transparent and access to assessment should be smooth.	
216.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment. The recommendation has now been changed to single point of referral for clarity. Local arrangements may vary as to how entry to the ASD pathway is managed, but the recommendation about the ASD Strategy group makes clear that it is their responsibility to ensure that relevant professionals are aware of how to access the pathway. The GDG has not made recommendations about access to administrative support, but it is assumed this would be required for any system of referral to secondary care. A single point of referral should improve administrative efficiency and equity of access.
217.	SH	Welsh Assembly Government	2	Full			Do NICE mean 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. Single point of entry needs dedicated	Thank you for your comment. The recommendation has now been changed to single point of referral for clarity. Local arrangements may vary as to how entry to the ASD pathway is managed, but the recommendation about the ASD Strategy group makes clear that it is their responsibility to ensure that relevant professionals are aware of how to access the pathway.

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							admin and you can't access it unless you use the single entry point.	
218.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment. In recognition of variability across the NHS, we have recommended that the ASD team should have a core component of three professionals who must be on the ASD team, and have access to a wider group of professionals who contribute to the diagnostic process. This needs to be flexible, depending on the size of the population being served as well as local commissioning arrangements.
219.	SH	RCN	4	NICE	1.1.6	11	This is important, as crucial information could be missed if not communicated properly or appropriately.	Thank you for your comment.
220.	SH	Whitstone Head Educational (Charitable) Trust Limited	4	Full	1.3.6		Our comments are as follows: Specific reference should also be made to "Children in Care/Looked After Children", as additional skills are often required with this group of young people.	Thank you for your comment, this amendment has now been made.
221.	SH	Optical Confederation/ LOC Support Unit	3	NICE	1.1.6	11	Section 1.1.6 mentions access to professionals that have skills needed to carry out ASD assessment. There is a need to have access to optometrists skilled in functional vision assessment and assessing	Thank you for your comment. The guideline does not make specific recommendations on which professionals should carry out each type of assessment. The recommendation has now been changed to severe visual impairment as suggested.

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							patients with limited or no communication and poor cooperation. Second bullet, same section, “blindness” needs to be changed to “severe visual impairment”.	
222.	SH	NHS Milton Keynes	1	Full	1.3	4	Our comment is that it would be helpful to clarify the meaning and age of transition as this can be interpreted in different ways by different services / teams / organisations. Also that the wording should reflect that that flexibility in approach should be retained, as not only does the age of transfer from children to adult services vary but also the availability of resources particularly across adult ASD teams.	Thank you for your comment. We agree that there should be flexibility in the time at which a young person transfers to adult care. It is recognised that there is variation in this regard. This may be appropriate. This recommendation does not address that issue but emphasises the need for joint working when a young person is soon to move to adult services.
223.	SH	HTA Ref 2	12	Full	1.3	4	Point 7 – young person's – (change apostrophe)	Thank you for your comment, the suggested amendment has now been made.
224.	SH	RCN	5	NICE	1.1.7	12	This is important for continuity.	Thank you for your comment.
225.	SH	Royal	29	NICE	1.1.	12	We would like clarification on	Thank you for your comment, the Autism Act 2009 makes this a

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		College of Paediatrics and Child Health			7		whether there is an adult ASD diagnostic team in every borough in the UK.	requirement.
226.	SH	Association of Child Psychotherapists	7	NICE	1.2	12	It may be helpful for the guidance to acknowledge that part of the complication of assessing for ASD is that a child may 'function' well with familiar people in familiar environments and this may serve to mitigate the concern of those who are considering whether they should evoke a referral to a local ASD strategy group. It may be helpful to acknowledge that a 'flag' may be the contrast in functioning (as for instance in familiar vs. unfamiliar settings).	Thank you for your comment. This is an important concern which the GDG has addressed in their recommendation on what to be aware of when considering the possibility of ASD.
227.	SH	Royal College of Paediatrics and Child Health	30	NICE	1.2 – 1.9	12 -29	We feel that the style of the writing read like a 'Personal Practice' article from a medical journal rather than a set of national guidelines. It is felt that at times the style is somewhat patronising; we think others may be put off by the writing. We do not doubt the evidence base for	Thank you. The guideline has been revised and in particular the presentation of evidence to recommendation on sections has been edited for clarity.

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							the information as this appears to be a well researched piece of work, but it would be a pity if it is let down by the style of writing.	
228.	SH	SCIE	8	NICE	1.2.2	12	Good point	Thank you.
229.	SH	SCIE	9	NICE	1.2.3	12	Good point	Thank you for your comment.
230.	SH	NHS Milton Keynes	2	Full	1.3.11	5	Our comment is that the word "explore" should replace the word "identify" ….the possibility of ASD.	Thank you. The GDG view is that 'identify' is a more accurate term for what professionals are required to do at this stage of the pathway.
231.	SH	Nottinghamshire Healthcare NHS Trust	4	Full	1.2.4	12	If providing such comprehensive tables as guidelines to untrained professionals, there needs to be some guidance included about the threshold numbers of such signs that would need to be seen before making a referral.	Thank you for your comment. The GDG carefully considered whether numbers of signs would be helpful and of course also considered tools to identify an increased likelihood of ASD which are constructed to give 'cut offs'. The latter were insufficiently sensitive or specific to recommend for use in all circumstances. The signs and symptoms are primarily designed to allow practitioners to gain an overall pattern of different behaviours that may indicate ASD. Training is extremely important for all professionals in recognition of signs and symptoms. The recommendations also make clear that the ASD team is available for consultation in cases of doubt with regard to referral. However, clinical experience of the GDG suggests that defining a specific threshold carries a risk of harm in terms of missing children and young people. They did note that regression of language or social skills in children under 3 years should lead to a referral for an ASD specific assessment.

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232.	SH	Airedale NHS Foundation Trust	6	NICE	1.2.4	12 -15	We like the inclusion of the tables to help identify the signs and symptoms of possible ASD across the age range.	Thank you for your comment.
233.	SH	SCIE	11	NICE	1.2.5	16	Good point	Thank you for your comment
234.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	2	NICE	1.2.5 and 1.3.3	16 18	The list of signs divided by age (tables 1.1 to 1.3) are helpful. But there should be some comment about how many signs might indicate a need for referral, or at least that there is a pattern, not simply one sign.	Thank you for your comment. The clinical question that underpinned the review on which these recommendations were based set out to establish whether it was possible to define a threshold for referral based on a particular number, level of severity or combination of signs and or symptoms. However, given the lack of good quality evidence that was found and their clinical experience of the variety of ways in which ASD can present, the GDG concluded that providing a specific threshold carried a significant risk of harm in terms of 'missing' children and young people who did not conform to the exact model. They did note that regression of language or social skills in children under 3 years should lead to a referral for an ASD specific assessment. For more details of their deliberations regarding these recommendations please see section 3.4 of the full guideline.
235.	SH	Derbyshire Mental Health Trust	8	Nice	1.2.6	16	As comment 3. Should not assume language delay is accounted for by early hearing difficulties	Thank you for your comment the GDG agrees with your view and the recommendation has now been amended to include hearing difficulties.
236.	SH	Derbyshire Mental Health Trust	9	Nice	1.2.6	16	As comment 4. regarding girls presentation	Thank you for your comment. This recommendation has been changed to "ASD may be under-diagnosed in girls"
237.	SH	GOSH Haringey	2	Full	1.2.6,		Lack of history seems to be a feature in dysfunctional and chaotic families and where	We agree that home circumstances may contribute to the non-availability of early history. We highlight the problem in relation to signs and symptoms in the recommendation for clinicians considering

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					last bullet		domestic violence is an issue but has not been disclosed.	the possibility of ASD. The importance of home life is now highlighted also highlighted in the recommendation about the components of the diagnostic assessment.
238.	SH	HTA Ref 2	42	Full	1.3	5	Point 13 – add *ASD may also be missed in intellectually able individuals as their ability may mask their difficulties*	Thank you for The GDG agreed that this point should include a wider group than those who are intellectually able, and have amended the bullet point to highlight children and young people who are verbally able.
239.	SH	British Psychological Society	1	Full	1	5	Use of 2nd person in pt 13 on p5 seems incongruous given the formal nature of the surrounding text/document.	Thank you. The GDG would like to keep the mix of styles in the bullet points
240.	SH	NHS Milton Keynes	5	Full	1.3.13	5	Our comment would be to say that when considering the possibility of ASD, be aware that: Signs and symptoms should be seen in the context of the child's overall development '**and environment'**.	Thank you for your comment. The assessment takes into account all the circumstances and there is a concern that there may be diagnostic overshadowing at primary care level for signs and symptoms of ASD if environment at an early stage in the pathway and discourage referral. The importance of home life is now highlighted also highlighted in the recommendation about the components of the diagnostic assessment.
241.	SH	Derbyshire Mental Health Trust	3	Full	1.3.13	5	You should not assume language delay is accounted for by early hearing difficulties e.g. glue ear	Thank you for your comment the GDG agrees with your view and the recommendation has now been amended to include early hearing difficulties.
242.	SH	Derbyshire Mental Health Trust	4	Full	1.3.13	5	The signs and symptoms of ASD may be more subtle in girls and they may present differently e.g. girls often have more innate or have learnt to imitate social	Thank you for your comment. There was no evidence for this, but the GDG agree with your viewpoint and believe that it is already reflected in their recommendation which advises health-care professionals to be aware ASD may be under diagnosed in girls, the rational for which can be found in section 3.4 of the full guideline.

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							behaviours, girls can show more kindness and understanding of others, specialist interests can be less intense and more socially acceptable, girls are often more passive and less disruptive than boys. Girls may have been given an earlier diagnosis of something else e.g. anxiety, depression, eating disorder, ADHD etc.	
243.	SH	Whitstone Head Educational (Charitable) Trust Limited	5	Full	1.3.13	5	Our comments are as follows: The insertion of a further sub-category stating, "when Children in Care present with possible ASD, signs or symptoms may have been 'overlooked' or 'masked' by the child's developmental history (including parental; neglect, multiple placements, the absence of relevant medical histories/records, other environmental and social factors)	Thank you. Your point relates to the potential difference in recognising symptoms and signs in a developmental context and where home life is disruptive (whether a child is looked after in care or living at home). These issues are addressed in relation to signs and symptoms in the recommendation for clinicians considering the possibility of ASD.
244.	SH	NHS Milton Keynes	3	Full	1.3.14	5	Our comment is that there should be reference made that a history of pretend play should not rule out ASD, as pretend	Thank you for your comment. The recommendation has been amended to advise readers not to rule out ASD because of reported pretend play or normal language milestones.

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							play can be a learnt behaviour.	
245.	SH	Derbyshire Mental Health Trust	5	Full	1.3.14	5	Do not rule out ASD because child or Young Person can make eye contact, but consider the quality/intensity of the eye contact	Thank you for comment. The GDG agree with your point and believe that it is already reflected in the third bullet of this recommendation.
246.	SH	British Psychological Society	1	Full	1	5	It is noted that the document's portrayal of diagnostic boundaries re: inclusion of ASD are relatively generous (eg pt 14 on p5).	Thank you for your comment. The GDG is aware that the diagnostic threshold for ASD is highly complex. The emphasis at the recognition stage is to not miss any children with ASD who should be investigated. Discussion of the diagnostic boundaries has been expanded further in the introduction.
247.	SH	Royal College of Paediatrics and Child Health	24	NICE	1.2.7	16	The DSM-IV criteria for autism do specifically state that there should be delay or abnormal functioning in at least one of the following areas with onset prior to 3 years: social interaction, language as used in social communication, and symbolic or imaginative play. With the DSM-V criteria lumping childhood disintegrative disorder under the umbrella term of autism spectrum disorder, then this may state that symptoms may not become fully manifest	We agree, and have amended the recommendation on that basis that symptoms will still have to be present in early childhood but they need not include early language delay thus if normal pre-school development is reported, ASD can still be diagnosed. The introduction to the full guideline now provides a discussion of the diagnostic boundaries of ASD.

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							until social demands exceed limited capacity – but that symptoms should still be seen in early childhood. We would like clarification on whether this change in terminology is affecting the NICE guidelines. The guidelines state, "do not rule out ASD because of a reported normal or advanced pre-school development". Does this mean that if, following an assessment, preschool development was in fact normal and not just reported, we could exclude autism spectrum disorder?	
248.	SH	SCIE	12	NICE	1.2.7	16	Suggest consideration of gender here –some evidence that girls mask the condition better. (This may be covered in full version, but , if so,worth including here also)	Thank you. The important matter of recognition of ASD in girls is addressed in the recommendations.
249.	SH	Derbyshire Mental Health Trust	10	Nice	1.2.7	16	As comment 5. regarding eye contact, consider quality/intensity of eye contact	Thank you. The GDG decided not to change the recommendation. This stage of pathway includes non-experts who could not be expected to judge this.
250.	SH	NHS Milton Keynes	4	Full	1.3.15	5	Our comment is that consideration should be given to	Thank you. The recommendation on what to be aware of when considering ASD has now been changed to clarify this point.

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							rewording this section to provide more clarity by adding that there may be new information or concern which was not present at the time of initial assessment.	
251.	SH	Nottinghamshire Healthcare NHS Trust	5	Full	1.3	17	Consent of either the parent or young person is always required prior to making a referral. Referrers should look at DoH guidelines on competence and consent if unsure about who might be able to consent to the referral.	Thank you for your comment. Reference is made to the Department of Health guidance on consent in the introduction (see section 2.1.8) and the GDG have also revised their recommendations to make it more explicit when consent should be sought and from whom.
252.	SH	SCIE	13	NICE	1.2.11	17	Good message	Thank you for your comment.
253.	SH	The Royal college of psychiatrists in Wales	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".	Thank you for your comment. We agree with your point of view and have amended the recommendation which now does not specify should be urgent.
254.	SH	Royal College of Paediatrics and Child Health	19	NICE	1.3.1	15	We note that repetitive behaviours **may** impact negatively - some children have great comfort from repetitive behaviours without detriment to their lives or that of others; it	Thank you for your comment. Repetitive behaviours may have different impacts on children's lives but we have concluded that their current description of these behaviours as 'unusual' does not necessarily carry a negative undertone. The recommendation is to alert healthcare professionals to look out for repetitive behaviours that are uncommon in the majority of children. The GDG decided not to

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							depends on type and frequency.	make an amendment in this case.
255.	SH	Welsh Assembly Government	3	Full			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 to me that the meaning is "should always refer without undue delay"	Thank you for your comment, the GDG with your point of view and have amended the recommendation so that it no longer advises that this referral should be urgent.
256.	SH	SCIE	14	NICE	1.3.4	18	In this context, what else would you suggest ?	Thank you. We are not making any other specific suggestions as there is no evidence base from which to do so. We have made a research recommendation that tools to gather information from other sources, such as schools and nurseries.
257.	SH	Association of Child Psychotherapists	8	NICE	1.3.4	18	We are in agreement that screening tools should not be used on their own to make or rule out a diagnosis of ASD.	Thank you for your comment
258.	SH	RCN	6	NICE	1.3.6	19	*Explain to parents what will happen after referral.* This is important as will help minimize their anxiety.	Thank you for your comment
259.	SH	Association of Child Psychotherapists	9	NICE	1.3.7	19	As at point 5, we have concerns about the recommendation to watch and wait if the clinician is unsure or if parents prefer not to be referred to the ASD team. The guidance does not make clear what is recommended after	The child or young person's interests should always predominate in any decision to proceed to assessment. We have opted for the word "consider" to allow the clinician to use judgement about whether this is in the child's best interests. We have also made a recommendation that clinicians should be critical about their own professional competence in this regard.

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							this if professional concern remains high and the family do not wish to pursue a diagnostic process. A situation where a clinician is unsure and/or the family unwilling can, understandably, often lead to a delay that is against the child's interests. We suggest that, if clinicians are uncertain, they should consult with colleagues and arrange a follow-up assessment sooner rather than later; and that parents who do not wish to be referred to the ASD team should be offered help and support to understand why such a referral is in their interest as well as in the child's.	
260.	SH	Association of Child Psychotherapists	10	NICE	1.4	19	We welcome the recommendation that there should be no delay in considering the type of assessment that is appropriate to offer once a child has been referred to the ASD team.	Thank you for your comment.
261.	SH	The Royal college of psychiatrists	10	Full	1.3	7	Recommendation 29: Would benefit from emphasising the need to involve	Thank you for your comment. The GDG recognise the need for involving the family and carers in decision-making throughout the guideline. At this stage, the family or care or the older child / young

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		in Wales					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."	person themselves has agreed to the referral to the ASD team and a decision is being made within the team about the appropriateness of the referral. Once that decision has been made, there should be no undue delay in proceeding to the assessment. However this recommendation has been re-worded in light of other stakeholder comments to clarify that these referrals are not necessarily of higher priority than others.
262.	SH	GOSH Haringey	3	Full	1.4.1		Every district is different. To suggest that a member of the asd team has to consider without delay cannot be implemented. In this district the referrals are all discussed at a weekly intake meeting chaired by a consultant community paediatrician who carries out asd assessments but is not a member of the ASD team. This works well and children are appointed within 8-10 weeks. There will be an inherent delay from date referral is recd to a weekly intake meeting. Therefore the phrase “ consider without delay” will increase parental/referrer expectation and unnecessary enquiries about referrals.	Thank you for your comment. Reference to timing has been removed from this recommendation. The key message in is that the assessment should be done by the ASD team. More specific details about timings are given in other recommendations.
263.	SH	Welsh	4	Full			Would benefit from emphasising	Thank you for your comment. The GDG recognise the need for

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		Assembly Government					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"	involving the family and carers in decision-making throughout the guideline. At this stage, the family or care or the older child / young person themselves has agreed to the referral to the ASD team and a decision is being made within the team about the appropriateness of the referral. However, the GDG reconsidered the wording of this recommendation in light of all stakeholder comments and removed the 'without delay' for clarity.
264.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment. The GDG view is that specific factors should rule out a referral first as this depends on all the strength of the evidence taken together when considering referral. The GDG view is that lowering the threshold for recognising the signs is a move in the right direction if those children who have other conditions are also recognised early on. The guideline recommends gathering information and making decisions about referral so that ASD can be ruled out early and those children who do not require a full ASD diagnostic assessment are not on the pathway longer. They can be referred on to other services that meet their needs.
265.	SH	NHS Milton Keynes	13	NICE	1.5 1	21	Our comment is for some clarification to be made on whether the assessment is to be completed within three months or for the assessment to be started within three months of initial referral.	Thank you for your comment. The timeframe for three months applies to when the assessment should begin; an amendment has been made to the recommendation to clarify this.

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266.	SH	Optical Confederation/ LOC Support Unit	5	NICE	1.4.4, second bullet	20	The need for a hearing test is mentioned. There is also a need for a vision test.	Thank you for your comment, the GDG agrees and has amended the recommendation to make it clear that any available information from healthcare professionals should be gathered.
267.	SH	Royal College of Paediatrics and Child Health	31	NICE	1.4.4	20	If a child is known to education services, either to pre-school teachers or attending a school, then we think that information should be sought from them with parental consent from the outset, without waiting till there are diagnostic uncertainties. This will provide crucial information about peer relationships that cannot be obtained by individual assessments. There are times that they will provide information that differs from parental reports, and that itself is important in making diagnostic judgements.	Thank you for your comment. The GDG agree that, with parental consent, a school report is essential when making a diagnostic assessment because it gives crucial information about peer relationship and social function which is a core diagnostic feature. The recommendations now state that a report from school or nursery be sought.
268.	SH	Airedale NHS Foundation Trust	7	NICE	1.5.1	21	We agree with the timescales identified here.	Thank you for your comment.

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269.	SH	Royal College of Speech and Language therapists	17	NICE	1.5	21	Section 1.5 provides very clear and useful guidance on what should happen following an ASD diagnostic assessment.	Thank you for your comment.
270.	SH	British Psychological Society	1	Full	1	7	There are occasional points that need clarifying in the real clinical world, e.g. (p7, line 33 and p75, pt 33). We feel that clarification of "Once it is decided ...." is necessary.	Thank you for your comment the recommendation has been amended for clarity.
271.	SH	Royal College of Speech and Language therapists	8	Full	1.2	2	Comment *A case coordinator should be appointed from the ASD team* We are concerned that that this comment does not clarify who the case coordinator should be and how this person should be selected. We recommend further guidance on how this role would be determined.	Thank you for your comment. We have clarified the role of the case coordinator as a single point of contact, a means for communication between the parent/carer and other member of the team and as a person able to update the family about the assessment, provide information and support and gather information. The recommendation has been clarified to make these points explicit.
272.	SH	Royal College of Paediatrics and Child	32	NICE	1.5.2	21	A case coordinator to liaise across agencies and to help families receive appropriate support after assessment would	Thank you. The GDG saw the appointment of a case coordinator to facilitate communication and support families throughout the potentially complex process of a diagnostic assessment. This could be seen as a model of good practice for patient pathways more

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		Health					indeed be a positive development. We do, however, question why there should be a case coordinator specifically for those referred for ASD diagnostic assessment. This may be unfair to other client groups. We feel that case coordinators should be appointed according to need and not according to diagnosis. This relates not only to the complexity of the child's condition, but also to family factors and social factors. We suggest that some children with straight-forward diagnoses (e.g. Down's Syndrome) have more need for case coordination than some children assessed for ASD. We support the recommended practice in 1.5.3 but feel that this should apply to all clients and not only to those assessed for ASD.	generally.
273.	SH	GOSH Haringey	4	Full	1.5. 2		The case coordinator as suggested is a professional who	Thank you for your comment. The GDG sees the appointment of a case coordinator to facilitate communication and support families

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					, 1.5.3		is a member of the asd team. This is a waste of resources (with or without a recession) and can be done by a named secretary for asd. She carries out functions in 1.5.3, 1st and 3rd bullet. Bullet 2 can be is carried out by HV, SENCO or referrer and could be incorporated.	throughout the potentially complex process of a diagnostic assessment as being of central importance. The case coordinator needs to be a member of the ASD team as their role is not a secretarial one, but required a detailed understanding of the assessment process. This would not be an additional appointment but an assignment within the team. This could be seen as a model of good practice for patient pathways more generally.
274.	SH	SCIE	15	NICE	1.5.3	21	Good points	Thank you for your comment
275.	SH	Royal College of Speech and Language therapists	9	Full	1.2	2	Comment *social and communicative skills* We consider that the guidance needs to make an explicit recommendation that an SLT will be responsible for the assessment of *the social and communication skills* element of the ASD assessment process.	Thank you for your comment. The recommendations now state that a speech and language therapist should be part of the core constituency of every ASD Team.
276.	SH	SCIE	4	NICE		8	Developmental history – good point	Thank you for your comment
277.	SH	SCIE	5	NICE		8	Assessment through interaction- good point	Thank you for your comment
278.	SH	HTA Ref 2	41	Full	1.2	2	Line 47 – add assessments or	Thank you.

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							reports based on observations across a variety of settings and situations with and without other children and adults (eg home, school, community)	The GDG considered that not all children would need detailed observations across a variety of settings as it may not be necessary for all children and young people to reach a diagnosis to develop a profile. The recommendations make clear which circumstances additional observation should be undertaken.
279.	SH	British Psychological Society	1	Full	1.2	2 line 44	We suggest replacing 'consider' with 'recommend'.	The GDG believe that consider is the right term as there are situations where a health care professional can take a good history focussing on the criteria in ICD and DSM without using a formal semi structured tool
280.	SH	British Psychological Society	2	Full	1.2	2 line 48	We suggest adding 'in a familiar setting if possible'.	Thank you for your comment, the GDG did not think that it was always necessary to observe the child in a familiar setting and therefore have chosen not to make this amendment.
281.	SH	British Psychological Society	2	Full	1	2 (lines 39-50)	The Society recommends the developmental history and interactive/observational assessments being listed prior to medical history with pre-, peri-natal and family history etc, in order to highlight their relative importance in determining a diagnosis of autism.	Thank you for your comment, this amendment has now been made.
282.	SH	Royal College of Paediatrics and Child Health	43	Full	1.3	8 and throughout guideline	We think that maltreatment should include domestic violence and this should be a standard question asked in all ASD assessments.	Thank you for your comment. The GDG recognised that maltreatment generally was an important concern and account is taken of that is taken in the recommendation about the components of the diagnostic assessment which advises that there should be specific enquiry into child's or young person's experience of home life. The GDG view was that it was not appropriate to make direct enquiry about domestic violence or maltreatment in every assessment.

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							We think that ODD and conduct disorder are descriptive. Anecdotal experience suggests that there are nearly always child protection issues. An attachment disorder/PTSD should be considered and all children should have a very thorough social and child abuse history taken.	We agree that a thorough history should be taken and individual clinical judgment is vital in interpreting this.
283.	SH	British Psychological Society	1	Full	1.3	8 para 36	We suggest adding 'in familiar settings' after 'observation' in fifth bullet point.	Thank you for your comment, the GDG view is that it is not always necessary to observe the child in a familiar setting to reach a diagnosis and develop a profile of needs. The recommendations provide guidance on when an observation in other settings is needed.
284.	SH	Nottinghamshire Healthcare NHS Trust	9	Full	1.5.4	21	Assessment should include educational reports or observations, including information regarding social interactions specifically	Thank you for your comment. It has now been clarified that at this stage of the pathway, assessments from schools or other educational settings will already have been gathered for every child or young person before they proceed to the face to face ASD specific assessment.
285.	SH	Nottinghamshire Healthcare NHS Trust	10	Full	1.5.4	21	Guidelines should include specific names of appropriate assessment tools, such as ADI-R, ADOS, DISCO, SCQ	Thank you for your comment. The GDG considered naming the assessment tools that could potentially be used to help gather information during the ASD specific diagnostic assessment, however, given the lack of evidence to support their use identified in the systematic review ultimately concluded that this would be inappropriate.
286.	SH	Royal College of Speech and Language	18	NICE	1.5.4	21	We agree with the elements as set out in 1.5.4 must be included in every ASD diagnostic	Thank you for your comment.

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		therapists					assessment. In particular, we agree that assessment must include an interaction and observation element to assess a child's social and communicative skills and behaviours.	
287.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	4	NICE	1.5.4 and 1.6.2	21 26	The list of steps to be included in every ASD assessment does not make clear that they should include 'assessment through interaction AND observation of the young person's social and communication skills'. Indeed 1.6.2 states the team, where in doubt, should "consider carrying out further ASD-specific observations". Many young people, especially those referred after age 5 years, do have some skills in interaction with a friendly adult in a clinic, and so observation or other information gathering concerning behaviour in other settings is essential basic information for the assessment.	Thank you for your comment. We agree with this point. The recommendation about the components of the diagnostic assessment includes assessment through interaction with and observation of the child or young person. We have not recommended that all children require observation in other settings at the diagnostic stage as this may not be required to reach a diagnosis, or to determine the profile of strengths and weaknesses. Some will require this and we have made recommendations on how this should be decided.
288.	SH	Association	11	NICE	1.5.	21	The guidance appropriately	Thank you for your comment - your support for understanding the

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		of Child Psychotherapists			4	-23	indicates the importance of including the 'young person's experiences of social care and education' and the necessity of entertaining alternative diagnoses in some cases. Although maltreatment is mentioned, it would be valuable to include consideration of traumatic factors as possible contributors to the presentation, and in addition to the functional categories noted it would be useful to include 'other mental health issues', as implied later in 1.5.15.	young person's experiences is noted. We agree that traumatic factors may contribute to a presentation and trust that this is covered by the differential diagnosis recommendation that lists other conditions that should be taken into account using clinical judgement. This recommendation is also a key priority for implementation.
289.	SH	Royal College of Paediatrics and Child Health	20	NICE	1.5.5	22	We think that physical examination should be conducted in all children as standard (does not include genital examination); otherwise, we will miss important cutaneous stigmata and other physical signs in those patients we deem 'not needing' examinations. Beware NF1: anecdotal evidence is of two cases in a 9 and 12 year old who were referred as "odd" and	Thank you for your comment. The GDG reconsidered the recommendation on physical examination and concluded that there should be a physical examination for all children and young people as a key element of the ASD diagnostic assessment.

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							questioned with Aspergers Syndrome.	
290.	SH	Royal College of Paediatrics and Child Health	33	NICE	1.5.5	22	We question the evidence for this recommendation, as we think that a physical examination should be offered to all children and young people assessed for ASD, not selected groups.	Thank you for your comment. The GDG reconsidered the recommendation on physical examination and concluded that there should be a physical examination for all children and young people as a key element of the ASD diagnostic assessment.
291.	SH	Northern Ireland Genetics Service	1	NICE	1.5.6	22	In the physical examination add in comment that signs of dysmorphism or asymmetry should be examined for	Thank you for your comment. The GDG was aware that the physical examination should cover a wide range of differential diagnoses and their recommendation addresses dysmorphic features specifically.
292.	SH	British Psychological Society	3	Full	1	3	On p3, the list of differential diagnoses is very DSM-orientated rather than formulation based.	Thank you for your comment. The list of differential diagnoses was generated by the GDG from their clinical experience and described as symptoms and disorders.
293.	SH	Royal College of Paediatrics and Child Health	15	NICE	Key priorities for implementation	8	Any of these diagnoses may occur **in addition** to ASD. We would like clarification how these conditions are considered and excluded. Attachment or emotionally based symptoms clearly overlap considerably with ASD (there are lots of references on this, and would like clarification on whether any searches are	Thank you for your comment. It was beyond the scope of the guideline on ASD to cover in detail the consideration of other conditions with similar signs and symptoms to ASD. The methodological approach is described in the full guideline. There is a wide range of conditions to consider in the differential diagnosis of ASD. This guideline did search for evidence underlying diagnosis other than ASD. We strongly agree with this point. The guideline recommends multidisciplinary assessment of ASD as a profile of strengths and needs requires it.

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							included). It is difficult sometimes to separate, and clearer guidance is needed. To diagnose these requires a multi faceted usually multi professional approach. What are the pointers to these other diagnoses, and how is this best done? Not being clearer about this multi faceted / disciplinary approach risks undermining the resourcing of services. Local experience has found that multi professional assessments sometimes reveal unexpected findings and, when the diagnosis is ASD, are essential in producing the profile of the child that the guideline recommends. This is important for commissioners.	
294.	SH	Royal College of Paediatrics and Child Health	16	NICE	Key priorities for	8	We think that the differential diagnosis list needs to include more specific reference to severe neglect/abuse as well as attachment.	Thank you for your comment. The GDG recognised that maltreatment generally was an important concern and account is taken of that is taken in the recommendation about the components of the diagnostic assessment which advises that there should be specific enquiry into child's or young person's experience of home life also in the list of

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					implementation			differential diagnosis.
295.	SH	Royal College of Speech and Language therapists	19	NICE	1.5.7	23	We agree that a differential diagnoses for ASD must be carried out as part of the ASD assessment process. If an alternative diagnosis is suspected then there must be a referral pathway to other appropriate services. We agree with the list of other appropriate services that broadly include: ▪ Neurodevelopment disorders; ▪ Neuropsychiatric disorders ▪ Conditions in which there is developmental regression ▪ Other conditions (severe hearing impairment, severe visual impairment, maltreatment, selective mutism).	Thank you for your comment.
296.	SH	Royal	41	Full	1.2	3	This should read "Rett	Thank you for your comment, this amendment has now been made.

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		College of Paediatrics and Child Health					syndrome" not "Rett's syndrome". Also throughout guideline.	
297.	SH	Royal College of Paediatrics and Child Health	42	Full	1.2	3	We wondered why CDD and Landau-Kleffner are omitted (but mentioned later on p140 as EE - hence should we ignore)? Rarity? Important in intervention.	Thank you for your comment. Our view is that LKS is an epileptic encephalopathy so it is included in the differential diagnosis table under conditions in which there is a developmental regression. We agree that there is an inconsistency and this whole section has now been edited so that the inconsistency has been removed. CDD is late autistic regression therefore the GDG did not consider this to be a differential diagnosis in its own right.
298.	SH	British Psychological Society	2	Full	1.2	3 line 15	We suggest adding Pathological Demand Avoidance (PDA).	Thank you for your comment. PDA is not a recognised disorder in the sense that is not included in the ICD/DSM. The GDG acknowledge this and explain the term in appendix K, The text in appendix K has been amended as follows: "The oppositional outburst behaviours in ASD are likely to be due to a liking for sameness, sensory sensitivities and anxiety, in ODD, such behaviour is likely to be due to a feeling of being overwhelmed with angry upset feeling and feeling thwarted."

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299.	SH	British Psychological Society	3	Full	1.2	3 line 30	We suggest adding 'socialisation skills'.	Thank you for your comment. We agree, and socialisation skills have now been added to the list of assessments.
300.	SH	Whitstone Head Educational (Charitable) Trust Limited	2	Full	1.2. 24 -25	3	Our comments are as follows: The insertion of an additional category for 'theoretical conditions' under which specific reference can be made to "sensory processing disorder" (previously called "sensory integration dysfunction/disorder"), as this is gaining popularity and can prevent an early diagnosis of an autism spectrum disorder.	Thank you for your comment. The GDG have recognised the importance of sensory problems and have emphasised the need for assessment of sensory features in the differential diagnosis recommendation.
301.	SH	GOSH Haringey	5	Full	1.5.7, 4th bullet		Consider foetal alcohol syndrome/association	Thank you for your comment. The GDG looked at the evidence for FAS as a potential differential diagnosis. The evidence was lacking and the GDG concluded from their clinical experience that it was not a sufficiently common differential diagnosis compared to other conditions to be included in the list.
302.	SH	SCIE	16	NICE	1.5.8	23	Very good point and could be stronger – repeated information gathering very stressful for	Thank you.

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							families, as well as being redundant professional activity.	
303.	SH	Tees Esk and Wear Valleys NHS Foundation trust	2	Full		3 , 9 and 10	Neuropsychiatric disorders should also include psychosis as a differential diagnosis.	Thank you. We agree psychosis should be a differential diagnosis. It has also been added to the tables in appendix K.
304.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	5	NICE	1.5.10	24	Consideration of other assessments should also include those behaviours raised as urgent problems by parents/carers, which often include sleep, eating, toileting, resistance to change, non-cooperation. The assessment is step one in helping the child and family with such stressors.	Thank you. We have amended the recommendation to incorporate behaviours likely to affect day to day functioning and social participation.
305.	SH	Royal College of Psychiatrists	5	Full	1.5.10		Assessment of behavioural problems Mention is made in 1.5.10 about assessments required to profile the child's difficulties and includes 'mental and emotional health' and 'behaviour likely to affect participation'. In our experience of working with children with autism (with and	Thank you for your comment; we agree that the behavioural challenges for this group are highly diverse. We have amended the recommendation to incorporate behaviours likely to affect day to day functioning and social participation.

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							without learning disabilities) is that there is a very broad range of severely challenging behaviours requiring detailed assessments regarding the functions of the behaviour in order to develop detailed behavioural plans. This aspect does not appear to have sufficient emphasis within these recommendations at present.	
306.	SH	Nottinghamshire Healthcare NHS Trust	11	Full	1.5.11	24	Diagnosis should only be made following post-assessment consultation with other team members by the named case-coordinator	Thank you for your comment. We agree the case coordinator role is pivotal but we do not consider that diagnosis can *only* be made by the case coordinator as others may have the skills to do this. The GDG have clarified the role of the case coordinator in the recommendations.
307.	SH	Royal College of Paediatrics and Child Health	25	NICE	1.5.11	24	This seems only a tiny / passing reference to something that should be a major feature of an assessment. We would like clarification on what is meant. For example, request school comments on a standardised series of questions about the child; go and observe if in doubt.	Thank you for your comment We presume this comment relates to the recommendation above. We did not identify evidence for a standardised mechanism for gathering that information and consequently it forms one of our research recs. The clinical guideline makes it explicit that not all children require assessments in multiple settings. This is clear in the clinical pathway as well.
308.	SH	Autism	6	Full	1.3.	10	developmental age is more	Thank you. The wording of this recommendation has now been

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		Education Trust			45		meaningful than mental age	amended for clarity.
309.	SH	Nottinghamshire Healthcare NHS Trust	12	Full	1.5.13		Diagnostic uncertainty is also common in teenagers or older children presenting for the first time for diagnosis. There may be, in addition to co morbid mental health problems, uncertainty about information earlier in life (including milestones which may be hard to remember a number of years later) – in theses cases observational assessments such as the ADOS and school observation may assume much greater significance).	Thank you for your comment. We agree with this point. This group can present difficult diagnostic challenges and the recommendation as it stands already highlights for example the difficulties of the absence of early life. The recommendation for those considering the possibility of ASD draws attention to the masking of behaviours by coping strategies in older children and young people and older teenagers are also listed in the recommendation about when uncertainty regarding diagnosis.
310.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	6	NICE	1.5.14	25	While appreciating that the guideline does not cover how to conduct other assessments, including assessments of mental health, it would nevertheless seem helpful to reference material on how to interpret the diagnosis of disorders such as anxiety – ie. distinguishing	Thank you for your comment. We have not considered the evidence for integrating considerations of other diagnoses such as OCD. This is a complex area requiring a high level of professional skill and therefore beyond the scope of this guideline. No specific recommendations are made in this regard.

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							specific phobias and OCD from autism characteristics thoughts and behaviours.	
311.	SH	Northern Ireland Genetics Service	2	NICE	1.5.14	25	I would suggest expanding sentence to include +/- referrals e.g. Clinical Genetics	Thank you for your comment. We have added 'and referrals' to the recommendation but have not specified who the referral should go to.
312.	SH	GOSH Haringey	9	Full	1.5.14		There needs to be a statement that neuropsychiatric assessments should be done by CAMHS as this is a major issue. Whilst many paediatricians can diagnose ADHD most paediatric teams to not have a multidisciplinary team to deal with family therapy /behaviour management. Many CAMHS teams will not accept referrals for children with asd for neuropsychiatric assessment unless they have moderate learning disabilty	Thank you for your comment. We have emphasised the involvement of mental health specialists in every aspect of the diagnostic process. We have strengthened the recommendation on who should be in the ASD team to emphasise the need for a psychologist in the core group of professionals. The guideline does not make recommendations specific service arrangements as this will vary and should be determined locally.
313.	SH	Association of Child Psychotherapists	12	NICE	1.5.15	26	We welcome the statement that it may be difficult to recognise mental health problems in children and young people with communication disorders. Even where these problems do not warrant a psychiatric diagnosis,	Thank you for your comment. We recognise these difficulties and have recommended that mental health professionals are in the core ASD team.

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							they can impact severely on the child's capacity to make use of help offered and to reach whatever his ceiling may be. As already stated above, the presence of a Child and Adolescent Psychotherapist as part of the ASD team can help to address this difficulty.	
314.	SH	Royal College of Paediatrics and Child Health	21	NICE	1.6.1	26	Reassessing within six months is impractical, at least for children over five years. For "carry out another ASD diagnostic assessment within 6 months" substitute: "the ASD diagnostic group should plan to carry out another assessment in one to three years, as appropriate, or encourage re-referral after such an interval." (Perhaps give alternative bullet points for under- and over-fives.)	Thank you for your comment. We have given further consideration to this recommendation and have removed the specific timeline for repeat assessment. The recommendation now advises follow up and reassessment based on clinical judgement.
315.	SH	Royal College of Paediatrics and Child Health	22	NICE	1.6.1	26	Regarding the recommendation for children in whom there is diagnostic uncertainty "carry out another ASD diagnostic assessment within 6 months". It may be better to have the repeat diagnostic assessment in 1 year,	Thank you for your comment. We have given further consideration to this recommendation. Reference to timelines has been removed and it is now a "consider" recommendation to indicate that follow up and reassessment should be based on clinical judgement.

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							for the following reasons: • Referral pathways within the NHS often mean that it takes 4 - 5 months (18 week waiting time) for the necessary assessments to take place to consider the ASD diagnosis. If the '2nd' assessment were to take place 6 months after the first assessment, the child would effectively have to be re-referred to the diagnostic team at the time that diagnosis was considered uncertain. • The school environment for a child may not change appreciably within 6 months. Children may be with very good teachers who are accommodating and meeting their needs (so that difficulties are less apparent), or with less able teachers who are not able to meet other needs that a	

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							child may have (learning difficulties, for example). Six months may not allow enough time for these concerns to be addressed and for subsequent change in a child's behaviour. • It may take 6 months for families to access the services that were recommended following the initial assessment (mental health, social care, speech and language therapy). Time will be needed to review the response to these services before a diagnosis can be re-considered.	
316.	SH	Tees Esk and Wear Valleys NHS Foundation trust	3	Full		11	If diagnostic uncertainty, the guidance advises review in 6 months- is this too early? 1 year later might be more appropriate.	Thank you for your comment. Reference to timelines has been removed and it is now a "consider" recommendation to indicate that follow up and reassessment should be based on clinical judgement.
317.	SH	Airedale NHS Foundation	8	NICE	1.6.1	26	We are concerned that for quite a number of children where there is uncertainty that 6	Thank you for your comment. Reference to timelines has been removed and it is now a "consider" recommendation to indicate that follow up and reassessment should be based on clinical judgement.

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		Trust					months is too short a period in which to carry out another diagnostic assessment. We feel that there should be an agreed timescale for each child for when they will be reassessed, reflecting the individual need, which is confirmed with the family and other professionals.	
318.	SH	CAMHS Wales	6	Full	Table Following assessment	21	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 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.	Thank you for your comment. We have added the word "consider" to the recommendation keeping a child or young person under review to allow for a decision to live with uncertainty. We have removed the recommendation that review should be within 6 months and based this on clinical judgment. We have also added a recommendation specifically for children who do not meet diagnostic criteria
319.	SH	Royal College of Paediatrics	26	NICE	1.6.2 1.6.	26	Observations in a social setting, e.g. nursery or school (not just a one-to-one) seem to receive	Thank you for your comment. This recommendation has now moved up into the section on ASD assessments. We have added the word 'social' to the bullet in the recommendation regarding observation in a

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		and Child Health			3		relatively little emphasis and yet can provide considerable information when there is uncertainty after standard assessment in our experience.	different setting.
320.	SH	British Psychological Society	1	Full	1.3	11 para 51	We suggest adding 'socialisation skills' to the last sentence.	Thank you. We agree and this amendment has been made. The recommendation has been moved to ASD diagnostic assessment section and focuses on the assessments required to construct the profile.
321.	SH	SCIE	6	NICE		9	Construct a profile – this strengths based approach with social and family dimensions is a mainstream on for social workers. Suggest the text specifically includes expands the social work contribution here. This is distinct from the possible referral to social care in following para.	Thank you for your comment. We have strengthened the recommendation on who should be in the ASD team and have included social workers as professionals who should be in the team or who the team should have regular access to.
322.	SH	Royal College of Speech and Language therapists	20	NICE	1.6.4	27	We strongly agree with point 1.6.4 that looks to construct a profile for every child who has had an ASD diagnostic assessment. This profile should include the child's strengths, skills, impairments and needs to create a tailored personalised management plan. We further	Thank you for your comment

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							agree there should be a focus on learning, communication, behaviour, emotional health and the child's family environment context when developing a management plan.	
323.	SH	Sheffield PCT	4	NICE	1.6.4	27	There was feeling that it should be emphasised that a "needs-based management plan" may not include all members of the multi-agency team. For example, an older child with milder difficulties may need primarily an Education plan, which Education are better equipped to formulate, given a clear report from the diagnostic team.	Thank you for your comment. We agree with this point. We have amended the recommendation about creating a profile to make it clear that the profile is separate from the management plan. The ASD team is responsible for creating the profile, but the professionals who use this information to create the ensuing management plan is not specified in the recommendation.
324.	SH	Royal College of Paediatrics and Child Health	23	NICE	1.7	27	We note these paediatric investigations look a bit on the thin side. We think that all children going through an ASD assessment should have a hearing and vision check.	Thank you for your comment. The recommendations now make clear that results of prior hearing and vision tests should be gathered before the ASD assessment commences and the differential diagnosis recommendation ensures the ASD team consider hearing and vision assessments to help interpret ASD history and observations.
325.	SH	Autism in	14	NICE	1.7.	27,	*'Do not routinely perform any*	Thank you for your comment. This recommendation relates to the

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		Mind			1, 4.3	32	*medical investigations as part of an ASD diagnostic assessment…'* We recognize that the guidance is concerned only with diagnosis, that a diagnosis of ASDs focuses on only three aspects of the child's behaviour - impairments in social interaction and communication and restricted, repetitive and stereotyped behaviours - and that physical characteristics associated with autism, such as dietary intolerances, digestive problems, sensory processing abnormalities, hypermobile joints and poor co-ordination do not feature in the diagnostic criteria for ASDs.	diagnostic assessment for children with suspected ASD. We recognise the importance of recognising and evaluating co-existing conditions in many children with ASD. However, specific advice on the investigation of co-existing conditions is not in the scope of this guideline. The recommendations do state that assessments should be carried out as appropriate.

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							However, since there is general agreement that ASDs have biological causes and many children with ASDs have physical signs and symptoms such as those mentioned above, paragraph 1.7.1 appears to be recommending that such characteristics should be ignored. Although a medical investigation might not routinely constitute part of the *diagnosis* of ASDs, the guidance is not clear about whether the follow-up healthcare it recommends should be related solely to the child's autistic characteristics or to all the child's signs and symptoms. Parents have told AIM that they have had significant problems getting support for their children's	

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							medical problems because these are frequently seen as 'part of the autism', the implication being that we don't know what causes them so there's no point investigating them. The physical characteristics can cause more difficulty than the autistic ones. A child with disrupted sleep, auditory and visual processing problems, abnormal bladder and/or bowel function and difficulties with motor co-ordination is unlikely to function well even if their social and communicative skills were developing normally. The guidance recommends biomedical investigations in the	

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							section on Research Recommendations (4.3). We would point out that since it is likely that autistic characteristics have different causes in different children, biomedical investigations for children with ASDs *as a group* might not be as useful as biomedical investigation of *individual children*, the child's physical signs and symptoms possibly acting as more useful pointers to the underlying cause of the child's autism than their autistic characteristics. We would recommend that the child's presenting signs and symptoms are assessed as part of their individual profile, that medical investigations constitute	

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							part of the follow-up procedure after diagnosis, and that biomedical data are then pooled to inform research.	
326.	SH	NHS Milton Keynes	6	Full	1.3.53	11	Our comment would be that we would suggest the wording be strengthened to reinforce that there is a lack of evidence for certain investigations.	Thank you for your comment. The lack of evidence for the investigations is described in chapter 8 and the recommendation makes it clear that these should not be used routinely
327.	SH	Association of Child Psychotherapists	13	NICE	1.8 and 1.9	28 and 29	The assessment and diagnostic process should also include consideration of further referrals to other services, for example Occupational Therapy, Speech and Language Therapy and CAMHS, to aid adjustment and support development and well-being and to address co-morbid problems. If the child is already being seen by these services, the importance of good liaison with them should be underlined.	Thank you. The importance of good liaison between agencies underpins this guideline. We have highlighted the importance of differential diagnosis and identifying co-existing conditions, referrals to other services (and back to the ASD team) is also recommended where other needs are identified at every stage of the diagnostic process.
328.	SH	Northern Ireland Genetics Service	3	NICE	1.7.1	27	In comment on "genetic tests as recommended by your regional genetics centre when there are specific dysmorphic features +/-	Thank you for your comment. The recommendation has now been amended and reflects your suggested wording.

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							evidence of intellectual disability", I would suggest adding in +/- ≥1 congenital anomalies	
329.	SH	HTA Ref 2	44	Full	1.3	12	Point 54 – can you add a specific point about the dangers in giving the diagnosis to the parents WITH THE CHILD PRESENT – SEE MY POINT ABOVE- parents should discuss the pros and cons of this with the ASD team	Thank you. The recommendation has now been revised to make it clear that the person communicating the diagnosis should give consideration to whether or not the child or young person should be included. We have made a specific recommendation how to share the diagnosis early on in the diagnostic pathway.
330.	SH	NHS Milton Keynes	7	Full	1.3.54, 1.3.61	12	Our comment is that the statements are too prescriptive and we suggest that it is reworded to allow more local flexibility to meet needs of the child and family within local models and resources.	Thank you for your comment. We considered this point carefully and agreed that a strong recommendation was required in order to change current practice. The recommendation leaves open the option of refusal.
331.	SH	Autism in Mind	4	NICE	1.8.1 general, 1.8.1	3, 28	Although a diagnosis might bring relief to some families and young people, the guidance needs to make clear that we don't know what causes autistic spectrum disorders, so a diagnosis of ASDs is a matter of	Thank you for your comment. The introduction now emphasises more strongly that diagnosis might not provide relief. The GDG recognise that a diagnosis might not be reached and that judgement needs to be used on whether to continue with further assessments and this is reflected in their recommendations.

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							judgement and is not conclusive. Because it is subjective there is likely to be disagreement between practitioners about the diagnosis and a diagnosis cannot be referred to as 'certain' (see 1.8.1). Parents and young people need to be made aware of this.	
332.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	7	NICE	1.8.2	28	"Generic guidelines for sharing and disclosing diagnosis" should be referenced, as they may not have featured in the training of the professionals.	Thank you for your comment. While the GDG was aware that various guidelines on good practice are available to professionals, these could not be referenced as they have not been developed using NICE guideline methodology.
333.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	8	NICE	1.8.4	28	"Provide information specific to the child" would usefully have reference to guidance, or examples.	Thank you. The recommendation has now been changed to clarify the type of information that should be offered. The GDG considered that this should focus on what ASD means and how it affects the individual child or young person. We have not recommended specific guidance or examples as these would be out of date after the publication of this guideline.
334.	SH	GOSH Haringey	6	Full	1.8.5		Further clarity please regarding	Thank you for your comment. The GDG recommends discussing with parents and carers the risk of ASD occurring in siblings and future

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							referral to geneticist when positive family history and sibling group with asd	children. We have not covered referral to a geneticist as this is outside the scope of the guideline.
335.	SH	NHS Milton Keynes	8	Full	1.3.59		Our comment is that we would welcome feedback on why the recommendation identified in the National Autism Plan for children relating to including parents contribution to written reports does not appear to be included in the guidance.	Thank you for your comment. The GDG agree that parental involvement is critical. While we have not been specific about the written report, parental contributions are not ruled out in the guideline. Parent's views and concerns are fully integrated into each step of the pathway. For example: during recognition parental concerns should always be taken seriously; take time to listen to parents discussing concerns and agreeing actions.
336.	SH	Northumberland and Tyne and Wear NHS Foundation Trust	9	NICE	1.8.8	28	The offer of a follow-up appointment with an appropriate member of the ASD team would surely include the case coordinator if available, for continuity.	Thank you for your comment. This point is noted, However flexibility to deploy the appropriate resource has been maintained in the recommendation.
337.	SH	NHS Milton Keynes	9	Full	1.3.61		Our comment is to change the wording to "consider giving a	Thank you for your comment. The GDG has reconsidered this point and concluded that a follow up appointment should be available to all children or young people who have received a diagnosis of ASD.

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							follow up appointment" rather than "offer a follow up appointment" as our view is the necessity of a follow up appointment can be dependent on the child and families individual needs.	They also concluded that the use of the word 'offer' was sufficient to ensure that the recommendation was patient centred and the appointment could be refused.
338.	SH	Sheffield PCT	5	NICE	1.8.8	28	We felt that it might be helpful to include a range of options for follow-up. Some families and young people find an appropriate workshop or the provision of clear contact information more helpful than the offer to attend a further appointment and we hope the NICE guidelines would give us scope to provide the approach that's appropriate for each child	Thank you for your comment. The GDG concluded that every child or young person be offered a follow up appointment after diagnosis as a baseline for appropriate support. This does not preclude other follow up services being designed to meet the needs of children and families with different needs.
339.	SH	Royal College of	21	NICE	1.8.9	29	We strongly agree that after an	Thank you for your comment.

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		Speech and Language therapists					assessment and diagnosis of ASD, the profile of identified conditions are made available to professionals across education and, if appropriate, social care so that they can contribute to the child's individual education plan and other aspects of the needs based management plan.	
340.	SH	British Psychological Society	1	NICE	1.8.9	29	It might be better to be explicit re parental consent for sharing this information.	Thank you for your comment, the recommendation has now been amended to make explicit that consent should be sought for sharing information.
341.	SH	British Psychological Society	1	NICE	1.9	29	It would be helpful if reference was made to Health and Social Care provision of intervention and support services for people with ASD and their families.	Thank you for your comment. The provision of health and social care provision for people with ASD is outside the scope of this guideline. The scope of the upcoming guideline on the management of ASD in children and young people may cover this.
342.	SH	Department for Education	10	Full		166	"information to help prepare for the future for example, transition	Thank you for your comment. The GDG are aware of this but it was outside the scope of this diagnostic guideline.

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							to adult services. Here and earlier in the chapter the GDG might want to be aware that there is a statutory transition planning process for children with statements of special educational need, beginning in Year 9 of schooling and a Government programme, the Transition Support Programme, which aims to improve the transition process for disabled young people and those with SEN. I have attached a paper from my colleague Catherine Bradshaw on the Transition Support Programme which gives more details. It is from last November. The Education, Health and Care Plans mentioned earlier will be from the 0 – 25 for young people with	

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							SEN and disabilities who stay on in education. They will include long-term objectives for young people and should further improve the transition process for these young people.	
343.	SH	The Royal college of psychiatrists in Wales	12	Full	1.3		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.	Thank you for your comment. Although service provision is outside the scope of this guideline, the GDG agree that it is likely that professionals in the ASD team who diagnose ASD will also provide a range of interventions post diagnosis.
344.	SH	British Association for Art Therapists	3	Full	1.3		Information and support provided to families and carers should also include details or art organisations both local and national	Thank you for your comment. Art therapy has not been reviewed as part of this guideline on diagnosis.

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							ASD strategic action plan for Wales (Welsh assembly government, April 2008). Section 23 Arts therapies are identified as a key intervention for ASD assessment and education (p. 52, 53) and education (p.54), and as a core therapeutic intervention (p.57 and 59) Section 23 (p.30) states that arts therapies provide an accessible and appropriate form of psychotherapy for those with ASD. And that services should be provided through Tiers 1-4 (p. 24)	

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							Article 13 of the United Nations convention on the rights of the child (September 1990) states that: "The child shall have the right to freedom of expression; that this right shall include freedom to seek, receive and impart information and ideas of all kinds either orally, in writing or in print, in the form of art, or through any other media of the child's choice". Outcome studies show long term and individual art therapy is effective in promoting cognitive	

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							and emotional development, enabling relationships and lessening destructive behaviours, referenced in the below- Shaping experience and sharing meaning: art therapy for children with autism, Evans, K. (1998) Art Therapy with Children on the Autistic Spectrum: Beyond Words, Evans, K & Dubowski, J, 2001 Shaping vitality affects: enriching communication, in D. Sandle (ed.). Development and diversity: New applications in art therapy. London: Free association (1998)	

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							Annihilation anxiety and fantasy in the art of children with Asperger's Syndrome and others on the autistic spectrum, Henley, D. 2001 The world is attacked by great big snowflakes: art therapy with an autistic boy, American Journal of Art Therapy, Kornreich, T. and Schimmel, B. 1991 Art making processes may assist the development of communication skills and thereby the therapeutic relationship with children with autism.	

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							Shaping experience and sharing meaning: art therapy for children with autism, Evans, K. (1998)	
345.	SH	HTA Ref 2	45	Full	1.3.1 Table 1	14	Table 1 – instead of lack of meeting gaze – put unusual or inappropriate eye contact	Thank you this wording has been amended in light of stakeholder comments to reflect the social use of eye contact.
346.	SH	HTA Ref 2	46	Full	1.3.1 Table 1	14	Table 1 – instead of lack of response to name – put – often delayed response when name called.	Thank you - delayed has been added.
347.	SH	HTA Ref 2	47	Full	1.3.1 Table 1	14	Table 1 – add to rejection of cuddles from others, but may cuddle others on own terms	Thank you – this has been amended.

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348.	SH	HTA Ref 2	48	Full	1.3.1 Table 1	14	Table 1 – instead of lack of gesture – put lack or limited use of gestures	Thank you - reduced or absent has now been used throughout the table.
349.	SH	HTA Ref 2	49	Full	1.3.1 Table 1	14	Table 1 – change to limited imitation of others' actions	Thank you - reduced or absent has now been used throughout the table.
350.	SH	HTA Ref 2	50	Full	1.3.1 Table 1	14	Table 1 – change to limited social pretend play	Thank you - reduced or absent has now been used throughout the table.
351.	SH	HTA Ref 2	51	Full	1.3.1 Table 1	14	Table 1 – change abnormal vocalizations to unusual vocalisations	Thank you – this wording has been amended to non-speech like.
352.	SH	HTA Ref 2	52	Full	1.3.1 Table 1	14	Table 1 – change to reference to self by name, delayed use of I and you	Thank you – by name has been added.
353.	SH	HTA Ref 2	53	Full	1.3.1 Table 1	14	Table 1 – change to Excessive reaction to certain taste, smell or texture of foods and/or very	Thank you –this has been amended to taste, smell, texture or appearance.

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							limited diet	
354.	SH	British Psychological Society	1	Full	Table 1	14 -16	There is possibly a lack of understanding of/emphasis on the importance of early social communication in an interactive context and the relevance of this to Autism. This impression is perhaps conveyed in Tables 1, 2 and 3 (on p14-16 and p97) where signs and symptoms of ASD acknowledge "poorly integrated eye-gaze, gestures, facial expressions and body orientation in social communication" for children over 5 but omit to emphasise this lack of reciprocity and difficulty with interactive flow that also characterises younger children.	Thank you for your comment. Lack of reciprocity has been added to the text above the tables.
355.	SH	Royal College of	17	NICE	Table	13 14	"Delay in language	Thank you: this has been clarified and an example given of 10 words by 2 years of age.

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		Paediatrics and Child Health			1.1 Table 1.2		development" should be clarified as there is not general agreement about this among professionals who are seeing children during these years (health visitors, preschool teachers, speech and language therapists). For example, a guide of no single words by 1 year (quite conservative) or no single words by 2 years (less sensitive, but more specific to children who are likely to have an ASD).	
356.	SH	NHS Milton Keynes	10	Full	Tables 1-2	15 -16	Our comment is that it should be clarified that isolated findings on the tables should not be a trigger for ASD referral.	Thank you, we agree. This will be added to the headings of the tables.
357.	SH	Autism in Mind	13	NICE	Tables 1.1,	13 , 14	'Delay in language development	Thank you for your comment. We understand this point; however the guideline makes a specific recommendation for clinicians considering referral to be aware that they should not rule out ASD because the

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					1.2		(babble or words)’ The DSM-IV diagnostic criteria for Asperger’s Disorder include the following; ‘There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years)’ Although language delay is common in ASDs, it is frequently absent in children diagnosed with Asperger’s Disorder. We are concerned that some children with autistic characteristics but no language delay will be excluded from a diagnosis. The variability of the characteristics listed in the	exact features described in the signs and symptoms tables are not present. This means that children without language delay but with other manifestations would still potentially require referral.

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							tables should be emphasized.	
358.	SH	British Psychological Society	2	NICE	Table 1.1 to 1.3	13	We would like to see consideration being given to noting the difference in female presentations across the ages and stages.	Thank you for your comment. There is a lack of evidence for this. The GDG have indicated that in their clinical experience females are more apparently sociable can lead to failure to diagnose.
359.	SH	Ambitious about Autism/Autism Alliance	2	NICE	Table 1.1 -1.3	7	The guidelines state that one of the aims of the strategy group will be to improve early recognition and referral through awareness training. The document does not set out who this awareness training will be targeted at, how it will be delivered, or who will pay for its delivery. Ambitious about Autism would like clarification on this point.	We have added that the GDG conclude that the training should be multiagency. Detailing implementation costs are beyond the scope of this guideline.
360.	SH	Sheffield PCT	3	NICE	Tables	13 - 15	There is concern that there	Thank you. We agree there is always a danger that that lists will be a used as a tick box exercise. But the key must be using them for

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					1.1 to 1.3		should be some stronger guidance as to how to interpret these behaviours in the context of the autism triad, otherwise it is feared that these lists will be used as a tick list, either to admit or to exclude children to the autism spectrum.	multiagency training. The GDG specifically examined the evidence for tools to identify an increased likelihood of ASD (see chapter 4), but the evidence for these was poor.
361.	SH	Optical Confederation/ LOC Support Unit	4	NICE	Tables 1.1, 1.2 and 1.3	13-15	All mention eye contact, responses to social smiling and other social visual clues. Care should be taken to rule out not only severe visual impairment but reduced visual acuity due to refractive error, cataract or other pathological causes. Optometric, orthoptic or ophthalmological input is required here too.	Thank you. We have added a prompt to the tables "assuming adequate vision" and leave this to individual clinical judgment.

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362.	SH	Royal College of Paediatrics and Child Health	18	NICE	Table 1.2 Table 1.3	14 15	The items in the first category, social interaction and communication behaviours, could be altered or supplemented to include the following: • Difficulty identifying emotions in self and others • Difficulty imagining another's point of view • Few close or intimate friends • Usually a preference for being alone and a lack of interest in others; occasionally a thwarted desire to be with others; sometimes both • Language difficulties, often quite subtle – construes expressions literally – may misunderstand	Thank you for these extremely helpful comments. The signs and symptoms tables have been amended to take on board the concepts and some of the specific wording you have suggested. The exception to this is "Although play may be imaginative; it seldom shows social imagination" which the GDG did not consider a phrase that would be readily understood by non experts. However, the concept of reciprocity and in ability to share play is incorporated. Text has also been added to the introduction of the guideline that relates to this.

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							humour, sarcasm, puns or double-meanings – may repeat words or phrases without meaning (echolalia) – may use certain words out of context, whose meaning therefore jars or is not clear • Often infrequent or reluctant eye contact; occasionally a tendency to stare • Problems with turn-taking, reciprocity and two-way communication • Speech may be unusual in several ways – monotonous tone – lack of appropriate gesture, facial expression or other non-verbal accompaniment	

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							– content dominated by own interests – fulfils a need to express things (rather than a need to share in a two-way conversation) • Responses to others can appear odd, rude or inappropriate (perhaps as a result of the last four bullet points) The items in the second category, unusual and/or rigid/repetitive behaviours, could be altered or supplemented to include the following: • Preference for established routines, which are often idiosyncratic • Distaste for change, which	

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							often leads to anxiety or other forms of distress • Play is likely to be repetitive and oriented towards objects rather than people • Although play may be imaginative; it seldom shows social imagination • The range of interests is likely to be limited and obsessional in character, and not shared with others • Repetitive, 'stereotypical' movements may occur, such as hand flapping, body-rocking, spinning, finger movements or chewing (these are more common in autism than milder conditions on the spectrum) Reference: Primary Child and Adolescent Mental Health, Radcliffe Medical Press (in press 2011), Spender Q, Barnsley J, Davies A and	

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							Murphy J.) The third category of symptom, other factors that may support a concern about ASD, should include developmental coordination disorder (problems with fine or gross motor coordination) – as a separate sub-category from the unusual profile sub-category.	
363.	SH	SCIE	10	NICE	Table 1.3	15	Clear and comprehensive	Thank you for your comment.
364.	SH	Northumberland Tyne and Wear NHS Foundation Trust	3	NICE	Table 1.4	18	The list of risk factors should include Becker muscular dystrophy alongside Duchenne muscular dystrophy.	Thank you for your comment. This has now been amended to muscular dystrophy which would include Becker as well as Duchenne muscular dystrophy. A corresponding amendment has also been made in the co-existing conditions recommendation.
365.	SH	HTA Ref 2	54	Full	1.3.1	15	Table 2 – delay in language	Thank you – the GDG concluded that this was an appropriate for preschool children

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					Table 2		development in some children and young people	
366.	SH	HTA Ref 2	55	Full	1.3.1 Table 2	15	Table 2 – instead of lack of meeting gaze – put unusual or inappropriate eye contact	Thank you this amendment has been made.
367.	SH	HTA Ref 2	56	Full	1.3.1 Table 2	15	Table 2 – instead of lack of response to name – put – often delayed response when name called.	Thank you this has been amended.
368.	SH	HTA Ref 2	57	Full	1.3.1 Table 2	15	Table 2 – relative lack of social interest in others, or socially attracted but odd approach	This has been amended in tables 1 and 2.
369.	SH	HTA Ref 2	58	Full	1.3.1 Table 2	15	Table 2 – lack of enjoyment of situations which most children like (eg birthday parties)	Thank you - reduced enjoyment is in the tables and the example of parties has been added to for the preschool child.
370.	SH	HTA Ref 2	59	Full	1.3.1 Tab	15	Table 2 – change to reference to self by name, delayed use of I	This is not in table 2 but has been amended in table 1.

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					le 2		and you	
371.	SH	HTA Ref 2	60	Full	1.3.1 Table 2	15	Table 2 – change to Excessive reaction to certain taste, smell or texture of foods and/or very limited diet	Thank you this has been amended.
372.	SH	HTA Ref 2	61	Full	1.3.1 Table 3	16	Last bullet point – put lack of awareness and understanding of expected behaviour	This amendment has been made.
373.	SH	Nottinghamshire Healthcare NHS Trust	6	Full	1.3.1 Table 3	17	It needs to be clear why there would be a more urgent referral in the case of regressions. It is likely to be more appropriate that such children are seen urgently in the medical setting as there may be a number of other causes for developmental regression that might be missed by focussing on the possible ASD first. As a secondary	Thank you for this comment. The recommendation has been altered. It now emphasises the importance of referral but no longer stipulates a time frame because we agree they do not automatically have a priority over other patients.

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							service, there should be no need for urgent assessments.	
374.	SH	HTA Ref 2	62	Full	1.3.1 Table 4	17	Table 4 risk factors – add A parent with ASD	Thank you for this comment. There was no evidence identified that supported the inclusion of family history in the list. The GDG considered whether it should be included based on consensus. Although there was some agreement that in children with ASD there is perceived increased likelihood that a parent will have autistic trait, expert opinion within the GDG was that a parent with ASD is not routinely considered a risk factor in clinical practice. Therefore a parent with ASD it was left off the list of risk factors.
375.	SH	British Psychological Society	1	Full	Table 1	9	We suggest adding 'rejection of others' to list of behaviours shown pre-school.	Thank you – this has been added.
376.	SH	GOSH Haringey	1	Full	Table 1.1, 1.2,		There needs to be statement that a combination of factors should raise concern about autism and should prompt referral. Otherwise there is a danger that there will be an increase in inappropriate referrals. Eg severe language	Thank you. The GDG have recommended that those considering referral take account of the range of factors so that the child or young person's signs and symptoms are considered in context.

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							delay, child maltreatment where the referral should be to social care in the first instance.	
377.	SH	British Psychological Society	2	Full	Table 2 Social interaction and communication behaviours		We suggest adding 'insistence on following own agenda'.	Thank you this amendment has been made.
378.	SH	HTA Ref 2	13	Full	Table 3	16	Section 1 -Bullet point 14 - Naivety – spelling	Thank you this amendment has been made.
379.	SH	HTA Ref 2	14	Full	Table 4	17	Down syndrome – be consistent	Thank you for your comment.

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							throughout the guide	
380.	SH	Royal College of Speech and Language therapists	12	Full	1.7 Care pathway	17-21	The tables on pages 17-21 are a very valuable representation of the care pathway for the assessment of ASD, particularly for those who are less experienced in this field. We agree with the categories as set out in these tables, which are: ▪ ASD recognition and referral; ▪ Following a referral ▪ ASD specific diagnostic assessment ▪ Following the ASD specific diagnostic assessment.	Thank you for your comment.
381.	SH	Royal College of Psychiatrists	4	Full	1.4	17	Care pathways The care pathway is detailed in 1.4. It is hoped that there will be an abbreviated version of this	Thank you for your comment. Although only the NICE and Full versions of the guideline were available for consultation, when the guideline is published NICE will also release a Quick Reference Guide' (QRG) version for health care professionals and this will contain the abbreviated recommendations and the care pathway.

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							included in the key recommendations.	
382.	SH	Nottinghamshire Healthcare NHS Trust	7	Full	1.4	19	There should be pre-diagnostic counselling before undertaking the assessments regarding the possible effects of being diagnosed	Thank you for your comment. The GDG were unable to make any recommendations about pre-diagnostic counselling as this was outside the scope of this guideline.
383.	SH	Nottinghamshire Healthcare NHS Trust	8	Full	1.4	19	Pre-diagnostic counselling should include the limits regarding what information parents request to not be shared (i.e. the team would always be required to report findings to GP, whatever the outcome)	Thank you for your comment. The GDG strongly agree with your point and have made recommendations further down the pathway about appropriate sharing of information between primary care, parent and carers, and the ASD team – see section 5.25. The GDG regarded pre-diagnostic support as generic to good clinical practice and not specific to ASD and so have not drafted a recommendation that addresses sharing information at this specific point in the pathway.
384.	SH	The Royal college of psychiatrists in Wales	14	Full	Table Following	21	The resource implications of recommendations are recognised. But there is an	Thank you for your comment. The universal 6-month review period has been removed from this recommendation. There is now a recommendation for professionals to consider keeping the child or

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					assessment		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.	young person under review, taking into account any new information.
385.	SH	College of Occupational Therapists	2	Full	Following the ASD specific diagnostic	21	If ASD is not diagnosed, according to the flow chart the child should exit the pathway. There is no recommendation about follow up with these parents to help them think about their child's difficulties and how to frame these if their original	Thank you for your comment. The GDG have now made new recommendations about children who do not receive a diagnosis of ASD to indicate that if they have needs they should be referred by the ASD team to appropriate services. The recommendations on communicating the results of the assessment have now been clarified to indicate where they apply to all children, including those who do not receive a diagnosis of ASD. The subsequent review of children who are not diagnosed with ASD is

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					assessment		thoughts were of ASD. I think this is a vital part of the ASD assessment pathway.	beyond the scope of the guideline.
386.	SH	The Royal college of psychiatrists in Wales	15	Full	2	22-34	Methodology seemed very thorough and investigation extensive	Thank you for your comment.
387.	SH	CAMHS Wales	7	Full	2	22-34	Methodology seemed very thorough and investigation extensive	Thank you for your comment.
388.	SH	Association for Family Therapy and Systemic Practice (AFT)	3	FULL	2	220	Re: definition of 'systemic'. Given the range of issues for the families, schools or community that are involved with someone with autism, it would be helpful to include a definition of 'systemic' that incorporates the broader system for the young person with autism - siblings, parents, families, friends and	Thank you for your comment. The Introduction has been amended as follows: "The term also incorporates the broader system for the young person with autism - siblings, parents, families, friends and wider communities, including the different services involved".

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							wider communities, including the different services involved. Systemic family therapy and systemic practice is used for working together with the people involved as well as working with families, parents, or individuals - keeping the family in mind.	
389.	SH	HTA Ref 2	63	Full	2.1	22	Line 7 - rather than something wrong – use the term different or unusual about their child's development– or put 'wrong' in single quotes	Thank you for your comment, this amendment has now been made.
390.	SH	HTA Ref 2	64	Full	2.1	22	Line 10 – social care	Thank you for your comment, this amendment has now been made.
391.	SH	HTA Ref 2	65	Full	2.1	22	Line 14 – instead of qualitative abnormalities – put with unusual and atypical reciprocal social interaction and communication	Thank you this amendment has now been made.

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392.	SH	HTA Ref 2	66	Full	2.1	22	Line 16 instead of qualitative abnormalities – put with unusual and atypical reciprocal social interaction and communication	Thank you this amendment has now been made.
393.	SH	HTA Ref 2	67	Full	2.1	22	Line 26 – instead of usually has – put can have	Thank you this section has been revised and the 'usually' has been removed.
394.	SH	Autism Education Trust	7	Full	2.1. 13/ 20	22	the description of autism is based on a medical model of disability focusing on the negatives and within child factors. It would be more helpful to provide a social model where the environment is the most significant disabling factor and is the variable that is most accessible to change especially after diagnosis	Thank you for your comment. This is clinical guideline and ASD is a medical diagnosis, however, the GDG agree that the environment is an important factor and this is now highlighted in the introduction.
395.	SH	British Association for Art	4	Full	2.1. 3	23	Manifestations of ASD "cognitive, emotional and	Thank you for your comment. This is not intended to be a comprehensive account of ASD. The importance of these aspects is discussed in 2.1.3.

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		Therapists					motivational changes recognised through creative art therapies in the classroom". American Journal of Dance Therapy Volume 11, Number 2, 85-100, DOI: 10.1007/BF00843773 "Autistic children do not develop imagery schema, and they show little interest in drawing or even doing a scribble". Art Therapy: Journal of the American Art Therapy Association, 21(3) pp. 143-147 © AATA, Inc. 2004	

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							"Skill in realistic drawing is associated with a strong local processing bias and a tendency towards repetitive behaviours, showing that traits found in individuals with ASD irrespective of artistic talent are also found in typically developing children with artistic talent". Journal of autism and developmental disorders, June 2010, vol./is. 40/6(762-73), 1573-3432 Two experiments were conducted to explore the extent to which individuals with ASD as	

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							well as typically developing children are explicitly aware of their own and others intentions. The study suggests that individuals with ASD have a diminished awareness of their own and others intentions. Representing intentions in self and other: Studies of Autism and typical development, David Williams and Francesca Happe: Developmen science 13:2 (2010) pp307-319 “The skilful teacher or parent can help the child with autism to have access to his or her mental states and to tag them as mental states (beliefs, desires) by	

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							making them concrete (pictures, words) and explicit for examination. Theory of mind and self-consciousness: What is it like to be autistic? Uta Frith and Francesca Happe, Mind and language Vol 14, No 1, March 1999	
396.	SH	British Psychological Society	2	Full	2.1.3	23	Autism is a descriptive term referring to a specific syndrome of behavioural impairments that emerges in childhood. The consultation document does not use the terms autism and ASD purely descriptively, however,	Thank you We have incorporated these suggestions in the introduction and agree that ASD is a behaviorally defined syndrome whose diagnostic criteria are on DSM/ICD and that there are many causes.

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							but to refer to specific disorders defined by certain behavioural characteristics as listed by ICD-10 and DSM-IV. Para 2.1.3 describes ASD as a 'neurodevelopmental and biologically based disorder' and outlines a conceptual model as follows: Potential candidate genes are emerging from the advances in molecular genetic techniques but current thinking is of a genetically heterogenous disorder producing phenotypic heterogeneity (differing physical and behavioural characteristics). Adoption of this 'fan in-fan out' model is presumably what has led to ASD being referred to,	

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							throughout the consultation document, as a (sing.) disorder as if it refers to: the signs and symptoms as defined in ICD-10/DSM-IV • and an underlying disorder that causes the signs and symptoms. It seems reasonable to speak of autism as a disorder at the behavioural level in the sense that children with autistic characteristics show behaviour that is disordered in broadly similar ways. However it cannot be assumed that those similarities arise from a disorder at the biological level. As the consultation document also points out (2.1.3), many medical conditions are	

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							associated with autistic characteristics and some are likely to have a causative role (8.1). This means that a diagnosis of ASD is a diagnosis only at the behavioural level, not at the underlying causative level. It is recommended that 'or disorders' be inserted following 'heterogeneous disorder' in line 11 of paragraph 2.1.3.	
397.	SH	HTA Ref 2	68	Full	2.1.3	23	Line 28 – creative social play and social thinking	Thank you for your comment, this amendment has been made.
398.	SH	Autism Education Trust	8	Full	2.1.3 .22	23	"due to a delay or disordered pattern of usual development" may be more accurate description than "an absence"	Thank you for your comment this amendment has now been made.

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399.	SH	Autism Education Trust	9	Full	2.1.4	24	It needs to be made more explicit that recognition and diagnosis of autism is important for children and young people as it leads to the provision of support to families and more appropriate education which can in turn lead to more positive outcomes for the individual	Thank you for your comment, this amendment has now been made "Recognition and diagnosis of autism is important for children and young people as it leads to the provision of support to families and more appropriate education which can in turn lead to more positive outcomes for the individual."
400.	SH	HTA Ref 2	69	Full	2.1.4	24	Line 13 – Autism can impact significantly	Thank you for your comment, this amendment has now been made.
401.	SH	Department for Education	3	Full	2.1.5	25 (2.1.5, lines 6 – 9)	the heading for this section is Appropriate educational support but this quotation seems to have nothing to do with educational support.	Thank you for your comment, this amendment has now been made.
402.	SH	HTA Ref 2	70	Full	2.1.5	25	Lines 16 and 27 – social care	Thank you for your comment, this amendment has now been made.
403.	SH	Autism Education	10	Full	2.1.5.1	25	the two quotes do not make	Thank you. These quotes are meant to be illustrative only but we agree they do not show the full extent of educational support.

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		Trust					clear the difference that appropriate educational support can make. I am sure that the AET could provide some that could highlight the difference more clearly	
404.	SH	British Psychological Society	3	Full	2.6, 4.2.5, 5.6.5	29 ff., 60, 91	We also recommend that a clear distinction is maintained between a diagnosis in descriptive terms and a diagnosis in causal terms. If not, there are implications for policy makers. Although the diagnostic criteria for ASD have good face validity and reliability (i.e. there are children exhibiting the core behavioural impairments of ASD, and there is good agreement that the behaviour of these children meets certain criteria), ASD as a disorder	Thank you for your comment. We agree that ASD is a descriptive term for likely heterogeneous causality and we have made this explicit in the Introduction – see section 2.1.

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							remains a hypothetical construct and the usefulness of talking about false positive and false negative results (5.6.5), or children ‘wrongly identified’ as having ASD (4.2.5) is questionable; false positives and false negatives measured against what standard? A diagnosis of autism is, by definition, a subjective matching of the behavioural characteristics of an individual against broad behavioural characteristics of a diverse group. We recommend that caution is exercised when it is not known whether or not an experimental	

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							group is homogeneous. If it is not, any statistical analysis that assumes homogeneity runs the risk of becoming 'statisticulation'.	
405.	SH	HTA Ref 2	16	Full	2.6.2	31	Line 3 Checklists – need to make plural	Thank you for your comment, this amendment has now been made.
406.	SH	HTA Ref 1	3	Full	32 2.6.7	34-40	2.2 Please comment on the health economics and/or statistical issues depending on your area of expertise. This paragraph gives a good introduction to the problems of including an economic component to this guideline. I think the section would benefit from better linking to the next paragraph (see also next comment) and the one after. At present the three economic	Thank you – linking sentences have now been drafted in this section to improve the flow of ideas.

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							elements to the guideline seem disjointed.	
407.	SH	British Association for Art Therapists	5	Full	2.6.8	33	The GDG membership has no representation from art services, how can this justify promoting patient choice and equality?	Thank you for your comment. The GDG constituency was agreed at scoping stage with NICE.
408.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment.
409.	SH	CAMHS Wales	11	Full	3	35 -54	Really helpful that GDG have attempted to identify and	Thank you for your comment.

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							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.	
410.	SH	National Autistic Society	4	Full	3	35 – 54	The NAS believe the GDG's recommendations in relation to recognition are extremely useful and we are particularly pleased that you have re-emphasised that diagnosing ASD in children with an intellectual disability is important to providing the right kind of help and support. We are also very happy that the guideline has recommended the creation of ASD teams, but that	Thank you for your comment.

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							will be discussed in more detail later. One point, which came out of a focus group held by the South Gloucestershire branch of the NAS, was that parents felt that after struggling to initially get a diagnosis for one child they found it just as hard if not harder to get help for siblings if they suspected they had autism. There was a consensus amongst the parents in the room that there should be an easier way to access the right support. We are therefore pleased that the GDG have included having a sibling with ASD as a risk factor and we would hope this point is emphasised so that parents do have to battle against a system on numerous occasions.	

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411.	SH	HTA Ref 2	17	Full	3.1	35	Line 5 – most of whom – not who	Thank you for your comment, the suggested amendment has now been made.
412.	SH	HTA Ref 2	71	Full	3.1	35	Line 5 – social care	Thank you for your comment, this amendment has now been made.
413.	SH	BACD	3	Full	3.1.16		3.1.16 Good to highlight that not all children will have all features.	Thank you for your comment.
414.	SH	HTA Ref 2	18	Full	3.1.2	35	Line 19 – NAP-C – should be 2003 not 2002	Thank you for spotting this error. We have now changed this to 2003.
415.	SH	NHS Milton Keynes	11	Full	3.1.3	36	Our comments is that if there is any evidence that relates to school aged children alone, then it would be useful to have it included.	We attempted to arrange the evidence for this review into the different school age groups (pre-school, primary school and secondary school) but there were no studies which only included secondary school aged children. The systematic review did identify one study that included a mix of primary and secondary school age children but due to the way the results of the study were reported, it was not possible to separate out the information for the secondary school age children, and for this reason this study was presented separately.
416.	SH	British Association for Art Therapists	6	Full	3.1.3	36	You have not listed the included studies does it consider any of	Thank you for your comment, full citations for all the included studies are given in chapter 11 'References, abbreviations and glossary'. The data extracted from included studies can be found in Appendix H 'Included studies' that was made available for consultation as a

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							the following? (Please see attached list)	separate file as stated on p234 of the draft guideline.
417.	SH	BACD	5	Full	3.1.36		3.1.36 Physical examination - not sure why the guideline is only suggesting to examine some children? There is no evidence that an examination is or is not necessary but ample evidence that certain conditions are associated with ASD. Children with several of these conditions would not necessarily be dysmorphic or have an obvious intellectual disability (other than asd features.) Personal experience - 6 year old seeing CAMHS service for	Thank you for your comment. The recommendation has been amended so a physical examination is part of the ASD assessment.

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							behaviour problems - asked to see purely because of bedwetting. On examination multiple café au lait, no FH. Diagnosis NF1 and ASD. Looking at these criteria he would not have been examined and the underlying disorder 'missed'. Why are we not saying all children with an ASD deserve an examination, and a vision and hearing test? There is also no reference to head circumference - again no paper on microcephaly - several spurious papers relating to macrocephaly associated with ASD but if no one measures then an underlying micro or macro cephalic will be overlooked	

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							which may be very relevant to investigation Personal experience:- e.g. 5 year old boy with attention problems. Having treatment for ADD but still no better. Paediatrician finds microcephaly refers to neurodisability consultant -, Wood's light positive, further MRI and CT - diagnosis TS with ASD plus ADD. This guideline would not be suggesting a head circumference as part of detailed examination is necessary in children with a developmental impairment being considered for an ASD.	
418.	SH	The Royal college of	16	Full	3.1.6	40 -48	Too much emphasis placed on	Thank you for your comment. Diagnosis is not the only outcome of either recognition or the ASD assessment. As important as a

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		psychiatrists in Wales					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.	diagnosis is the profile of needs which is relevant to all children and young people with signs of ASD and impact on function. The follow on guideline to this will address variation in provision of management interventions.
419.	SH	CAMHS Wales	8	Full	3.1.6	40 -48	Too much emphasis placed on the benefits of a diagnosis of	Thank you for your comment. Diagnosis is not the only outcome of either recognition or the ASD assessment. As important as a

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							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.	diagnosis is the profile of needs which is relevant to all children and young people with signs of ASD and impact on function. This has been made more explicit in the guideline. The follow on guideline to this will address variation in provision of management interventions.
420.	SH	The Royal college of psychiatrists in Wales	21	Full	3.1.6	44	Another common way in which children and young people present is with severe emotional	Thank you for your comment. The signs and symptoms tables cover social and behavioural difficulties in all age groups.

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							and behavioural difficulties and disorders of conduct.	
421.	SH	CAMHS Wales	13	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.	Thank you for your comment. The signs and symptoms tables cover social and behavioural difficulties in all age groups.
422.	SH	National Autistic Society	5	Full	3.1.6	46	**The ASD strategy group** The NAS keenly welcomes the GDG's recommendations for strategy groups to be established. Having a group responsible for improving recognition, referral and diagnosis – which covers a broad range of services and individuals – is vital to ensuring that the recommendations in this guideline are implemented in full. We are a little concerned, however, about the lack of detail	Thank you for your comment and your support for the implementation for ASD Strategy groups. Exactly how the ASD Strategy Group recommended in the draft guidance will interact with other statutory bodies at a local, regional and national level is not defined within the guideline. However it is hoped that there would be very close coordination between agencies in each local area. The guideline has been developed with service flexibility in mind. It is designed to be used across a range of current and future health and social care frameworks. As reforms change the way that health and social care is organised, this should not impede the implementation of these recommendations. The lack of detail is deliberate as it is not possible to proscribe how services should be organised at a local, regional or national level. As

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							in this guideline about the role of such a group, how they will interact with adult autism partnership boards, how they will work with a senior autism lead(s) in a local authority and what role they will play in feeding into Health and Wellbeing Boards. • **Adult autism partnership boards** Adults with autism and particularly those with an IQ above 70 are often excluded from local services, as they are not seen as eligible for learning disability services as their IQ is too high, nor are they seen as eligible for mental health services, as they do not have a co-occuring mental health problem. Consequently they fall in the gap between services. To help counter this structural problem and to ensure that services are properly planned for at a local level, the NAS has	you clearly state, the reform of health and social care is still in flux and we await the outcome of the government's final decisions. The GDG did not proscribe who should lead or be responsible for local ASD teams or how they should fit in with current statutory and local arrangements as this will vary widely around the country. There are good examples of local practice and the GDG view was that there was a risk of undermining good quality care with a recommendation that was too specific about how the ASD pathway should develop in each area.

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							long called for the establishment of autism partnership boards in every area, particularly for adult social care. These boards bring together relevant commissioners and others from across health and social care as well as people with autism and their families at a local level to identify these gaps and help plan appropriate services for people with autism. A significant proportion of local areas already have such a board, including the 10 local authorities of the Greater Manchester Autism Consortium[1] and 80% of the local authorities in the South West. Some of these boards are currently children only, some are adults only and some work across children and adults. The experience of our regional teams, who work closely with	

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							local authorities and the NHS, is that the presence of these boards encourages joined up working and leads to better outcomes for people with autism. It would, therefore, be helpful if the GDG would clarify the strategy groups' role and specify how best local areas can go about creating such a group, so not to confuse existing groups. Also, with the ongoing health reforms, it is vital that local authorities know the difference between these groups. It is the NAS's view that ideally you would have two strategic autism groups (one for children and one for adults) supported by the same secretariat and chaired by a senior autism lead who was a senior commissioner that sat on the local authorities Health and Wellbeing Board. It is vital to the success of both groups that information is	

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							shared between them and that, when appropriate, they coordinate their activities. - **Pathway for diagnosis** Further to this, it is also vital that the GDG is clearer on who should lead on the pathways for diagnosis established in each area for children and adults and ultimately which statutory body is ultimately responsible. The adult autism strategy states that each local area should put in place a pathway to diagnosis for adults. To help secure this requirement, the statutory guidance states that: *"Each local authority should appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area. This should be done in conjunction with the Local Strategic Partnership."*	

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							With the demise of Local Area Agreements and the creation of Health and Wellbeing Boards, many Local Strategic Partnerships (LSPs) are reviewing how they work and if they will continue. In this context, it would seem logical that health and wellbeing boards or GP commissioning consortia accept responsibility for establishing a pathway for diagnosis. This guideline, recommends that "the local ASD strategy group should be responsible for the pathway for recognition, referral and diagnosis." The NAS believes that this group would be well placed for leading on the development of the pathway to diagnosis and its oversight. However, it will be essential that the group feeds into health and wellbeing boards and GP consortia and one of	

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							these bodies takes the ultimate responsibility, not least because the majority of the NHS budget will be spent through these bodies.	
423.	SH	HTA Ref 2	72	Full	3.1.6	49	Table 1 – see points above for changes to this table	Noted with thanks.
424.	SH	HTA Ref 2	73	Full	3.1.6	50	Table 2 – see points above for changes to this table	Noted with thanks.
425.	SH	HTA Ref 2	74	Full	3.1.6	51	Table 4 – see points above for changes to this table	Noted with thanks.
426.	SH	Autism Education Trust	11	Full	3.1.6 (recommendations 13)	47	the explicit reference to signs of ASD in girls being more subtle is welcome as many are being missed and are suffering as a result. It would be helpful to have more information on this area within the document as a whole.	Thank you for your comment. The GDG decided to change the wording of this recommendation following consultation to clarify that girls may be under diagnosed as the precise meaning of the word subtle was not clear to all stakeholders. The systematic review did not identify any information around this so we could not provide any more information on this point.

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427.	SH	Autism Education Trust	12	Full	3.1.6.1	49	the inclusion of the term "symptoms" goes back to the medical model as described in point 7 above. The use of "signs" alone is more helpful as the diagnosis is based on observable behaviours and is not a "medical" diagnosis	Thank you for your comment. We fully recognise that many of the manifestations of ASD would be described as signs, however, some children and young people do present with symptoms supporting a diagnosis of ASD and for that reason it is important to include both terms.
428.	SH	Airedale NHS Foundation Trust	9	NICE	4.1	31	We agree with this research recommendation.	Thank you for your comment.
429.	SH	HTA Ref 2	19	Full	3.1.7	52	End bracket missing in Equality section	Thank you, this section has now been amended.
430.	SH	HTA Ref 2	20	Full	3.1.7	52	Feasibility section needs revising	Thank you for your comment, this section has now been appropriately re-phrased.
431.	SH	British Association for Art Therapists	7	Full	3.1.8	52	Vignettes describing different presentations of ASD- many case studies have been done to display manifestations of ASD	Noted with thanks.

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							signs and symptoms via art, for e.g. The girl who spoke with Pictures: Autism through art by Eileen Miller, London, Jessica Kingsley, 2008 The book goes through different manifestations in chapters like communication, emotions, perception and relationships. The author mentions several communication methods which were tried and failed including visual timetables and signing and facilitated communication but art therapy and analysis of her drawings that worked.	
432.	SH	HTA Ref 2	75	Full	3.1.8	52	Line 6 – add appeared very non	The vignettes have been removed from the final draft as they have not been seen as useful illustrations of the type of presentations clinicians may encounter.

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							compliant	
433.	SH	HTA Ref 2	76	Full	3.1.8	52	Line 15 – change this to unable to change behaviour – rather than not concerned	The vignettes have been removed from the final draft as they have not been seen as useful illustrations of the type of presentations clinicians may encounter.
434.	SH	HTA Ref 2	77	Full	3.1.8	53	Line 20 – delete complex before flapping arms	The vignettes have been removed from the final draft as they have not been seen as useful illustrations of the type of presentations clinicians may encounter.
435.	SH	HTA Ref 2	78	Full	3.1.8	53	Line 23 – delete mum – from Am I all right?	The vignettes have been removed from the final draft as they have not been seen as useful illustrations of the type of presentations clinicians may encounter.
436.	SH	HTA Ref 2	79	Full	3.1.8	54	We need another vignette of a child who is non-verbal with severe learning disabilities (as this is a significant group of children who come for diagnosis)	The vignettes have been removed from the final draft as they have not been seen as useful illustrations of the type of presentations clinicians may encounter.
437.	SH	BACD	4	Full	3.1.6	40	20 those with regression but no mention in document of Paed neurology see page 40	Thank you for your comment. We have now amended the translation and corresponding recommendation for recognition to refer to paediatric neurologist for certain types of regression. We also recommend including in the referral letter information about

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							24 information in referral? is family history (FH) relevant the document draws attention to heightened risk if FH of asd so this should be included here as may help prioritisation of referrals	known risk factors for ASD where available, which will include a sibling history of ASD.
438.	SH	HTA Ref 1	4	Full	32	41-46	This is a very confusing paragraph and I suggest that it is re-drafted.	Thank you. This concern has now been addressed and the section has now been edited to improve the flow of the rational.
439.	SH	HTA Ref 1	5	Full	32	47	I'm not clear what evidence to recommendation 'translation' is.	Thank you for your comment. The evidence to recommendations section comes after the summary of evidence. It is sometimes referred to as the 'translation' of the evidence by the GDG. The sentence you refer to has been amended as follows: 'Finally, every "evidence to recommendation section" includes…'
440.	SH	HTA Ref 1	6	Full	32-33	47-04	It might be helpful to emphasise here that recommendations are only made on the basis of expert opinion when no evidence is	Thank you for your comment. The section following Health Economics discusses the approach by which the GDG arrives at recommendations in the absence of evidence. We have added the following sentence to the second paragraph to make the circumstances in which expert consensus was used more explicitly:

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							available from the literature.	'Recommendations were only made on the basis of expert opinion when no evidence was available based on the inclusion criteria specified in the review protocol.'
441.	SH	GOSH Haringey	7	Full	4 further research		Research topic : Increasing evidence that asd is more frequent in children from African continent and of Afro Caribbean origin.	Thank you for this suggestion. However, the GDG have not prioritised this as a research topic from the guideline.
442.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comment. The GDG reconsidered this point and the recommendation has been split to take account of the fact that information may not be available or the referrer may not have the skills to evaluate all the signs and symptoms in the tables. The two recommendations now distinguishes between information that should always in be included (which can be reported by any professional) and information which should be included if available. At the single point of referral further information gathering may be required. The GDG recognise that in some instances full information (e.g. developmental milestones) may not be available for a child or young person and this should not delay referral to a the single point of access.

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							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.	
443.	SH	CAMHS Wales	14	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	The pathway has been designed so that referral into a single point of access is made. In addition awareness of how to access diagnostic services (across agencies) should be improved. At the single point of referral further information gathering may be required. The GDG recognise that in some instances full information e.g. developmental milestones may not be available for a child or young person and this should not delay referral to a the single point of access.

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							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.	
444.	SH	British Psychological Society	4	Full	4	60	It is regrettable that none of the screening tools were considered	Thank you for your comment.

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							of appropriate accuracy/quality (p60).	
445.	SH	British Psychological Society	5	Full	4	75	Please see our comment 16 above.	This point relates to the timelines in the draft recommendations. We have kept the 3 month timeline in recommendation about when the ASD diagnostic assessment should start as we believe it is reasonable to gather all relevant information within that time. Also assessments of language, school reports and developmental assessments of very young children may not be clinically useful if undertaken more than three months before the start of an ASD diagnostic assessment. The GDG took this into account when making the recommendation.
446.	SH	BACD	6	Full	4.1		4.1 Presentations with school refusal, anxiety etc. Excellent	Thank you for your comment. However, all the vignettes have now been removed as there were only a few and as such, did not show a complete range of possible presentations.
447.	SH	National Autistic Society	6	Full	4.2.5	62	The NAS believes the GDG recommendations in this area are very sensible. We understand that the GDG can not make recommendations, particularly something as important as screening and diagnostic tools, without a great deal of peer reviewed research.	Thank you for your support for these guidelines recommendations. The GDG considered a research recommendation on diagnostic tools but the consensus view was that the diagnostic and screening tools were more useful in collecting information to inform the assessment of needs and that any further studies on the diagnostic accuracy of these tools was not a priority.

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							We would suggest that this is an important area for future research. The NAS would like the GDG to consider making this a research recommendation as they have in section 4.4.7 p.75 to encourage further investigation. Thank you.	
448.	SH	HTA Ref 1	14	Full	61 Table 4.2.5		')' missing from after signs and symptoms	Thank you for your comment, this amendment has now been made
449.	SH	Autism Education Trust	16	Full	4.3.3	63	the introduction of autism and ASD as separate terms needs to be explained if this is a document that is intended for a wide range of professionals	Thank you. The section on the term ASD has now been expanded in the introduction.
450.	SH	Royal College of Paediatrics and Child Health	45	Full	4.3.5	66	We would like clarification on why these conditions were chosen. We agree with all, but presume again that Cong	Thank you for your comment. The GDG selected these conditions on the basis of their clinical experiences. The GDG considered that identifying any of these conditions in a child/young person presenting with signs of ASD could make them suspect ASD rather than another developmental problem. Evidence on the three conditions mentioned

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							Rubella, PKU and Hypomealanosis of Ito are [excluded because they are?] very rare. However, on p137, think they would because of treatments?	was not sought because the GDG considered them to be rare.
451.	SH	HTA Ref 2	21	Full	4.3.5	66	Line 24 – has an increased likelihood – delete the	Thank you for your comment, this section has now been revised.
452.	SH	HTA Ref 2	22	Full	4.3.5	66	Line 30 – ASDs – no apostrophe needed	Thank you for your comment, this amendment has now been made.
453.	SH	BACD	7	Full	4.3.8		4 3.8 Highlight presence in females good ? Sodium valproate an anticonvulsant / psychotropic drug.	Thank you. We have explained the presence of sodium valproate in the evidence to recommendations translation in chapter 4.
454.	SH	HTA Ref 2	81	Full	4.3.	72	Table 4 – add A parent has an	The GDG considered whether it should be included based on

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					9		ASD	consensus. Although there was some agreement that in children with ASD there is perceived increased likelihood that a parent will have autistic trait, expert opinion within the GDG was that a parent with ASD is not routinely considered a risk factor in clinical practice. Therefore a parent with ASD it was left off the list of risk factors.
455.	SH	GOSH Haringey	8	Full	4.4		Information gathering from schools with standardised questionnaires does improve diagnostic certainty. Locally training is provided by SLT/community consultant/ed psych with an interest in autism and autism advisory service at SENCO meetings	Thank you for your comment. We did not identify evidence for a standardised mechanism for gathering that information and consequently it forms one of our research recs.
456.	SH	Royal College of Paediatrics and Child Health	46	Full	4.4.6	72	The guideline indicates that assessment for ASD should start within three months of referral. However, no guidance is given on how long the assessment should take and when parents can expect the ASD team to reach a	We recognise this point. However the time required completing assessment would be highly variable depending on individual needs. For some children continued diagnostic follow up is necessary even after completion of the initial assessment therefore the GDG did not feel that it was appropriate to give an end point for assessment.

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							conclusion. We perceive this as a risk, as this could lead to lengthy periods of assessment. As the NHS now has a standard referral to treatment time of 18 weeks, we suggest that these standards be applied to the diagnosis of ASD in this guideline.	
457.	SH	National Autistic Society	7	Full	4.4.6	73	"…the consensus was that the diagnostic assessment be arranged without delay and should start within 3 months of the initial referral to the ASD team." The NAS welcomes that the GDG have suggested that the assessment should start right away and occur no later than 3 months. Timescales are extremely important. Early diagnosis is vital to get the right support in	Thank you for your support for this recommendation. The ethos running through the guideline is that appropriate support is offered to children, young people and their families based on need and not a diagnosis. This should mitigate against the problems you describe of families 'falling into crisis' while waiting for assessment.

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							place as soon as possible. In our experience, many people with autism and their families benefit from having a diagnosis. Having an explanation for the problems that someone has been experiencing, possibly for many years, can bring a sense of relief. As well as this, an accurate diagnosis is vital to providing an individual with the services and support that are most appropriate to their needs or, put another way by an attendee to a NAS focus group in Peterborough, "*a diagnosis is not a label, its a signpost*." Autism is a complex disability, but parents regularly tell us that they constantly have to battle across all areas to get professionals to believe something is wrong with their child. This can be particularly acute for families during the months they were waiting to get to see someone about a	

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							diagnosis. During this wait, families can often fall into crisis and need support both during and after the process. We regularly hear stories of children who have been in the social care and/or mental health system for years before referral or assessment for ASD. This guideline – and the other two guidelines in development – is a fantastic start, but even current best practice still means that families are having to wait for a considerable amount of time, before being able to access diagnosis. The NAS would welcome recognition of this and for the GDG to make improving the user experience a priority.	
458.	SH	Autism Education Trust	13	Full	4.4.6.32	74	information gathering at referral and all other stages of assessment should be a collaborative process that	Thank you. We have clarified the role of the case coordinator and the recommendation now specifies that they should gather information relevant to the ASD diagnostic assessment.

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							involves all who know and work with the individual. Preschool and school staff probably already have valuable information as the child or young person involved may be on a stage of the SEN Code of Practice. Involvement of education staff throughout will ensure that assessment and diagnosis lead to positive outcomes as all will feel included and will "own" the outcome	
459.	SH	HTA Ref 2	23	Full	4.4.7	75	Feasibility – undertake – not undertaken	Thank you for your comment, this section has now been revised.
460.	SH	Airedale NHS Foundation Trust	10	NICE	4.4	33	We as a team feel this is an important part of the assessment process and should be included as part of it. We have found this aspect of our	Thank you for your comment. The GDG is encouraged to find that others support the idea of research to increase the effectiveness of liaison with education during diagnostic assessment.

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							assessment process invaluable and it has helped resolve a number of our diagnostic dilemmas, where the situation has been unclear.	
461.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comment. We agree that not all children need an ASD assessment and this is built into the pathway. The ASD assessment is also intended to be a broad assessment which profiles needs. In addition the pathway gives the opportunity for the ASD team to refer for other assessments where appropriate.

Comment No	Type	Stakeholder	Order No	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
							help to guide recommendations re intervention Not all children with autistic traits warrant ASD diagnosis or benefit from ASD specific interventions.	
462.	SH	CAMHS Wales	12	Full	5		Think that 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	Thank you for your comment. We agree that not all children need an ASD assessment and this is built into the pathway. The ASD assessment is also intended to be a broad assessment which profiles needs. In addition the pathway gives the opportunity for the ASD team to refer for other assessments where appropriate.

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							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.	
463.	SH	BACD	8	Full	5		5 Diagnostic assessments Agree clinical mdt diagnosis outweighs additional cost But core element of an assessment should include a clinical examination surely - at least ensure this has been done by a clinician competent with knowledge and reference to the examination in relation to a child	Thank you for this supportive comment. The recommendations have been amended to include a physical exam for each child or young person going through the ASD diagnostic assessment. The physical examination includes investigation of macro- and micro-encephalopathy.

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							or yp with LD or neurodisability or asd. In addition from adult studies those with a LD get a poorer quality of health care and this group deserve good examinations to exclude the ‘ordinary ‘problems too e.g. Undescended testes etc. This is stated in 5.5.1 but appears to get diluted; in addition HC measurement is not mentioned as a decider to consider investigating for a potential underlying diagnosis.	
464.	SH	Calderstones Partnership NHS Foundation Trust	1	Full	5		Within the diagnostic assessment guidelines, I think that new advanced nursing roles such as the role of ‘Advanced Practitioner in ASC’s’ should be included as a possible member within the diagnostic multi-	Thank you. We recognise this contribution and have expanded the recommendation to include other professionals to reflect local arrangements.

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							disciplinary team. Our organisation has Advanced Practitioners who currently assess and diagnose autism as part of a specialist MDT. The Advanced Practitioner is a clinically based advanced nurse with many valuable skills which can contribute to the diagnostic team.	
465.	SH	British Psychological Society	6	Full	5	84 & 93 for example	In clinical environments, the 3di for example, tends to be promoted as though it has a much stronger basis than was found within the comprehensively reviewed material. In addition, we are concerned that "No evidence was identified for the DISCO" (re: use of use of diagnostic tools in isolation p93) despite its	Noted with thanks.

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							prominence in clinical settings. The conclusions helpfully distinguish between evidence relating to autism and that relating to ASD (eg p84).	
466.	SH	British Psychological Society	7	Full	5	92 line 2	"be" is missing before "representative".	Thank you for your comment, this section has now been revised for clarity
467.	SH	British Psychological Society	8	Full	5	97	Please see our comment 10, above.	Thank you for your comment. Lack of reciprocity has been added to the text above the tables
468.	SH	HTA Ref 2	24	Full	5.1	76	Clinical questions – Bullet point 2 – is confusing – as I think the examples should be of other assessments – not the diagnostic tools	Thank you for your comment. We agree that the components of diagnostic assessment are wider than diagnostic tools. This is reflected in the recommendations. The systematic review focussed on diagnostic tools as this is a key part of the assessment where there is published evidence on accuracy in diagnosing ASD.
469.	SH	HTA Ref 2	80	Full	5.4	66	Should the risk factor Parent has an ASD be added?	The GDG considered whether it should be included based on consensus. Although there was some agreement that in children with ASD there is perceived increased likelihood that a parent will have autistic trait, expert opinion within the GDG was that a parent with ASD is not routinely considered a risk factor in clinical practice. Therefore a parent with ASD it was left off the list of risk factors.

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470.	SH	Welsh Assembly Government	5	Full	5.5		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 to what other professionals think 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!	The guideline developers recognise that a diagnosis may sometimes be done by single professional. However, the profile always requires input from a wider group of professionals.
471.	SH	The Royal college of psychiatrists in Wales	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	The guideline developers recognise that a diagnosis may sometimes be done by single professional. However, the profile always requires a wider group of professionals.

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							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!	
472.	SH	Royal College of Paediatrics and Child Health	44	Full	5.6.5 Recommendations 37 5.6.5	8 91	It is of great concern that the guideline is only recommending physical examination of the child in selected circumstances. The guideline contradicts itself by including motor coordination difficulties and dysmorphic features as indications for physical examination, when	Thank you we agree with this comment and the recommendation has been amended so that each child or young person has a physical examination.

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							physical examination would be required to know that these exist. Dysmorphology is not restricted to the face and requires careful, systemic examination of the whole child, including assessment of height, weight and head circumference and ascertainment of percentiles. The guideline clearly states that there are numerous (60 is stated) medical conditions known to co-occur with autism spectrum disorders. It also states that investigations should be tailored to the individual child. It is not possible to draw up a differential diagnosis and list of appropriate investigations to test diagnostic hypotheses without	

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							first physically examining the child. Furthermore, this physical examination should be done by a clinician with competence in the breadth of neurodisability, to give the best possible opinion to inform differential diagnosis, plan investigations and thus correctly identify co-occurring conditions. Reference: Assessment and investigation of the child with disordered development. Horridge KA. Arch Dis Child Educ Pract Ed 2011:96:9-20 doi:10.1136/adc.2009.182436	
473.	SH	National Autistic Society	8	Full	5.6.5	p.93	"The GDG view was that the value of a multidisciplinary team arriving at a diagnosis outweighed the additional costs of more than one person's involvement in deciding whether	Thank you for your support for this recommendation. To describe the optimal catchment area for an ASD team is beyond the scope of a clinical guideline but the introduction to the Full guideline now describes the likely workload for a defined population, as requested by a number of stakeholders.

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							a child or young person has ASD." The NAS strongly supports this recommendation. In our experience, where the best outcomes are being seen for people with autism, this has been as the result of the development of a local multidisciplinary team, which not only carries out diagnosis, but also offers support following diagnosis. The NAS would like see such a team in each area. With this in mind it would be useful for the GDG to make a recommendation as to what planning population these teams should cover. With the emergence of GP commissioning consortia of various sizes this information will be vital for commissioners. For instance, it has been suggested that in Birmingham there could	

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							be as many as eleven GP consortia operating in the area, while in Cumbria there will be just one. In addition to this, Health and Wellbeing Boards will be operating out of each top-tier local authority. Going forward, therefore, it would be extremely useful for all those involved in health to have a clear recommendation on the desired catchment area for these teams to give clearer direction to consortia and Health and Wellbeing Boards.	
474.	SH	Humber Foundation NHS Trust	1	Full	5.6.5	96	Our comments are as follows: We felt that the guidance was unclear regarding whether a multi-agency discussion is required before a diagnosis of ASD can be reached. Clarity regarding the role of the team in the diagnostic process would be helpful. There is still room for interpretation in that it could be	Thank you for this comment. The guideline developers recognise the multi professional approach that is required in the assessment and profiling of a child or young person. However, the developers also recognise that in some (not all) instances a diagnosis may be finally confirmed by a single experienced professional using information and against the DSM or ICD criteria.

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							interpreted that the proposed diagnostic process could be completed by one person reviewing all the relevant information alone without discussion. It is clearly stated that a variety of models of service provision can exist and that aspects of the assessment can be carried out single handedly but wider expertise is required to develop the comprehensive profile BUT clarity regarding the ultimate decision regarding diagnosis needing to be multi- professional or uni-professional is still required.	
475.	SH	Humber Foundation NHS Trust	2	Full	5.6.5	97	Our comments are as follows: We felt it was important to point out that there is a difference	Thank you for your comment. The GDG have changed the recommendation on the ASD team to say the team should have as a

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							between the role of the clinical and educational psychologist, when considering membership of the proposed ASD team. Clinical Psychologists have further training in more complex mental health, developmental psychology and neurodevelopmental psychology relating to health conditions. Educational Psychologists have a more education based focus. Clarity regarding the role of the psychologist and what skills and experience they would bring would be helpful.	core member a 'clinical and/or educational psychologist' and should also have access to 'educational or clinical psychologist'
476.	SH	British Psychological Society	9	Full	5.6.5	97	The currently proposed multidisciplinary ASD team (point 3) list 'Clinical or Educational Psychologist'. The Society feels that these should	Thank you for your comment. The GDG have changed the recommendation on the ASD team to say the team should have as a core member a 'clinical and/or educational psychologist' and should also have access to 'educational or clinical psychologist'

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							be listed separately as they provide very distinct roles/skill sets.	
477.	SH	HTA Ref 2	82	Full	5.6.5	97	Recommendations on the ASD team – as educational interventions are currently the most useful for the majority with ASD – it is very important to have a strong educational component in the ASD team – so I would want to have Educational Psychologist as separate from the Clinical Psychologist – and/or – to have a specialist teacher listed. The latter may be more realistic given the resource implications.	Thank you for your comment. The GDG have changed the recommendation on the ASD team to say the team should have as a core member a 'clinical and/or educational psychologist' and should also have access to 'educational or clinical psychologist'.
478.	SH	British Psychological Society	1	Full	5.6.5	98	Assessment process. The Society recommends that	Thank you for your comment. We have emphasised the importance of systematic enquiry into co existing conditions and the assessments required to assess them, and full consideration of differential diagnosis. Mental and behaviour problems are key areas for such

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							assessment includes a full mental health assessment and that information beyond development/medical history is gathered. Additionally, we feel there is a need to examine life experiences and the influences these can have on the child's development e.g. early developmental trauma, attachment difficulties, relationship difficulties.	assessments. Life experiences as a component of history have also been inserted.
479.	SH	British Psychological Society	1	Full	5.6.5	98	We recommend consideration is given to encouraging the use of information from at least 2 contexts – this can include direct observation or reports from other settings.	Thank you for your comment we agree that obtaining information from varied contexts is essential and this is made clear in the recommendations about information that should be sought prior to, and during the ASD diagnostic assessment.

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480.	SH	British Psychological Society	1	Full NICE	5.6.5 1.6.5	99 27	Point 52 - It is unlikely to be necessary or appropriate to consider assessment of risk in all cases of ASD Diagnosis.	Thank you for your comment, the recommendation has now been altered to suggest that clinicians should 'consider the potential risk of harm' to reflect the need for clinical judgement in this decision.
481.	SH	British Psychological Society	1	Full NICE	5.6.5 1.5.13	99 24	There is concern about diagnosing children before 24 months and under the mental age of 18 months with ASD, considering normal variations in the stages of development. A stronger statement would be helpful in 1.5.13.	Having identified the difficulty in diagnosing under 24 months chronological age or 18 month developmental age the developers retain the position that diagnosis before this age cannot be completely excluded as it is possible in some cases.
482.	SH	British Psychological Society	1	Full NICE	5.6.5 1.1.7	99	Transition to adult services. Onward referral to an adult ASD assessment team. This is based on a premise that such services exist. Significant investment would be required to develop such services.	Thank you for your comment. The current legal obligations outlined in the Autism Bill mandates the availability of this service.

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483.	SH	Autism Education Trust	15	Full	5.6.5.36	97	there needs to be more emphasis on observation of the child or young person in a social setting such as their educational setting	Thank you for your comment. The recommendation that advises observation in different settings (school, nursery etc) in cases of uncertainty has been moved into the ASD assessment section. Please also note that following referral to the ASD team the guideline developers emphasise that further information (e.g. from school) may be required. Also once the decision to proceed with an ASD assessment has been made, interaction and observation of the child is part of every ASD diagnostic assessment.
484.	SH	Autism Education Trust	17	Full	5.6.5.4	97	the ASD team should work in collaboration with others not just "give advice". Information is shared more effectively if all involved, including schools, are included in the process	Thank you for your comment. The GDG fully support collaborative working and have made several recommendations to that effect, in particular they have recommended that after the assessment and diagnoses, the child's or young person's profile should be shared with professionals in education and that a school visit by the member of the ASD team may be an appropriate way to achieve this. The recommendation also highlights that consent should be obtained before information is shared with other agencies.
485.	SH	Autism Education Trust	14	Full	5.6.5.7	97	the reference to transition and collaborative working between teams is very welcome	Thank you for your comment.
486.	SH	Department for Education	6	Full	5.7.6	105, 5.7.6	Trade-off between clinical benefits and harms – fifth paragraph. "Evidence	Thank you for your comment. This reference has now been added to the translation of evidence to recommendations in chapter 5.

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							suggested that parents value being signposted to sources of help and support". The GDG might want to refer here to the existing "Early Support" programme – it would certainly make the reference on page 178 line 10 to the Early Support Keyworking Service less opaque. I am grateful to my colleague Eileen Strevens for the following:	
487.	SH	National Autistic Society	9	Full	5.7.6	107 - 109	The NAS runs Consultative Groups which are made up of adults with autism who use our services. The groups are consulted regularly and are invaluable in helping us understand the issues that people using services face. Most of the group members have high support needs and would not generally access	Thank you for these insightful comments. The guideline recommends face- to- face discussion with children, young people, families and carers, as well as information appropriate to the child or young person's chronological and developmental age. The GDG has given consideration to the fact that young people may wish to discuss the ASD diagnostic assessment and its conclusions directly with the professionals, with or without a carer present, and that professionals need to be mindful these issues whenever information is shared with older children and young people. We have consulted with the Patient and Public Involvement Programme at NICE for advice in how to phrase recommendations on information sharing so that issues of consent are addressed appropriately in the guideline.

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							meetings and forums independently, so the majority are accompanied by support workers. The meetings are clearly structured and run in order to make sure that everyone can participate in the most meaningful way. Papers for the meetings are provided in 'easy read' format and sent to the members along with a clear agenda, in advance, so that they can discuss them with their support worker before the meeting. Visual aids such as symbols and photographs are used to help people answer questions and stimulate discussion, and meetings are held in autism-friendly venues where break-out rooms are available if people need to take time out from the meeting at any point. In our last meeting in December, we discussed diagnosis. The majority of group members	The guideline does not recommend reading lists or specific advice and guidance for children and young people going through an ASD diagnostic assessment as the guideline has a specific clinical focus. It cannot cover all aspects of care and support for children and young people and their families before, during and after the ASD diagnostic assessment. We welcome clear, supportive and objective information for families and carers and hope this information will be updated to incorporate and explain the recommendations set out in the NICE guidance for assessment and diagnosis of ASD.

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							had been diagnosed relatively late: either as teenagers or in adulthood. Many felt they had not been fully involved in the process, and would have liked more information following the diagnosis to help them understand what it meant and what support was available to them. *"It should be made easier for people [to get a diagnosis]."* *"I can't remember [when I was diagnosed] but before I started college, maybe 18 or 19 … my mum thought I had autism but had a fight on her hands for a diagnosis."* *"I still don't understand everything about autism. I don't know what it is… I would like to find out more information about autism to help me understand."*	

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							"More face to face interaction with me. A leaflet or 'welcome pack'. – information available so I didn't have to go and look for it myself." *"If the lady who told my parents I had Asperger's had spoken to me directly it might have made the condition even more understood by me."* The NAS believes that there is no one right way of telling a child about their diagnosis and we welcome the advice set out in this section of the guidance. However, there are some points additional points that the GDG may wish to add. Firstly, it is important to think creatively about who is best placed to explain the diagnosis to the child. In some situations this may be the clinician, but in others a family member may be more appropriate, whether this is a parent or another family	

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							member who is close to the child. Secondly, it is also important that every step is taken to tell the child about the diagnosis in a room that is comfortable, quiet and as calm as possible. Next, if the family has other children, the clinician may want to, with the parents consent, talk to them separately about the child's condition. Furthermore, some children will need reassurance that their new diagnosis does not mean that they are seriously ill and in need of intense treatment. Moving on, the NAS recommends a number of books aimed at explaining what autism is to children and siblings. In an Appendix, it might be useful for NICE to produce a reading list that teams may want to suggest to children and families.	

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							Finally, the NAS welcomes that the GDG have recommended a follow-up appointment within 6 weeks. In our experience, many areas do not currently offer this and there is a marked difference between families who have had a follow-up meeting and those that have not. Along with the other points already mentioned, the NAS believe this is an important point to emphasise.	
488.	SH	BACD	10	Full	5.75		5 75 'Do not make telephone calls to a parent informing them of an appointment' - may need qualifying?????	Thank you for your comment, but we cannot qualify this information as it is an evidence statement and therefore reflects the content of the study.
489.	SH	BACD	11	Full	5.8		5.8 Evidence to recommendations Trade off	Thank you for your comment. The evidence to recommendations has now been edited to remove these repetitions.

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							Good to see second opinion being encouraged but theses paragraphs are a little repetitive and therefore become unclear.	
490.	SH	Autism Education Trust	18	Full	5.8	109	this section is very helpful	Thank you.
491.	SH	British Association for Art Therapists	8	Full	5.8.2	109	Line 11- no specific intervention.... ASD strategic action plan for Wales (Welsh assembly government, April 2008). Section 23 Arts therapies are identified as a key intervention for ASD assessment (p. 52, 53) and education (p.54), and as a core therapeutic intervention (p.57 and 59)	Thank you for your comment. We could not cover all the varied diagnostic approaches adopted throughout England and Wales but have reflected the need for a multidisciplinary approach to diagnostic assessment and recommended that a range of different professionals is either on the ASD team and is accessible to available to the team, depending on local arrangements. This would include professionals in art therapies.
492.	SH	Autism Education Trust	19	Full	5.8.49	111	observations in different settings should be integral to the	Thank you for your comment. The GDG agree that information from other settings including schools can be invaluable to clinicians when making decisions about a diagnosis of ASD. Please note that both the

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							assessment process not just if there are discrepancies in the signs and observation in the clinic setting	child's or young person's experiences of education and assessment through interaction and observation are part of every diagnostic assessment. However, the GDG concluded that, in some cases, it is possible to reach a diagnosis without observing the child in different settings which is why they have emphasized this step in cases where diagnosis is uncertain.
493.	SH	HTA Ref 1	8	Full	110 5.8.6	Table	Section on 'Trade-off between net health benefits and resource use'. Again, I have a similar issue here. I see that it's stated as the GDG's view that referral and enhanced monitoring of children…would be a cost-effective use of NHS resources, but I still think its pretty strong language for opinion. Even well conducted economic evaluations alongside clinical trials acknowledge elements of uncertainty by concluding that an intervention is likely to be cost-effective. As it's quite	Thank you for your comment. The statement has been amended here and throughout to reflect the uncertainty of the cost-effectiveness of these interventions.

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							possible that the guideline will be quoted by various stakeholders I would think it's important to get the language right.	
494.	SH	British Psychological Society	1	Full NICE	5.8.6 1.6.3	111	Onward referral to a Tertiary ASD assessment team. The consultation implies that there will be a team above the standard ASD assessment teams who will be able to provide further assessment when diagnosis is uncertain. We have practical concerns over whether these teams exist.	The developers confirm such teams do exist around the country.
495.	SH	HTA Ref 1	15	Full	52 Table		4.2 Please comment on whether the research recommendations, if included, are clear and justified.	n/a

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496.	SH	HTA Ref 2	25	Full	6.2.1	113	Line 1Data are not is – data needs checking throughout the guide	Thank you for spotting this. We have now changed data to plural throughout the guideline. The full document will also be edited professionally at a later date by a medical editor which will ensure that any mistakes such as this are corrected prior to publication.
497.	SH	HTA Ref 2	26	Full	6.2.7	121	Line 5 – Tourette's – check apostrophes throughout – or delete it as for Down and Asperger?	Thank you for your comment, this amendment has now been made.
498.	SH	BACD	12	Full	6.22		6.22 Only one study reported 145 – typo?	Thank you for your comment. This is an error with the appearance of the references in the document - the number 145 and the other reference tags should be in superscript format. We rectified this issue throughout the guideline now.
499.	SH	BACD	13	Full	6.24		6.24 Complete analysis Not sure whether 'behaviour problem' should be grouped under neuropsychiatric problem. Think the categorisation of	Thank you. We have re-grouped the conditions in the tables and evidence statements to address this concern.

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							following paragraphs could be reviewed e.g. developmental disorder appears as a diagnosis rather than a problem, Rett = neurological, motor problem categorised as medical	
500.	SH	British Psychological Society	1	Full	6.3.5	127	Pt39 Categories for 'Differential Diagnosis'. Again the focus on diagnosis may be limiting as many young people do not fit into these categories but may have significant functional impairment mimicking ASD difficulties. The categories lean towards a medical model e.g.	Thank you for your comment. The medical model of diagnosis is used alongside and integrated with a model of needs. Attachment difficulties have been described in the differential diagnosis section. The diagnostic assessment emphasises the need for a 'life experiences' history. Throughout, the term disorder as defined by WHO is used. The guideline uses the ICD -10 or and DSM-IV criteria for diagnosis and these do not recognise auditory processing. The developers have emphasised that the ASD assessment should enquire about life experiences which would include early trauma.

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							neuropsychiatric disorder instead of mental health difficulties. The use of the term 'Attachment Disorder' is limiting as this only covers a small group of individuals with attachment problems who present with difficulties in line with ASD. We recommend that consideration is given to: • using a more general term e.g. 'Attachment Difficulties'; • the addition of a category of 'Early Developmental Trauma'. • the addition of APD (Auditory Processing	

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							Disorder) as a possible 'differential diagnosis'.	
501.	SH	British Psychological Society	1	Full	6.3.5	127	We would like to see a clear distinction being maintained between a diagnosis in descriptive terms and a diagnosis in causal terms. If not, there are implications for practitioners. There is a risk that defining autistic disorders in behavioural terms and in terms of similarities rather than differences, could lead to the somatic symptoms and learning difficulties associated with autism being overlooked in individual cases. Although individual variations have to be overlooked when defining the characteristics of the entire autistic population,	Thank you for your comment. We agree that ASD is a descriptive term for likely heterogeneous causality and we have made this explicit in the Introduction – see section 2.1.

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							health practitioners will not be diagnosing the entire autistic population, but an individual child with a specific (if unknown) cause or causes for his or her specific signs and symptoms - including somatic ones. Cont'd/ ….. Since the causes of autism are unknown, consideration should always be given to the possibility that the child's autism is a consequence of co-existing medical conditions, in addition to the possibility that the autism indicates a distinct disorder in its own right. This is particularly important when the child has mild visual, auditory, motor and other health problems (with a	

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							potentially traceable aetiology) that are not sufficient to warrant a separate or differential diagnosis, nor prioritisation by other specialist services, but which together could give rise to autistic characteristics.	
502.	SH	BACD	9	Full	5.6.5	97	Recommendations Page 97 'There should be a multidisciplinary team (ASD) which may include a':- Should this not be which SHOULD - if it looks like we are ambivalent whether SLT is present or not then our argument up and down country will be irrelevant? Throughout the guideline we recommend consideration of differential etc.	We recognise the importance of these three professionals and have re-structured our recommendation about the core team membership and access to professional expertise outside the team to allow for variation in local arrangements. We now recommend that there should be a paediatrician either in the core team or available to the team and in many cases although perhaps not universally this may be a community paediatrician.

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							should not this mean that this will need a SLT present. The minimum team should be a Paed / child psych. and SLT. - Speech and Language Therapists should definitely be part of the team as some will hopefully be ADOS trained and can contribute to the diagnostic process. They are also more likely to pick up the consequences and be highly involved in the intervention from a number of perspectives (family counselling following diagnosis, social communication programmes and feeding difficulties). Community Paediatricians will be crucial in the care of this	

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							group but most importantly in getting the appropriate educational placement. I know the SEN arrangements are changing but we should still facilitate joint agency working across health and education and I am sure Community Paediatricians should be key players in this process.	
503.	SH	British Psychological Society	1	Full	7		We have concerns that some diagnoses of ASD are initially mis-diagnosed, for instance as ADHD. We would therefore strongly recommend that diagnoses are only undertaken by those with relevant experience and training.	Thank you for your comment. The GDG were unable to make specific recommendations about the competencies of professionals as this was excluded from the scope, however, they have recommended that a multi-disciplinary team (the ASD team) who either have the skills, or access to other professionals that do, carry out the ASD specific assessment and that this assessment should include consideration of differential diagnoses including ADHD.
504.	SH	British Psychological Society	1	Full	7		We recommend cautioning against the use of 'attachment	Thank you. The GDG are aware that differentiating the social impairments of ASD and attachment disorders can be extremely challenging. However the GDG do not think that attachment difficulties

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							disorder' as a dual diagnosis with ASD. Given the core social interaction deficits in ASD it would be unlikely for anyone with ASD not to have some attachment difficulties. See also our comment 44, above.	are fundamental to ASD and therefore they have decided not to remove it from their list of differential diagnosis.
505.	SH	The Royal college of psychiatrists in Wales	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.	Thank you for your comment. Epilepsy is on the list of coexisting conditions for consideration. No evidence was found that identified either attachment disorder or PTSD as a common coexisting condition. The GDG acknowledge from experience that attachment disorder can occur in children or young people with ASD. However, based on GDG opinion taking account of frequency and potential impact it was not considered appropriate to include it in the list of co-existing conditions in the recommendation.
506.	SH	CAMHS Wales	15	Full	7	129	Think that PTSD, attachment driven behaviours and epilepsy need to be mentioned.	Thank you for your comment. Epilepsy is on the list of coexisting conditions for consideration. No evidence was found that identified either attachment disorder or PTSD as a common coexisting condition. The GDG acknowledge from experience that attachment disorder can

Comment No	Type	Stakeholder	Order No	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
								occur in children or young people with ASD. However, based on GDG opinion taking account of frequency and potential impact it was not considered appropriate to include it in the list of co-existing conditions in the recommendation.
507.	SH	BACD	14	Full	7.1		7.1 Clinical questions Co-existing disorders Here TS and NF are categorised as medical problems which also includes 'functional gastrointestinal problems' (not sure what this means? coeliac)? Re-categorise?	Thank you. TS and NF are conditions with increased prevalence of ASD, and possible co-existing conditions. Many children/ and young people are reported to have gastrointestinal symptoms and there is evidence for greater constipation and abdominal pain. These are included in functional gastro intestinal problems.
508.	SH	BACD	15	Full	7.17		7.17 Here epilepsy, seizures are categorised as medical problems not neurological – possibly put them all under	Thank you for your comment, the evidence for these conditions has now been combined under the heading of 'medical conditions'.

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							medical or review categorisations?	
509.	SH	HTA Ref 1	9	Full	136 7.1.8	Table	Section on 'Trade-off between net health benefits and resource use'. "…considered this to be a cost-effective use of a health care professional's time". Same point as above.	Thank you for your comment. The statement has been amended here and throughout to reflect the uncertainty of the cost-effectiveness of these interventions.
510.	SH	HTA Ref 1	7	Full	70	Table	Section on 'Trade-off between net health benefits and resource use'. I think the final paragraph uses language that is rather final for what is essentially the opinion of the group. It may be more appropriate if changed to "likely to be a cost-effective trade-off" or similar.	Thank you for your comment. The statement has been amended here and throughout to reflect the uncertainty of the cost-effectiveness of these interventions.
511.	SH	HTA Ref 1	16	Full	73 Table		Another interesting research recommendation. Again, would	Noted with thanks.

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							be good to see a recommendation of what might be a useful outcome and an acknowledgement that cost-effectiveness depends on outcomes as well as costs.	
512.	SH	BACD	18	Full	8	156	Yield using MR low - agreed but example supporting this is that out of 1000 children only one found with TS, but MR would not pick up calcification which is one of the neuroradiological signs of TS so MR may not be the gold standard diagnostic test for TS. Agree small yield but from MR but the other 999 could have had a calcified e.g. hamartoma not seen via MRI .	Thank you for your comment. The guideline focuses on routine testing. We agree this is important and evolving area and have designed a key research recommendation in the hope this will be addressed in update.
513.	SH	BACD	16	Full	8.1.4		8.1.4	Thank you. Physical health and nutrition have been added to the list of considerations in the profile.

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							Blood tests Low quality studies but research based studies did reveal 58% of children with abnormal results and 3% for routine studies. I would suggest you reconsider in the guideline that children with ASD often have faddy eating and iron deficiency anaemia (IDA) to name one mineral / vitamin deficiency is not uncommon in those with restricted diets. Perhaps the consensus view should draw attention to this 'old fashion 'problem of IDA – so take a good dietary history and consider possibility of IDA?	Feeding problems including restricted diets are acknowledged in the recommendation on co-existing conditions.

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							- Restricted diets should be highlighted. Some of these children end up as non oral feeders (NG tubes and gastrostomies). It can be life threatening and causes untold distress to parents. Reference to specialist behavioural feeding clinics could also be made.	
514.	SH	Royal College of Paediatrics and Child Health	47	Full	8.1.8	158	We think this is a useful discussion. This should go on clinical opinion. One member informed us that they are trying to devise a flowchart for CAMHS colleagues regarding thinking of investigation (and examination), and noted that the more they work together the better they complement each other.	Thank you.
515.	SH	HTA Ref 1	17	Full	158 Tab		This is an interesting research	Thank you. The GDG consensus is that biomedical investigations are not a national priority for diagnosis of ASD, but that it is a growth area

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					le 8.1.9		recommendation, but I agree with the GDG that it is not a priority area.	of research and practice in the NHS. Therefore research needs to focus on what is important to the welfare of children, young people and their families.
516.	SH	BACD	17	Full	9.2.1	160	LKS needs to be written as Landau - Kleffner and added to glossary	Thank you. The full name is also given earlier in the section but the abbreviation has now been changed to the full name in the "Other Considerations" section as well and the term has been added to the glossary.
517.	SH	British Association for Art Therapists	9	Full	9.2.3	162	Parent's expectations, as for 1.3 about providing the relevant information about resources that are available including local art organisations, support groups etc.	Thank you for your comment. The guideline recommends that children and young people and their families and carers should be directed to local support groups and this could include relevant art organisations where they are available.
518.	SH	National Autistic Society	10	Full	9.2.5	164 - 166	From focus groups we have held with parents regarding diagnosis, information is often the key issue that arises. All too often parents are surprised to find that they are left feeling unsure what to do next and felt very isolated. Therefore, having the right information at the right time can make all the difference.	Thank you for your comments. The GDG hopes that the balance of information sharing in the guideline provides adequate flexibility to meet the individual needs of children, young people, families and their carers. The guideline includes specific recommendations to provide information and support, and the case coordinator's role is to ensure this support is specific to the families' needs and offered in a timely way throughout the ASD diagnostic process. We have not been able to recommend specific information (which may become out of date on publication of this guideline) but it is the GDG's strong wish that information is now produced that reflects the ethos and specific

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							The NAS is keenly aware that there is a fine balance between having not enough information and having too much. For many years the NAS has been concerned that all too often people with autism, and their families, are not given enough information. To take just one example, during the diagnosis process the person with autism and the family carer needs reassurance, guidance and information. We often receive calls to our helpline from individuals who have been given very little information about the diagnostic process and are not given adequate support post diagnosis or signposted on to appropriate services. This is compounded by the lack of accessible information provided by the NHS and social care services in general, especially information provided in an 'easy-read' format and the lack of	recommendations of this guideline to improve the experience of children and young people and their families and carers.

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							support available to help people with autism and others to understand and use the information available. On the other hand, at a recent focus group coordinated by the NAS several parents said they were given too much information. For instance, one parent of a three year old child was given information on puberty and autism. Another parent, following the diagnosis, was put in a room and shown a 3 hour DVD. The parent told us she wanted to fast forward it but didn't in case she was being watched. It is essential that the information provided to families is age appropriate and tailored to the child's and parent's needs. We are therefore very pleased that this guideline directly addresses much of this, but we	

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							would urge NICE, when promoting the guideline, to emphasise the importance of this and for NICE to produce a list of useful information that multidisciplinary teams might want to use that is age appropriate. The NAS would be happy to help the GDG and NICE with the development of such a resource.	
519.	SH	HTA Ref 2	29	Full	9.3.4	171	Line 35 – social care	Thank you for your comment. The term 'social services' is used here because it reflects the terminology used in the study being reported in the evidence statement. However the GDG have now changed 'social services' to 'social care' in their recommendations to reflect current terminology.
520.	SH	British Psychological Society	3	Full	10		Descriptions of the service models are very helpful.	Thank you for your comment.
521.	SH	British Psychological Society	4	Full	10	176 and p180 line 14, for example	The stress on strengths and weaknesses within an ASD profile is particularly welcome.	Thank you for your comment.

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522.	SH	British Psychological Society	5	Full	10	183, for example	The resources tables for different clinical teams are particularly useful and interesting. Their worth would have been increased if the relative costs of various components could have been included (p183 etc).	The GDG considered that a report of the costs for each service would not be helpful in this guideline as this information could be misinterpreted as an average cost of a diagnostic assessment across England and Wales and used to create tariffs, which is not the purpose of these descriptions of services.
523.	SH	HTA Ref 2	32	Full	10.1	175	10.1 line 9 - ASD	Thank you for your comment, this amendment has now been made.
524.	SH	HTA Ref 2	33	Full	10.1	176	Line 19 – a study design that could – delete the to	Thank you for your comment, this amendment has now been made.
525.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comment. This is noted and the chapter has been amended to reflect this exact point.

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							worth a mention somewhere.	
526.	SH	CAMHS Wales	16	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.	Thank you for your comment. The services included in chapter 10 are not representative of all services across the UK. The GDG considered that an aggregated estimate of time taken could be misinterpreted and that this information could be used to compare teams against one another.

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527.	SH	CAMHS Wales	17	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.	Thank you for your comment. This is noted and the chapter has been amended to reflect this exact point.
528.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comment. The services included in chapter 10 are not representative of all services across the UK. The GDG considered that an aggregated estimate of time taken could be misinterpreted and that this information could be used to compare teams against one another.

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							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.	
529.	SH	HTA Ref 1	10	Full	177 10.2	30	I understand the reasoning for the service descriptions not being costed but I do think that it is a real limitation on the usefulness of the chapter. The salary costs included in the Unit costs of health and social care can be adjusted to higher rates and hourly costs re-calculated without too much difficulty. Yes, it would involve a series of assumptions about the services and the clinics, but isn't that what we economists do? As	Thank you for your comment. The GDG considered that a report of the costs for each service would not be helpful in this guideline as this information could be misinterpreted as an average cost of a diagnostic assessment across England and Wales and used to create tariffs, which is not the purpose of these descriptions of services. The GDG was not convinced that a report of the cost across 5 different services in England and Wales would provide any additional useful information.

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							such care has been taken to write down and break down each element of the assessment process, the total cost of assessment at each of the featured clinics would be a useful starting point for economic modelling and service development. Essentially, here I feel as though a natural step has been missed out, whilst it is not possible for the guideline to include information on the cost-effectiveness of referral and diagnosis, it would be possible to include an estimate (however limited) of the cost.	
530.	SH	Royal College of Paediatrics	48	Full	10.2	178	Lines 30-41: Allowed for 'rubber stamping'. Local evidence is that	Thank you the service description is an example of one model of provision in one area.

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		and Child Health					enormous waiting lists happen, as it is not possible to carry out a very similar process as outlined in this section.	In this guideline we recognise that the number of children referred for query ASD has been rising. Most of these children do have developmental problems and needs. Our guideline is recommending that a multi-professional approach.
531.	SH	Royal College of Paediatrics and Child Health	49	Full	10.2	178-179	We note that at least two of the services described appear to ask trainees to conduct a major part of the assessment of children with ASD (p178, Line 19 and p188). If this is suggested as a valid model, we believe the competencies required of those trainees should be made explicit. In particular, it should state that the trainee has been trained in the diagnosis of ASD and is working under close consultant supervision. While it is agreed that trainees	Thank you for your comment. The GDG acknowledge that is important to consider the different ways in which these services operate, and how trainees are supported and supervised. The descriptions are not meant as specific blue prints for how services should operate.

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							need experience of assessments to achieve the skills required, there are often high expectations of such assessments and much depends on the outcome in terms of appropriate support for the child. Diagnoses can at times be challenged by parents and others, which places pressure on the trainee and service, as well as affecting support for the child. We are particularly concerned that service model 1 implies that, in some cases, the consultant paediatrician sees the parents for the first time to deliver feedback from the assessment (Type 1 assessment) We do not think this would be an appropriate model for general	

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							use.	
532.	SH	BACD	19	Full	10. 2.1 - 5	181	Lovely description of ASD teams but many areas of the country are (for resource and volume of need reasons) not able to either use this team or have this team. Any of the team modules will require an investment in the services - many populations are relying on community paediatricians to assess, gather information and with sometimes a little SLT (sometimes not) or an education worker e.g. portage, early years pre -school teacher, class observations , but often alone got to come to a conclusion. NOT good enough but the	Thank you for your comment. The service description is an example of one model of provision in one area. In this guideline we recognise that the number of children referred for query ASD has been rising. Most of these children do have developmental problems and needs. Our guideline is recommending that a multi-professional approach. The multidisciplinary ASD team is made up of those professionals already involved in diagnosing and profiling children and young people with ASD. The purpose of the recommendation is to make this group of professionals recognisable to other professional colleagues, to increase communication between members of the team and thereby reduce unnecessary delays of assessments. This may be cost reducing rather than cost uplifting.

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							reality. This guideline does emphasise the MDT is the model that has the best evidence base and therefore needs resourcing. Can this be unambiguous in the guideline??	
533.	SH	Royal College of Paediatrics and Child Health	50	Full	10. 3	184 (line 15)	There appear to be discrepancies between the summary of professional time required (suggested 3 - 4 hours) and what is allocated in the service models. It would appear that in most models the assessment itself takes 3 - 4 hours with feedback, and requires a number of professionals who each require 3 - 4 hours. The time allocated	Thank you for your comment. These are descriptions of specific services in specific areas of England and Wales, They are examples of good services where the practice recommended in the guideline such as working in multidisciplinary teams are already being followed. Not all the guidelines recommendations are followed in every service described so they are not a blueprint for every service. It is therefore the GDG view that ASD teams should follow this guideline and not these services.

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							for paediatricians in the models range from 6 – 12 hours. The reference in the text is therefore highly misleading and is likely to lead to significant misinterpretation particularly in the current climate when resources are tight. We believe the text should reflect the average time taken for assessment and for work around the assessment and could conveniently be described using the range of 6 – 12 hours for medical time.	
534.	SH	Royal College of Speech and Language therapists	13	Full	10.4	191	We were interested to see there are currently five different models of ASD assessment operating. We note that there appears to be a degree of	Thank you for your comment. These are descriptions of specific services in specific areas of England and Wales, They are examples of good services where the practice recommended in the guideline such as working in multidisciplinary teams are already being followed. Not all the guidelines recommendations are followed in every service described so they are not a blueprint for every service. It is therefore the GDG view that ASD teams should follow these guideline and not

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							variation in practice around the country. We welcome this guidance and hope this variation in assessment is minimised and a common assessment pathway is standardised.	these services.
535.	SH	Royal College of Speech and Language therapists	14	Full	Appendix K	238	The differential diagnosis advice in appendix K is very useful for clearly setting out the responsibilities of healthcare professionals, including SLTs. It reinforces point number 13 above specifying that other health professionals, such as mental health and clinical psychologists, need to be included along the ASD assessment care pathway. We would like the guidance to reflect this accordingly.	Thank you. The guideline fully supports and requires a multidisciplinary team to be involved in the ASD diagnostic assessment. This is a key recommendation.

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536.	SH	CAMHS Wales	18	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.	Thank you for your comment. The view of the GDG is that these diagnoses are very difficult and require considerable expertise. We have made a recommendation that the ASD team should seek more expert help when required.
537.	SH	The Royal college of	27	Full	Ap pen	238 onwa	Good idea to attempt to tease	Thank you for your comment. The view of the GDG is that these diagnoses are very difficult and require considerable expertise. We

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		psychiatrists in Wales			dix K	rds	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.	have made a recommendation that the ASD team should seek more expert help when required.
538.	SH	British Psychological Society	6	Full	Appendix	240	It is noteworthy that readers are advised that ASD should still be	Thank you for your comment. The guideline highlights that the diagnosis for these children and young people is a challenge in those with an intellectual disability. We have covered the point in the

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					K		diagnosed in cases of severe general intellectual impairment although (on p240) it is not clarified that such diagnosing inevitable becomes less accurate.	recommendation about diagnostic uncertainty.
539.	SH	The Royal college of psychiatrists in Wales	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	Thank you for your comments. The two current subdivisions of attachment disorder are clarified in the differential diagnosis table in appendix K. The importance of clinical judgment and adequate history is recognized in making this difficult differential diagnosis.

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							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.	
540.	SH	CAMHS Wales	20	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	Thank you for your comments. The two current subdivisions of attachment disorder are clarified in the differential diagnosis table in appendix K. The importance of clinical judgment and adequate history is recognized in making this difficult differential diagnosis.

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							nurturing environment. Also may not be able to place the child in a more nurturing environment to see how they change.	
541.	SH	The Royal college of psychiatrists in Wales	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	Thank you. The GDG agree with view and have made an amendment in appendix K.

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							anxiety in relation to a social difficulty.	
542.	SH	CAMHS Wales	22	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, high anxiety	Thank you. The GDG agree with view and have made an amendment in appendix K.

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							in relation to a social difficulty.	
543.	SH	British Psychological Society	62	Full	Appendix K	244	The pathways and differential diagnosis tables at the end of the document are helpful although PDA seems under represented. Its relationship with ODD on p244 is not sufficiently clear.	PDA is defined in the glossary and the section in appendix k has been amended.
544.	SH	The Royal college of psychiatrists in Wales	28	Full	Appendix K	245	Section on OCD. In ASD, a young person can be distressed by OCD symptoms.	Noted with thanks.
545.	SH	CAMHS Wales	19	Full	Appendix K	245	Section on OCD. In ASD, young person can be distressed by OCD symptoms.	Noted with thanks.
546.	SH	HTA Ref 2	34	Full	Glossary	215	PDA – should be Newson – not Newsom – and it would help to put Professor Elizabeth Newson,	Thank you for your comment; this has been incorporated in the glossary.

Comment No	Type	Stakeholder	Order No	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
							Consultant Psychologist…. And PDA description – - state part of the autistic spectrum (delete disorders) and then write individuals with PDA are said to possess superficial social skills, to mimic others, and to be much more demand avoidant than those with autism.	
547.	SH	HTA Ref 2	35	Full	Glossary	216	PDD – pervasive developmental – and in the last line of this – is should be used – not sued.	Thank you for your comment, this amendment has now been made

These stakeholder organisations were approached but did not respond

Autism Diagnosticians Forum Northern Ireland (ADFNI)
Action for ADHD - Northants
Action for Sick Children
ADDISS
ADHD North West

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Adverse Psychiatric Reactions Information Link (APRIL)
Alder Hey Children's NHS Foundation Trust
Alliance Pharmaceuticals Ltd
Ashton Leigh & Wigan Community Healthcare NHS
Assisted living South West
Association for Cognitive Analytic (ACAT) Therapy
Association for Continence Advice
Association of Dance Movement Psychotherapy UK
Association of Directors of Childrens Services
Association of Educational Psychologists
Association of Optometrists
Association of Paediatric Anaesthetists of Great Britain and Ireland
Association of Professional Music Therapists
Association of Psychoanalytic Psychotherapy in the NHS
Association of the British Pharmaceuticals Industry (ABPI)
Autism Centre for Education and Research
Autism Cymru
Autism London
Autism Medical
Autism North East
Autism Outreach
Autism Treatment Trust
Autistic People Against Neuroleptic Abuse (APANA)
Bangor University
Barnsley Hospital NHS Foundation Trust
Barnsley PCT
Behaviour Analyst Certification Board
Belfast Health and Social Care Trust
Berkshire Healthcare NHS Foundation Trust
Betsi Cadwaladr University Health Board
Birmingham Children’s Hospital NHS Foundation Trust
Birmingham City Council
Birmingham Early Intervention Service
BMJ
Bolton Council
Bradford District Care Trust
Bridge College
British Association for Adoption and Fostering
British Association for Behavioural & Cognitive Psychotherapies (BABCP)
British Association for Community Child Health
British Association for Counselling and Psychotherapy
British Association for Psychopharmacology

British Association of Drama Therapists
British Association of Paediatric Urologists
British Association of Play Therapists
British Association of Psychodrama and Sociodrama (BPA)
British Dietetic Association
British Medical Association (BMA)
British National Formulary (BNF)
British Paediatric Mental Health Group
British Paediatric Neurology Association
British Psychodrama Association
British Society for Human Genetics
British Society of Neuroradiologists
British Society of Paediatric Dentistry
British Society of Paediatric Gastroenterology, Hepatology & Nutrition (BSPGHAN)
Bromley PCT
Brook London
Care Quality Commission (CQC)
Central Lancashire PCT
Cerebra
CHILD DEVELOPMENT CENTRE
CIS'ters
Citizens Commission on Human Rights
Cleft Lip and Palate Association
Cochrane Devlopmental, Psychosocial and Learning Problems
Coeliac UK
College of Mental Health Pharmacy
COMMUNITY INTEGRATED CARE
Connecting for Health
Counselling and Psychotherapy Trust (registered charity No. 1063175)
County Durham PCT
Coventry and Warwickshire Partnership Trust
Department for Communities and Local Government
Department of Health
Department of Health Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI)
Department of Health, Social Services & Public Safety, Northern Ireland (DHSSPSNI)
Dimensions
Disabilities Trust, The
Down Syndrome Education International
Downs Syndrome Association
Downs Syndrome Research Foundation
East London NHS Foundation Trust
Encephalitis Society

European Association for Behaviour Analysis
Experimental Analysis of Behaviour Group, UK & Europe
FACT Kettering
FACT Northampton
Faculty of Dental Surgery
Fasawareuk
Federation of Ophthalmic & Dispensing Opticians (FODO)
Flintshire County Council
Foundation for People with Learning Disabilities
Gender Identity Research & Education Society
George Still Forum (National Paediatric ADHD Interest Group)
Gloucestershire Acute Trust
Gloucestershire Partnership NHS Foundation Trust
Great Western Hospitals NHS Foundation Trust
Greater Manchester West Mental Health NHS Foundation Trust
Guy's and St Thomas NHS Foundation Trust
Halton & St Helens PCT
Hampshire Partnership NHS Foundation Trust
Hampshire PCT
Harrogate and District NHS Foundation Trust
Healthcare Quality Improvement Partnership
Hertfordshire Partnership NHS Trust
Hinwick Hall College
Imperial Healthcare
Infermed Ltd
Institute of Psychiatry
International Autistic Research Organisation & Autism Research Ltd
Kent & Medway NHS and Social Care Partnership Trust
Lambeth Community Health
Leeds PCT
Liverpool Community Health
Liverpool PCT Provider Services
London Borough of Southwark
Manchester Children's Hospital Trust
Manchester Community Health
MBB Connections Healthcare
McTimoney Chiropractic Association
Medicines and Healthcare Products Regulatory Agency (MHRA)
Mencap
Mental Health Act Commission
Mental Health Foundation
Mental Health Nurses Association

Mersey Care NHS Trust
Ministry of Defence (MoD)
MK ADHD
Mother and Child Foundation
National CAMHS Support Service
National Centre for Young People with Epilepsy, The
National Day Nurseries Association
National Hospital for Neurology & Neurosurgery (NHNN)
National Institute for Mental Health in England
National Patient Safety Agency (NPSA)
National Treatment Agency for Substance Misuse
Neonatal & Paediatric Pharmacists Group (NPPG)
NETSCC, Health Technology Assessment
NeuroDiversity International(NDI)/NeuroDiversity Self-Advocacy Network(NESAN)
NHS Bath and North East Somerset
National Offender Management Service
NHS Bedfordshire
NHS Bradford & Airedale
NHS Bristol
NHS Buckinghamshire
NHS Camden (Mosaic CAMHS)
NHS Clinical Knowledge Summaries Service (SCHIN)
NHS Direct
NHS Hertfordshire
NHS Isle of Wight
NHS Kirklees
NHS Knowsley
NHS Milton Keynes
NHS Plus
NHS Quality Improvement Scotland
NHS Sefton
NHS Sheffield
NHS Western Cheshire
NORSACA
North East London Mental Health Trust
North Essex Partnership NHS Foundation Trust
North Somerset PCT
North Staffordshire Combined Healthcare NHS Trust
North Wales NHS Trust
North Yorkshire and York PCT
Northamptonshire county council
Novartis Pharmaceuticals UK Ltd

Oxfordshire & Buckinghamshire Mental Health Partnership NHS Trust
PAPYRUS (Prevention of Suicides)
Parents' Education as Autism Therapists
Parents Protecting Children UK
Partnerships for Children, Families, Women and Maternity
Patients Council
PDA Contact Group
Pepenbury
PERIGON Healthcare Ltd
Poole and Bournemouth PCT
Portland College
Progress Educational Trust
Public Health Agency
Public Health Wales
Pyramid Educational Consultants
Qbtech Ltd
Queens University Belfast
Research Autism
Ridgeway Partnership
Rotherham NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners Wales
Royal College of Midwives
Royal College of Nursing
Royal College of Obstetricians and Gynaecologists
Royal College of Pathologists
Royal College of Physicians London
Royal College of Radiologists
Royal College of Surgeons of England
Royal Pharmaceutical Society of Great Britain
Royal Society of Medicine
Ruskin Mill Educational Trust
Salford Royal Hospitals Foundation NHS Trust
Sandwell PCT
Sanofi-Aventis
SCHOOL AND PUBLIC HEALTH NURSES ASSOCIATION
Scottish Centre for Children with Motor Impairments
Scottish Intercollegiate Guidelines Network (SIGN)
Sensory Integration Network
Shrewsbury & Telford Hospital NHS Trust
Solent Healthcare

South Essex Partnership NHS Foundation Trust
South West Autistic Rights Movement
South West Essex PCT
South West London and St Georges Mental Health NHS Trust
South West Wales Home Educators
South West Yorkshire Partnership NHS Foundation Trust
Southampton City PCT
St Andrew's Healthcare
St John's RC School
Staffordshire County Council
Sussex Partnership NHS Foundation Trust
Swansea University
TACT
Talking Mats research and development center
Tavistock & Portman NHS Foundation Trust
The Autism Centre, Sheffield Hallam University
The Princess Royal Trust for Carers
The TreeHouse Trust
Triangle
Turning Point
UCLH NHS Foundation Trust
UK Clinical Pharmacy Association (UKCPA)
UK National Screening Committee
UK Young Autism Project
UNITE THE UNION-CPHVA
United Kingdom Council for Psychotherapy
University of Edinburgh
University of Liverpool
University of Nottingham
University of Ulster
WASP with asperger limited
Welsh Scientific Advisory Committee (WSAC)
West Hertfordshire PCT & East and North Hertfordshire PCT
West London Mental Health NHS Trust
West Midlands SHA
Western Cheshire Primary Care Trust
Western Health and Social Care Trust
Whitstone Head Educational (Charitable) Trust Ltd
Wiltshire PCT
Wirral University Teaching Hospital NHS Foundation Trust
Wolfson Neurodisability Service, The
Worcestershire PCT

Wound Care Alliance UK
York Teaching Hospital NHS Foundation Trust