National Institute for Health and Clinical Excellence

Autism spectrum disorders in children and young people
Scope Consultation Table
Tuesday 9th June – Tuesday 7th July 2009

Stakeholder	**Order No**	**Section No**	**Comments** Please insert each new comment in a new row.	**Developer's Response** Please respond to each comment
Alder Hey Children's NHS Foundation Trust	1.01	General	The overriding comment that I would make is one that is probably not going to be considered by this process but if it were possible to get it put forward that would be great. That comment is as follows: This is what is known as a threshold exercise i.e. it requires a child to have crossed a threshold of disability before their needs are recognised. I am fundamentally opposed to this approach as it used by the system to withhold support from children who do not cross that threshold. World experts in ASD such as the Gillberg's and David Skuse estimate that the prevalence of autistic trait (i.e. children who have all three of the characteristics mentioned at the beginning of the report) runs between 10 – 35%. I personally feel that it is probably around 30%. Of these only a small number will meet the diagnostic criteria for ASD. A substantial number of them will be in the moderate to severe area of social communication disorder i.e. they will have autistic triad but not of sufficient severity to reach threshold. These children will still have significant impairment – but because of thresholding will not receive appropriate support within the system. I am therefore deeply concerned about a recommendation that is going to imbed deeper into the system threshold diagnosis.	Thank you. We agree that there are issues of threshold and how to describe levels of severity of ASD and we will be discussing these in the GDG. We will be discussing needs as part of this, which is another way of looking at 'impact' of symptoms.
Alder Hey Children's NHS	1.02	General	The ADHD NICE guideline specifically mentions the	We will be addressing the issue of how the definition

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Foundation Trust			controversy of the construct of ADHD (and then proceeds to ignore them). So maybe something could go in *this* completed guideline that there are validity critiques.	of autism spectrum conditions and disorder are constructed in this guideline
Association For Family Therapy and Systemic Practice (AFT)	2.01	General	We are pleased to comment on the draft Scope, because AFT represents those who work with families in the public and independent sector of the UK, most often with children and young people. More details can be found on the website, www.aft.org.uk Systemic family therapy covers a range of work – with families, couples and individual children and adults, as well as multifamily groups and work with wider contexts as appropriate.	We welcome your comments
Association For Family Therapy and Systemic Practice (AFT)	2.02	General	There is more emphasis on qualitative research on family therapy practice and outcomes, often because families have more than one diagnosis or problem to deal with, as well as issues associated with culture, religion, ethnicity, race, class, gender and age. Families may also need to manage changes, such as birth, bereavement, or more commonly, separation or forming new families post separation. Information on the research and evidence base for systemic family therapy can be found on http://www.aft.org.uk/training/research.asp For an overview of current practice of family therapy and systemic practice with children and young people, as well as adults, in the UK, see *Current practice, future possibilities (2009*) on www.aft.org.uk	Thank you. The GDG will consider the appropriate level of evidence to answer questions on what should be included as part of the core assessment for ASD in children and young people as set out in the Technical manual. We also appreciate the complexities of the issues and context of diagnosis that the GDG will consider as they make their recommendations Please note the scope does not include the effectiveness of therapeutic interventions during diagnosis as this is seen as part of intervention/ management of ASD.
Association For Family Therapy and Systemic Practice (AFT)	2.03	3.1 b	Christopher Gillberg's criteria acknowledge the impact of the difficulties in 'reciprocal and social interactions' on relationships with peers, as well as	Thank you for raising this point. We will definitely be considering 'impact' of social impairment as part of the guideline development process

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			on 'social and emotional inappropriate behaviour', Eg. Gillberg, C. (1991): Clinical and neurological aspects of Asperger syndrome in Six Family Studies. In U. Frith (ed): Autism and Asperger Syndrome. Cambridge University Press.	
Association For Family Therapy and Systemic Practice (AFT)	2.04	3.1	The impact on relationships within the family (siblings and parents) as well as in school need to be acknowledged, as some children will not be diagnosed early, and this has implications for how parents, siblings, peers, and teachers deal with the difficulties that the child or young person has, and how this may add to the difficulties associated with autism.	Thank you. While acknowledging this issues you raise, the guideline's focus is to make recommendations on the core components of a multidisciplinary assessment of children and young people with features of ASD.
Association For Family Therapy and Systemic Practice (AFT)	2.05	3.2a & g	There are some positive referral and diagnostic procedures where family therapists are involved in one Inner London Borough, serving a culturally diverse population as part of the Integrated Service for Disabled Children. Here a family therapy team meets with families, including siblings of the child, during and after the diagnosis process.	Thank you for this comment. The GDG will consider tools and methods of the core components of a clinically and cost effective diagnostic process for the assessment of Autism.
Association For Family Therapy and Systemic Practice (AFT)	2.06	3.2. b, e	It is important to consider the family and social contexts in the diagnostic assessment. If the child is correctly diagnosed with autism it is likely that his or her autistic behaviours are not significantly influenced by family or social factors such as abuse; exposure to other traumatic events or poor parenting. However, it is also the case that children who have been exposed to experiences such as abuse, neglect or insecure attachments may present with autistic features. It is essential to rule these possibilities out before a diagnosis of autism is made. Family therapists are well placed to undertake part of such assessments	We recognise the issue of misdiagnosis where children present with autistic features which in fact are features of another underlying condition or experience (see 3.2 f). We will make recommendations on recognising features of ASD and the main conditions / experiences with similar features in the guideline.
Association For Family Therapy and Systemic	2.07	3.2.c, e	It is important that health, education and social care staff are aware of autistic-type behaviours that the	Thank you - we agree that this is an issue that crosses sectors. This guideline will identify the signs

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Practice (AFT)			child or young person may present with. This should help to ensure that children receive appropriate early intervention. There is a role for health professionals in providing training for school staff groups.	and symptoms of ASD in order to improve early recognition.
Association For Family Therapy and Systemic Practice (AFT)	2.08	3.2.f	Autistic-type features may be influenced by the quality of the parent-child relationship rather than the diagnosis of autism. The involvement of a family therapist during the diagnostic procedure means that these relationship difficulties can be explored, and the sessions used, for instance, to help the mother to recognise her need to change her ways of interacting with her child. Such treatments can go alongside other treatments, such as social skills group for the child to develop confidence in relating to peers.	Thank you, . The GDG will consider what should be included as part of the core assessment for ASD in children and young people. We also appreciate the complexities of the issues and context of diagnosis that the GDG will consider as they make their recommendations The scope does not include the effectiveness of therapeutic interventions during diagnosis as this is seen as part of intervention/ management of ASD.
Association For Family Therapy and Systemic Practice (AFT)	2.09	3.2 g	The process of assessment of autism may be a bewildering and frightening one for the child's family. As most professionals are likely to have a particular diagnostic focus, it is important that family members, including siblings, should have the opportunity to reflect upon the impact of the diagnostic process upon them.	The focus of this guideline is the core assessment to reach a diagnosis of a child with possible Autism. While it will identify information needs of children, young people and their families during referral and diagnosis, this cannot cover specific forms of therapeutic support this is seen as part of intervention Management of ASD.
Association For Family Therapy and Systemic Practice (AFT)	2.10	4.3.1e	Family and Systemic Therapy can be helpful during the diagnostic process, because of the issues for the family to manage, as well as the complexity of the issues for the child or young person who has other problems or whose behaviours have not been understood as a condition. As more people become aware of autistic spectrum, there will be more requests for diagnoses as happens in Australia - Stiefel, I., Shields, A.K., Swain, M.A. & Innes, W. (2008): Asperger's coming out of our ears: Making sense of a Modern Epidemic. ANZJFT. 29, 1, 1-9.	Thank you – the GDG will review the clinical and cost effectiveness of the core competencies of assessment in the context of multidisciplinary working. Their conclusion will be given in the draft guideline and widely consulted on.
Association of Child Psychotherapists	3.01	3.1 b)	This section highlights the importance of the emotional repercussions of autism spectrum	Thank you. The guideline approach the assessment of Autism in the context of multidisciplinary working

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			disorders (ASDs) for children and young people, hereafter referred to as children, which are important even in those whose cognitive function is good. This is supported by recent research with parents of children with disabilities, which found that many would like better access to Child and Adolescent Mental Health Services (CAMHS). Child and adolescent psychotherapists (CAPts) offer specialist expertise as part of a multidisciplinary team in helping children to manage difficult feelings and supporting parents to do the same.	
Association of Child Psychotherapists	3.02	3.1 c)	Features commonly found also include high levels of anxiety.	This will be included in the scope
Association of Child Psychotherapists	3.03	3.1 d)	The presentation can be more complex at times, as there may be overlaps between developmental disorders and associated co-morbidity.	This has been clarified in the scope
Association of Child Psychotherapists	3.04	3.1g)	Families with a child or young person with ASD often take the full brunt of their child's difficulties; strain on the family often feeds back into the experience of the child/young person with autism, further complicating the presentation. The impact of a child or young person with ASD on all family members should be considered.	There is a clinical question on the support and information needs during diagnosis where evidence for what type of day to day support is required will be reviewed.
Association of Child Psychotherapists	3.05	3.2 b)	The ACP agrees wholeheartedly with the need for good communication between healthcare, social care and education professionals and carers, as set out here. The specific need for ASD children and their families for a wide variety of professional input means that parents can feel overwhelmed in the absence of effective communication with them and between professionals.	Thank you. Multidisciplinary working will be included in the guideline
Association of Child Psychotherapists	3.06	3.2 e)	The emphasis here on the need to pick up on a variety of 'peripheral' symptoms is very welcome. We would also emphasise other possible precursors to an ASD diagnosis, which can include: strikingly	We will be looking at signs and symptoms that may highlight a need to consider ASD as a possible diagnosis while recognising that some behaviours noted retrospectively have limited sensitivity and

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			quiet behaviour during infancy, lack of eye contact, extreme difficulties in self-regulation including eating and sleeping, lack of babbling, excessive muscular flaccidity or rigidity, and persistent sadness or withdrawal.	specificity.
Association of Child Psychotherapists	3.07	3.2 f)	We welcome the recognition that other conditions can mimic the behaviours that define ASD. Misdiagnosis of ASD can be traumatic for parents and carers and mean that the child does not receive the most appropriate services. It would be helpful to emphasise that ASD should not be diagnosed on the basis of instruments alone, however helpful and essential these may be, without a clinical opinion from a professional with specialist experience.	Thank you, the need for multidisciplinary agreement on diagnosis with the support of diagnostic strategies will be the ethos running through the recommendations in the guideline.
Association of Child Psychotherapists	3.08	3.2 g)	It is important for families to be supported through the assessment process, which can be traumatic, by a professional who can explain the implications of what they are going through and help them to manage their reactions to it. This can result in stronger parental involvement in partnerships with professionals later on. See also our comments on 3.2 b), above.	The guideline will identify the day to day support needs of children, young people and their families during referral and diagnosis. It will not cover the effectiveness of specific therapeutic management interventions during diagnosis.
Association of Child Psychotherapists	3.09	4.2 b)	Since cooperation between different sectors is particularly important for children with ASD and their parents, it would be helpful for the guideline to include suggestions as to how this might best be implemented, even if these do not carry the authority of the main body of the guideline.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
Association of Child Psychotherapists	3.10	4.3.1 a)	It would be useful to specify whether this specialist assessment should be multidisciplinary or multi-agency at this stage, or whether there might be an intermediary stage e.g. a paediatric screening or speech and language therapist (SALT) assessment.	The GDG will consider initial recognition of signs and symptoms, when they should prompt referral into a multidisciplinary assessment process. The conclusion of the GDG will be available in the consultation draft of the guideline.

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Association of Child Psychotherapists	3.11	4.3.1 a)	There is a need for wider dissemination of knowledge concerning possible precursors. This is currently being researched in France by PREAUT, who have the cooperation of hundreds of GPs and are engaged in a ten-year study. See also our comments on section 3.2 e). The importance of early intervention in ASD cases is now widely recognised and further steps need to be taken to encourage this. Infants showing signs of possible precursors should be routinely monitored. In many cases, anxiety could be allayed at 18 months. Those children who did give cause for concern, for example levels 2 or 3 on the Checklist for Autism in Toddlers (CHAT), should receive input at 18 months rather than the present earliest age of at least two years. As things stand, health visitors no longer carry out an 18-month check unless requested to do so by the family. Understandably, parents with concerns are often too frightened to ask for this. Since professional concern would have had to be aroused by the presence of possible precursors, this should not be viewed as population surveillance, as mentioned at 4.3.2 a).	Thank you. We will include early signs and symptoms in the recommendations where the evidence supports their inclusion and the details of the assessment process
Association of Child Psychotherapists	3.12	4.3.1 d)	We would argue for the inclusion in the guideline of the clinical and cost effectiveness of all the autism-specific investigations, not only the biomedical ones as set out here. Costings should be carried out of the entire assessment and its component parts, including the Autism Diagnosis Observation Schedule (ADOS), Autism Diagnostic Interview – Revised (ADI-R), SALT assessment, CAMHS assessment etc., so that commissioners can be made aware of how much a good assessment costs.	Thank you, the cost-effectiveness of biomedical and diagnostic investigations are now included in the scope. In addition NICE carries out a separate costings analysis for commissioners once the guideline recommendations have been made.
Association of Child Psychotherapists	3.13	4.3.2 e)	Part of the ongoing information and support for families during the process of assessment of ASD	Review and reassessment of a confirmed diagnosis . are outside the scope of the guideline as the remit is

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			may include reassessment and review of diagnoses, so we think reassessment and review of diagnoses does need to be covered by the guideline. In our experience, for example, many diagnoses of Asperger's Syndrome are not borne out by the developmental history of the child.	the stage up to diagnosis only. We'd welcome a proposal for an additional NICE guideline on the next stage in the pathway to cover management and reassessment. Please see the NICE website for how to suggest topics to NICE.
Association of Child Psychotherapists	3.14	4.4	The reliability of the standardised assessment tools, for example ADOS and ADI-R, should also be examined.	Thank you, the GDG will consider including them in the clinical questions.
Association of Child Psychotherapists	3.15	4.5	Any review of the economic evidence should be multi-agency. For example, if a child attends a special school for autistic children, there may well be savings for CAMHS. Costs to education and health need to be thought about together.	Thank you. It is usual practice to consider the cost effectiveness from the point of view of the NHS. However, where considerable costs or savings may accrue outside this sector, these would be discussed in any economic analysis
Association of Child Psychotherapists	3.16	General	This submission draws on the research and clinical expertise of members of the Association of Child Psychotherapists with specialisms in working with children and young people with autistic spectrum disorders.	Very welcome, thank you.
Association of Professional Music Therapists	4.01	1	The Association of Professional Music Therapists welcomes this guideline development. Music therapy practice has developed in the UK since 1951 and as an applied intervention within the NHS since 1970. Music Therapists have worked closely with the client group this guidance addresses. While the scope is limited to recognition, referral and diagnosis, rather than intervention, we support this evidence based consideration and offer our expertise and practice knowledge in this area. We propose that the title of the guideline should be 'Autism Spectrum Conditions' as per section 3.1d	Thank you. We will be addressing the issue of how the definition of autism spectrum conditions and disorder are constructed in this guideline
Association of Professional Music Therapists	4.02	3.1 f	We suggest that this point could be expanded to consider all complex presentations where ASD is present.	Thank you. The GDG will consider tools and methods of the core components of a clinically and cost effective diagnostic process for the assessment

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			▪ It has been suggested that music therapy may be of use to anyone with autistic spectrum disorders, such as autism or Asperger syndrome. There is also a history of its use with clients with other forms of pervasive developmental disorder, moderate and severe learning disability, genetic and inborn metabolic disorders combined with mental health issues. Music therapists generally focus their resources on more complex presentations. See the following for further detailed information: ▪ Gold, C., Voracek, M., & Wigram, T. (2004) Effects of music therapy for children and adolescents with psychopathology: A meta-analysis. Journal of Child Psychology and Psychiatry and Allied Disciplines, **45**, pp.1054-1063 ▪ Gold, C., & Wigram, T. (2003) Music therapy for autistic spectrum disorder (Protocol for a Cochrane Review), *The Cochrane Library, Issue 3, 2003*. Chichester, UK: John Wiley & Sons, Ltd ▪ Gold, C., Wigram, T., and Elefant, C. (2006). Music therapy for autistic spectrum disorder. Cochrane Database of Systematic Reviews, Issue 2. ▪ Oldfield, A. (2006a). Working with Pre-School Children with Autistic Spectrum Disorder and Their Parents. In: Oldfield A.: *Interactive Music Therapy, a Positive Approach; Music Therapy at a Child Development Centre*. Jessica Kingsley,	of Autism. The guideline will focus on the core assessment of ASD in children and young people. The scope does not include the effectiveness of specific therapeutic interventions during diagnosis as this is seen intervention/management of children and young people with ASD.

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			Pp.41-91	
Association of Professional Music Therapists	4.03	3.2a, b & c	We agree that there is wide variation in the current models of multi professional working. Music therapists have responded to variations in team makeup by contributing significantly to the diagnostic assessment process. Where Music Therapy exists within specialist diagnostic settings there is a high level of consensus around delivery and outcomes, as well as positive patient and family experience of Music Therapy. Positive aspects of diagnostic profiling are well supported by Music Therapy assessment. Given that there is currently a disparity in the use of modalities such as Music Therapy in diagnostic assessment it is unfortunate that models of working are not being considered in these guidelines.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
Association of Professional Music Therapists	4.04	3.2f	We agree the diagnosis of ASD is historically linked to specific clinical contexts such as CDC's and CAMHS. This guideline offers the opportunity to think beyond clinical boundaries and develop greater awareness of the broader diagnostic context for these children and young people.	Thank you.
Association of Professional Music Therapists	4.05	3.2g	It is our experience that provision of information and support for families is often limited by unclear partnership working arrangements and process timeframes. This can often be ameliorated by the involvement of voluntary sector bodies at this point.	The guideline will review information and day to day support for children, families and carers that have been shown to be beneficial to children, young people, families and carers.
Association of Professional Music Therapists	4.06	4.3.1c	Research shows how a music therapy assessment component can add a more comprehensive understanding of complexity where standardised tests are limited or unavailable. This is particularly important in addressing the needs of patients with complex needs and unclear thresholds for diagnosis.	Thank you. The guideline will make recommendations on what should be included as part of the core assessment for ASD in children and young people. We will review the literature to establish the clinical value of specific diagnostic tools and methods. The guideline will be underpinned by an ethos of multidisciplinary working

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			Music therapists have engaged in research into this area and we would like the scope to take into account our awareness of the studies involved and their validity levels. Search teams for processes around diagnostic assessment should take into account the words "music" and "music therapy". A recent research investigation (Oldfield 2006b) showed that Music Therapy Diagnostic Assessments (MTDA) were picking up different information than the ADOS tests (Lord *et al* 1989) particularly with children who were borderline autistic spectrum disorder. The MTDA was less likely to consider the children's social overtures to be autistic but more likely to score autistic-type behaviours when looking at the children's ritualistic behaviours. There is clinical evidence that children with borderline autistic spectrum will need multidisciplinary assessments, which in some cases will be carried out at tier 4. It is with these children in particular that music therapy assessments provide an invaluable contribution. Oldfield (2006b) Research Investigation into Music Therapy Diagnostic Assessments. In: Oldfield A: Interactive Music Therapy in Child and Family Psychiatry, Clinical Practice, Jessica Kingsley, pp 157-188. Lord, C. et al (1989) Autistic Diagnostic Observation Schedule – A Standardised Observation of Communicative and Social Behaviour, Journal of Autism and Developmental Disorders, Volume 19, No.2, pages 185-212	to support diagnosis

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			The focus of this guideline should take into account Multi-disciplinary assessment to comprehensively support diagnosis	
Association of Professional Music Therapists	4.07	General	The Association of Professional Music Therapist would like to contribute to the work of the GDG with specialist expert opinion around consideration of music therapy and comprehensive multi-disciplinary assessment	Thank you, we are limited in the range of professions represented in the GDG, but we welcome your comments on this draft scope and of course on the draft clinical guideline when it is published.
Behavior Analyst Certification Board	5.01	4.2.h	Because there appears to be no other reference to autism treatment in the *Guidelines*, this section could become the default referent and sole source of information on treatment. If the *Guidelines* address clinical practice in this section only, you might wish to add some additional reports to broaden its scope, such as the New York State and Maine reports, as well as the **National Standards Project of the National Autism Centre report when it becomes available**. If the addition of these reports to the current section became too unwieldy, I suggest that the *Guidelines* include a separate clinical-guidance reference section that would list the relevant reports. New reports could be added to the reference list as they became available. Consumers will want applied behaviour analysis (ABA) services from Behavior Analyst Certification Board certificants and others who provide ABA services, and it would be most useful if they could point to references within the *Guidelines* that empirically evaluate its effectiveness.	Thank you, we have clarified in the scope that this guideline follows on from other guidance for clinical diagnosis published recently. It is not our intention to itemise all the current guidance on treatment as this is beyond the scope.
Behavior Analyst Certification Board	5.02	4.3.2 c & d	I am quite surprised at the omission of *c) Models of service delivery* and *d) Interventions and ongoing management of ASD* in the *Clinical Issues That Will Not Be Covered* section. These are apparently areas the *Guidelines* will not be addressing, but that	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the

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			comprise a central and critical component of autism for consumers. If the *Guidelines* don't address various treatments and their effectiveness, I should think the utility of the *Guidelines* for consumers would be severely compromised. Should the scope of the *Guidelines* be expanded to include these important areas, I would appreciate the opportunity to comment on the treatment modalities, their effectiveness, and the procedure for identifying qualified professionals, particularly as it relates to applied behaviour analysis.	specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
Belfast Health and Social Care Trust	6.01	3.2.a	Low referral rate for genetic investigation & genetic counselling of ASD relative to ASD prevalence	Noted, thank you.
Belfast Health and Social Care Trust	6.02	3.2.b	Defined multi-professional process of investigation for ASD is best way forward	Noted, this will underpin the ethos of the guideline, thank you
Belfast Health and Social Care Trust	6.03	3.2.c	No defined guidelines for genetic investigations +/- genetic counselling required for other health professionals dealing with ASD	We will undertake a review of the evidence for genetic counselling and assess what guidance falls out of that.
Belfast Health and Social Care Trust	6.04	3.2.f	Clear guidance for diagnosis of ASD required in order to differentiate it from other communication disorders & LDS prior to genetic investigation and referral	Thank you. The guideline will identify key issues for the differential diagnosis to effectively use resources
Belfast Health and Social Care Trust	6.05	General	Clear standard genetic guidance required for other health professionals prior to referral to Genetic Service for further investigation and genetic counselling	Thank you, the GDG will consider who should be referred to effectively use resources and improve outcomes for children..
Belfast Health and Social Care Trust	6.06	4.3.1.d	Clinical evidence required re recommended standard genetic tests for investigation of ASD i.e. clinical effectiveness (re diagnosis) and cost effectiveness	Noted, thank you.
Belfast Health and Social Care Trust	6.07	General	Increased resources particularly for genetic services re anticipated genetics workload with increased genetic referral rate	We aim to assess the cost-effectiveness of alternative strategies for genetic testing as part of the guideline
Belfast Health and Social Care Trust	6.08	4.4.c	Identification of underlying genetic syndrome/chromosomal abnormalities/familial	Noted, thank you.

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			autism with appropriate genetic counselling and support	
Belfast Health and Social Care Trust	6.09	4.4	Define nature of multi-professional assessment of ASD i.e. team members for e.g. geneticist, genetic counsellor, paediatrician	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country.
Belfast Health and Social Care Trust	6.10	4.4	Define most appropriate route(s) available to accomplish complete assessment of ASD patient	A clinical pathway / algorithm will be developed for the guideline.
Belfast Health and Social Care Trust	6.11	General	Establishment of definite diagnosis of ASD prior to any other referrals and in particular to the Genetics Service	Noted, please see response above.
British Association for Adoption and Fostering	7.01	General	This response is being submitted on behalf of the BAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for children and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence. We welcome this guidance and appreciate the opportunity to comment.	Thank you.
British Association for Adoption and Fostering	7.02	General and 4.1.1.b	Looked after and adopted children should be identified as a sub group of children who will be covered. Not only is ASD over represented in this group, but it is important to recognise the particular	Thank you for this. We fully support these comments and would welcome any evidence that might not be identified in a search of the literature that you could identify for the GDG to consider.

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			complexities of working with these children, which affect recognition, referral and diagnosis, as well as interventions and management (see comment 6). Briefly, these complexities include: • histories of trauma, abuse and/or neglect while living with birth family • loss of birth parents and possibly siblings and extended family members • moves in the care system may be frequent and involve changes of carer and school, plus disruption in health services • attachment is frequently disrupted in these children, adding to the complexity of diagnosis • over representation of emotional, behavioural and conduct disorders which do not fit well with DSM4 diagnostic categories • difficulties obtaining consent to obtain health and social history, and for interventions • missing information makes diagnosis and management more difficult The guidance must address the need for increased provision of skilled health teams to carry out comprehensive health assessments on entry to care, if children with features of ASD are to be identified early. This must then be followed by timely referral to CAMHS and other professionals whose training extends beyond conventional diagnostic categories and equips them to understand the complex needs of this vulnerable group (see comments 2 and 9).	Looked after children are identified in the guideline (under the equalities monitoring process) as a specific group who may have specific needs during diagnosis.
British Association for Adoption and Fostering	7.03	3.2.e	This document rightly identifies that social circumstances can affect how quickly autistic features are identified, giving looked after children as an example. This is another reason for naming	Noted, thank you. Individuals with an intellectual disability have been identified due to specific problems in undertaking a diagnostic assessment. We fully recognise the specific needs of looked after

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			looked after children as a sub group with specific needs (see comment 2) which must be addressed for the guidelines to be effective.	children and will ensure the GDG consider possible additional needs where appropriate in their conclusions..
British Association for Adoption and Fostering	7.04	3.2.h	This document rightly notes the importance of planning for transition to adulthood, and this is particularly relevant to looked after young people, who frequently lack stable family support at transition.	Noted, thank you. The guideline remit does not explicitly cover planning for care, in transition or otherwise, but we are aware of this as an important time in the lives of children and young people and their families. It requires another guideline to cover this important area adequately. This can be suggested to the topic selection panel on the NICE website.
British Association for Adoption and Fostering	7.05	4.2.b	The scope of this guidance is surprisingly narrow. Given the formation of Children's Trusts, the emphasis on multidisciplinary working, and the impact of autistic spectrum disorders on most aspects of a child's life, the contribution of social services and education professionals to recognition, referral and diagnosis should be examined.	Noted, thank you. We agree that interagency working is important in this area but our commission is focused on the NHS
British Association for Adoption and Fostering	7.06	4.3.2 c	To have the desired impact of improving the health and well being of children and young people, these guidelines should address service provision. Clear and definitive recommendations should be made regarding the quantity and quality of staff and non-staff resources which a PCT should purchase for a standard population. Without such authoritative guidance, it is very difficult to establish an appropriate standard of provision, particularly for sub groups such as looked after children and young people whose needs are especially great (see comment 2).	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
British Association for Adoption and Fostering	7.07	4.3.2 d	The health needs of autistic children & their families/carers do not end with the process of diagnosis. Unless this is the subject of a separate guideline development process, it is essential to address interventions (including pharmaceutical) and	We agree that treatment requires another guideline to cover this important area. This can be suggested to the topic selection panel on the NICE website.

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			management for this lifelong disorder. Some indication of the scale of health resources that each PCT should be purchasing for a standard population is needed. This should include the resources needed for interventions and management, in addition to recognition, referral and diagnosis. Furthermore, these recommendations should take into account the particular specialised needs of populations such as looked after children (see comment 2).	NICE guidelines include a cost impact assessment which is developed after guideline recommendations have been agreed to support commissioners in planning for and delivering services.
British Association for Adoption and Fostering	7.08	General	Consideration should be given to the development of 'minimal service/resource standards' against which PCT service provision can be measured. Such recommendations by NICE would considerably strengthen the guidelines.	Noted, thank you. The guideline will identify the core components of diagnostic assessment that should be offered across the NHS in England and Wales and Northern Ireland
British Association for Adoption and Fostering	7.09	General	For any guidelines to be effective, the twin issues of workforce capacity and training must be addressed. Health professionals must have a high standard of training and expertise. This is especially true for those providing services to a vulnerable group such as looked after children and young people, whose needs are inherently complex. Professionals need a good understanding of health, social and systemic needs, as well as expertise in ASD. This is applicable to medical advisers, specialist nurses for looked after children, CAMHS staff and consultants, as well as social and educational professionals. If all children and young people are to have uniform access to skilled professionals throughout the care pathway, there is an urgent need for considerable investment in workforce capacity.	Training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will address the specific needs of vulnerable groups going through diagnostic assessment.
British Association for Behavioural & Cognitive Psychotherapies	8.01	1	The guideline title should include '……*and intervention planning'*	Thank you, this has been noted and text changes made

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British Association for Behavioural & Cognitive Psychotherapies	8.02	2 c	'…*and emotional dysregulation'* should be added	Thank you, this has been noted and text changes made
British Association for Behavioural & Cognitive Psychotherapies	8.03	3.2 a	' There is wide variation in rates of *identification* & referral…'(add italics)	Thank you, this has been noted and text changes made
British Association for Behavioural & Cognitive Psychotherapies	8.04	3.2 c	'..variable time frame *involving* (not requiring) different competencies…'	Thank you, this has been noted and text changes made
British Association for Behavioural & Cognitive Psychotherapies	8.05	3.2 f	'..such as acute trauma, long term illness and *acquired brain injury*..'(add italics)	Thank you, this has been noted and text changes made
British Association for Behavioural & Cognitive Psychotherapies	8.06	3.2 g	'..information for the family *while awaiting diagnosis* and immediately after diagnosis…'(add italics)	Thank you, this has been noted and text changes made
British Association for Behavioural & Cognitive Psychotherapies	8.07	3.2 i	'…process of diagnostic assessment *and resulting care plan* to enable *longer term* future care..' (add italics)	We cannot directly address care planning in this guideline although during development the GDG will be continually mindful of this step along the clinical pathway. Text changes have been made.
British Association for Behavioural & Cognitive Psychotherapies	8.08	4.3.2 a	Although the process of intervention and management of ASD is not covered by the guideline, the guideline needs to state the importance of the diagnostic process leading to/resulting in a subsequent care plan, not just ending at the point that a diagnostic label is or is not given.	See response above
British Association for Counselling and Psychotherapy	9.01	General	BACP would like to thank NICE for the opportunity to comment on this draft scope.	Thank you.
British Association for Counselling and Psychotherapy	9.02	4.1	The scope suggests that the population to be covered includes '*Specific subgroups of children in whom ASD is known to be less likely to be recognised: Children diagnosed with an intellectual disability',* will this include children with other issues identified on pages two and three, for example mental health and medical health problems,	Noted, thank you. Individuals with an intellectual disability have been identified due to specific problems in undertaking a diagnostic assessment. Other sub-groups are also less likely to be recognised but the process of diagnostic assessment would be the same. We recognise the specific needs of other groups and will ensure the

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			developmental disorders and adaptive impairments?	GDG consider possible additional needs where appropriate in their conclusions.
British Association for Counselling and Psychotherapy	9.03	4.3.1	BACP is unclear why gastrointestinal function is included as a genetic test, given that Andrew Wakefield's research has been refuted?	Noted. To clarify, this should not be seen as a genetic test. It is an example of bodily function that needs specific enquiry but not a test unless there are specific symptom indicators. Text has been changed to reflect this in 4.3.1d
British Association of Art Therapists	10.01	3.1.(b)	When explaining Social Interaction I think it is relevant to include difficulty relating to others.	Noted, and text changes made
British Association of Art Therapists	10.02	3.1. (d)	Describing features on the autism continuum as ranging from 'minimal to severe' and then further stating that there may be 'minimal or no impact of a person's ability to function in the world', may imply that Aspergers syndrome or higher functioning autism is less severe or easier to live with than autism accompanied by a learning difficulty.	There is no implication intended that higher functioning ASD is easier to live with or has less impact. That phrase is intended to convey that those with traits of ASD may be living satisfactory lives with minimal symptom impact
British Association of Art Therapists	10.03	3.1.(f)	Should girls be included in this group?	Thank you, see response to 9.02
British Dietetic Association, The	11.01	4.3.1 e	Will this section 'ongoing support to….. families' incorporate information or how to access information in relation to concerns regarding children who have selective/self-limiting diets that potentially can compromise growth and development? Nutritional aspects in general?	The guideline will review information and support for children, families and carers that have been shown to be beneficial but will not look at the evidence of the feffectiveness of therapeutic support and treatment during diagnosis since this is beyond the specific remit of the guideline.
British Dietetic Association, The	11.02	4.3.1 e	Personalised dietary advice from a suitably qualified Dietitian should be an integral part of the ongoing support package for individuals with ASD. Exclusion diets (eg. gluten, casein and additive-free), nutritional supplements and fussy eating are some of key areas where specialist dietary advice from a Registered Dietitian are needed. This is especially important as without access to a	Noted, see response above

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			Dietitian, many parents / carers will act on unreliable sources of information from the internet and seek advice from unqualified 'practitioners / therapists'. The hazards of using faddy diets, unnecessary supplements and unchallenged food restrictions can cause severe nutritional imbalance that could exacerbate autistic traits and have a detrimental effect on physical and mental health.	
British Dietetic Association, The	11.03	General	In addition to the guidelines there seems to be no mention of dietary assessment/intervention or use of diet as a treatment in ASD.	Treatment of ASD is not covered by this guideline
British Psychological Society, The	12.01	General (& 4.3.1c)	The document does not make clear that it is important to be aware of the child's intellectual level before one can identify a relative social deficit in the child. There is some confusion about this in the field with some clinicians only diagnosing where there is clearly a relative social deficit and others diagnosing on the basis of social deficits regardless of where social skills could be expected given the child's intellectual level.	Noted. We will be clarifying the need to assess social behaviour in the developmental age context
British Psychological Society, The	12.02	General	The National Autism Plan for Children (NAPC) under the chairmanship of Professor Ann LeCouter was published in 2003, and it seems that the NICE guidelines could be developed from the NAPC, and the work that was put into that document. It might be more cost effective to produce a document on guidelines for interventions, as the NAPC does not include much detail on those complex issues.	We note the importance of the NAPC document for this guideline. Treatment of ASD is not covered by this guideline
British Psychological Society, The	12.03	General	No mention is made in the document of consideration of the cultural and linguistic needs of people with ASD, and how such issues may affect both diagnostic and intervention processes and choices. We would recommend that a separate section in the document be devoted to addressing	Noted, the GDG will consider equality issues as they make their conclusions.

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			these complex issues.	
British Psychological Society, The	12.04	3.1b	It may be timely to think about and develop new criteria as the concept of ASD has become rather unwieldy. Ensuring credibility is essential in the NICE guideline. Thus, it might be useful to derive criteria directly from internationally agreed measures such as DSM –IV or ICD-10, or nationally agreed criteria from the NAPC.	Noted.
British Psychological Society, The	12.05	3.1b	It is more usual to represent the triad of impairments as impaired sociability, communication (aspects of verbal and nonverbal language) and rigidity of thought and behaviour patterns. The representation/wording in the NICE scope document seems too much geared to the social aspects of autism so that it is harder to differentiate between different aspects of the triad.	Thank you, this has now been changed to reflect the DSM IV criteria in the scope.
British Psychological Society, The	12.06	3.1b and 3.1c	We as professionals and "neurotypics" always discuss ASD in terms of its social implications. People with ASD who are able to articulate themselves always talk about their altered sensory perceptions. It may be time to address this as a major component of ASD, rather than as an additional and optional "extra". Psychologically speaking, if sensory rather than social information is your predominant concern, then your social behaviours will be very different to those whose predominant concern is social information.	We recognise the sensory aspects of ASD and will be referring to them in the guideline as relevant to the behavioural manifestations of ASD in some individuals.
British Psychological Society, The	12.07	3.1d	We agree with the change of emphasis from "disorder" to "condition". We also agree with the notion of functioning. Psychologists work with children with ASD who are not verbal on the whole, and thus are not able to articulate themselves, and so, while ASD may well be a "diffability" rather than a disorder, it is absolutely imperative that we try to teach skills to people who have impairments of	Thank you.

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			functioning.	
British Psychological Society, The	12.08	3.2.b and 3.2.c	There will be resource implications for the NHS – NICE guidelines should comment on this?	NICE guidelines include a cost impact assessment which is developed after guideline recommendations have been agreed to support commissioners in planning for and delivering services.
British Psychological Society, The	12.09	3.2.e and 3.2.f	It might be useful to draw up a framework for other conditions that may appear to be ASD –and also a recommendation for a training framework to train relevant professionals so that the issue of differential diagnosis can be reliably addressed.	Noted. The GDG will consider the most common differential diagnosis but will not cover training needs.
British Psychological Society, The	12.10	3.2h	Whilst the ASD SAP for Wales was welcomed: it provided general themes for action and raising awareness, however it lacked focus and clarity in terms of what to do. The NICE guidelines could build on these existing documents. It is important to remember that there may be potentially immense regional variations in application as government priorities differ across the devolved nations. The NICE guidelines will need to address these issues so that people with ASD do not suffer from a postcode lottery.	Noted, thank you.
British Psychological Society, The	12.11	4.1	The focus on children and adolescents may be unnecessarily narrow (see below) – especially when considering the real need to develop assessment (and intervention) services for adults with ASD.	Noted, however we are strictly limited to the remit of the scope.
British Psychological Society, The	12.12	4.2	Whilst guidelines for healthcare are important, joined up working is of paramount importance for people with ASD. It would be useful for the NICE guidelines to address the issue of joint working.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country
British Psychological Society, The	12.13	4.3.1e	From experience in working in assessment and diagnosis for both children and adults with ASD, one	The guideline will review information and support for children, families and carers that have been shown

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			of the biggest complaints has not been the assessment itself, or the findings of the assessment, but the support, or rather lack of support of it, for families going through the process. However, many parents say that once the diagnosis is made they are sent home to fend for themselves with little or no signposting of where to go for help. The end result of the assessment process can be a shock for many when they receive a diagnosis, and there needs to be, at the very least, some provision for post diagnostic counselling sessions for parents to help them come to terms with, and understand, what the diagnosis may mean for them and their child.	to be beneficial but will not look at the evidence of the effectiveness of therapeutic support and treatment during diagnosis since this is beyond the specific remit of the guideline.
British Psychological Society, The	12.14	4.3.1f	It is timely to provide robust intervention guidelines for the field of ASD: there is a wealth of research supporting evidence-based interventions for children with ASD. These interventions have been evaluated extensively, and include international collaborative work. For example, there is much misunderstanding round Early Intensive Behavioural Interventions (EIBI), and it is time that national guidelines were developed around such interventions in a comprehensive way. For example, the USA and Canada have many examples of State-wide intervention provision guidelines that could be used as a framework for good practice. Similarly, there are many interventions proposed for ASD that have no evidence base to support their use at all. The NICE guidelines need to be very clear about dismissing interventions that have not been thoroughly evaluated in a scientific and rigorous manner.	Noted, but we are strictly limited by the remit of the scope to focus on recognition, referral and diagnosis.
British Psychological Society, The	12.15	4.5	Given that 4.3.2 d says that interventions will NOT be covered in the clinical management section, it is perhaps confusing that the Economic Section (4.5)	Noted, to clarify, the economic analysis will focus on diagnostic interventions only

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			covers making a choice between alternative interventions.	
British Society of Human Genetics	13.01	3.2 a)	Expectations of families with children affected by Autism and Autism Spectrum Disorders (ASD) are high when referred to Clinical Genetics services. Referrers who use Clinical Genetic services often seem unsure about when and whom to refer. Clinical Geneticists frequently perceive a lack of transparency about why and how this diagnosis was obtained. In addition, the overlap of Autism/ASD with global developmental delay and intellectual disability challenges the existing diagnostic categories.	Recommendations on who should be referred for when and for what type of genetic counselling will be covered in the guideline.
British Society of Human Genetics	13.02	3.2 a)	Autism Spectrum Disorder (ASD) is a very heterogeneous developmental disorder with a strong genetic component. Extensive media coverage about genetic research into Autism has raised patient and parent expectation of what genetics can do for them. However, rare genetic disorders and various chromosomal abnormalities are thought to account for only 10% - 20% of people with ASD.	Noted, thank you.
British Society of Human Genetics	13.03	3.2 a)	Referrals to Clinical Genetics services tend to be patchy, suggesting that some referrers are over-diagnosing Autism and some are probably under-diagnosing. Referral patterns can vary widely within the catchment area of a single Clinical Genetics centre and across the country. The referral numbers of patients with Autism per se or 'essential' autism are increasing.	Thank you. If you have evidence that we may not have identified in a search of the published literature then we would be very pleased if you could send it to us.
British Society of Human Genetics	13.04	3.2 a)	Autism can occur in isolation or as part of a wider syndrome. (some authors refer to 'essential' and 'complex' autism). Only for a minority of cases, mostly those with an underlying syndrome manifestation, specific genetic testing and individualised genetic counselling is currently	We are very grateful for the thoughtful response of the society and look forward to a further dialogue as we draft the recommendations for genetic tests

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			available. Patterns of physical features suggesting a syndromic aetiology are easily recognisable for the trained eye of the geneticist, but are often less obvious for referrers. More detailed guidance on how to recognise a syndromic presentation within the Autism diagnosis and the identification of specific pointers e.g. micro- and macrocephaly, which should prompt a referral, is required.	
British Society of Human Genetics	13.05	3.2 d)	There is general agreement within the Clinical Genetics community that karyotyping and genetic testing for Fragile X syndrome should be offered to all individuals with an Autism/ASD diagnosis. It is not entirely clear at which level of the diagnostic process this testing should be carried out and who would request it. Views vary widely about additional biochemical investigations and the use of CGH (comparative genomic hybridisation) Microarrays.	Thank you, the guideline will make recommendations on these issues.
British Society of Human Genetics	13.06	3.2 d)	Recent advances in array-based technology have increased the resolution in detecting submicroscopic deletions and duplications, referred to as copy-number variations (CNV). ASD-associated CNVs are currently extensively investigated and first results have been very promising. The biomedical relevance of copy-number variants and the genes that they affect remains unclear. Rapid progress in the field of Neuropsychiatric genetics might reveal new and relevant discoveries while work on these guidelines is ongoing.	Thank you.
British Society of Human Genetics	13.07	3.2 d)	Genetic counselling in non-syndromic Autism is currently based on empirically obtained recurrence risk estimates. There is large variation in who delivers counselling, which recurrence figures are given and which literature is referred to in support of such risk estimates. This area also requires urgent clarification.	Thank you. The evidence of who to refer issue will be considered in the guideline

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British Society of Human Genetics	13.08	4.1.1 b)	The overlap of Autism/ASD and intellectual disability is raising the question of whether there is one common underlying condition causing ASD within intellectual disability or whether this co-morbidity originates from different underlying entities, which require separate genetic work up.	Thank you. We anticipate the evidence will be considered in the guideline
British Society of Human Genetics	13.09	4.3.1 c)	There is limited scope in the use of first line genetic testing to identify coexisting conditions apart from molecular genetic testing for the Fragile X syndrome.	Noted, thank you.
British Society of Human Genetics	13.10	4.3.1 d)	There is currently a large variation in the availability of the CGH Microarray for individuals with Autism and ASD through NHS diagnostic laboratories across the country. The reasons for this are complex and resources play an important role. CGH Microarray analysis is likely to replace standard karyotyping in the future. Standardisation of indications and practical procedures is essential to ease this transition and to provide equitable access.	Noted, thank you for this information
British Society of Human Genetics	13.11	4.3.1 d)	The search for susceptibility genes for Autism is receiving a high profile in the media. The majority of cases of non-syndromic autism are likely to be caused by a number of different susceptibility genes of small or moderate effect, causing a variety of ASD sub-phenotypes. The lack of clear sub-phenotype definitions provides additional challenges.	Noted, thank you.
British Society of Human Genetics	13.12	4.3.1 d)	Tight budget restraints are likely to limit genetic testing opportunities for susceptibility genes in the NHS diagnostic service, but new low-cost/high-throughput technologies might be available in tomorrow's market. Cost-effectiveness of such pursuits is likely to be a major consideration.	Thank you. The cost-effectiveness analysis may be able to provide important information on this issue to help inform the recommendations
British Society of Human Genetics	13.13	4.4	Main outcomes from the perspective of the geneticist: Which children to refer to genetics?	Noted, thank you. Clarification made to the text

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			When to do genetic tests? Which genetic tests to do?	
College of Occupational Therapists	14.01	general	Will the guideline include information on interventions and necessary support? Although accurate and timely diagnosis is essential this needs to precede structured and positive support.	No, the remit is strictly limited to recognition referral and diagnosis of ASD
College of Occupational Therapists	14.02	3.1 c	We feel that the term 'Sensory sensitivity' is too narrow a label. Will it include the children who seek out more sensory inputs? In this section there is reference to 'altered sensory sensitivity' –we suggest it might be better to use the words 'sensory processing difficulties'. In literature referring to ASD, this is the phrase that is generally used, as it includes 'altered sensory sensitivity' but additionally difficulties with sensory modulation, both of which fall under the umbrella term of 'sensory processing'.	Thank you. We note that sensory 'processing' implies a clear understanding of mechanism. Sensory reactivity may be a better term. Whichever phrase, we intend to recognise the problem! Text added: 'sensory processing difficulties'
College of Occupational Therapists	14.03	3. 1 e	The two diagnostic classification systems, DSM IV and ICD10, have one major difference in relation to assessing motor difficulties. This is particularly important for people with dual diagnosis e.g. ASD and DCD. For the purposes of these guidelines whichever term is used i.e. ASD or PDD, it requires a clear definition. Should the term ASD be used it will be necessary to make a clear link in how it relates to the chosen diagnostic classification systems.	Yes, we will be linking our discussions to the recognised classification systems
College of Occupational Therapists	14.04	3.2 b	It would be helpful for the guideline to list the relevant healthcare professionals involved in the multi-disciplinary team, including occupational therapists.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country

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College of Occupational Therapists	14.05	4.3.1 b	There is a training need for all staff including health visitors as they can be one of the first professionals to identify features of ASD.	Training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will address the specific needs of vulnerable groups going through diagnostic assessment.
College of Occupational Therapists	14.06	4.3.1 c	The diagnostic assessment would benefit from occupational therapy skills in motor and sensory issues.	Thank you, please see response above (14.04)
College of Occupational Therapists	14.07	4.3.1 f	The important contribution occupational therapists working with children and young people with ASD makes should be acknowledged.	As above
College of Occupational Therapists	14.08	general	Will the guideline include information on interventions and necessary support? Although accurate and timely diagnosis is essential this needs to precede structured and positive support.	The guideline will review information and support for children, families and carers that have been shown to be beneficial but will not look at the evidence of the effectiveness of therapeutic support and treatment during diagnosis since this is beyond the specific remit of the guideline.
Department of Health	15.01	General	This organisation responded and said that they have no comments to make	Thank you.
Disabilities Trust, The	16.01	4.4.a	There needs to be clarification around what is included in the autism spectrum e.g. are Pathological Demand Syndrome, semantic pragmatic disorder, non-verbal learning disorder etc part of the autism spectrum?	Agreed, we will address the issue of definition of the guideline
Disabilities Trust, The	16.02	General	Who should diagnose?	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country

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Disabilities Trust, The	16.03	4.2.b	Given the current policy of joined up working, why is this not a collaborate exercise? We need to provide a structure for health, social services and education to work together.	Agreed. See response above
Down Syndrome Education International	17.01	3.1 f	We support the need for research into dual diagnosis for children with Down syndrome – whether under diagnosis as in 3.1(f) and 4.1.1 (b) or over diagnosis	Noted, thank you.
Down Syndrome Education International	17.02	3.2 f	This links with comment for 3.1 (f) above – perhaps the sentence should state *'Some of the behaviours that define ASD may also feature in other communication disorders and learning disabilities....'* (i.e. children with Down syndrome)	Agreed. Change to text made
Down Syndrome Education International	17.03	4.3.1 c	Please fully consider information from research and issues in relation to dual diagnosis of Down syndrome and ASD	Noted, thank you.
European Association for Behaviour Analysis	18.01	3.1a	Worth pointing out that there is uncertainty about the true increase in prevalence versus wider diagnostic criteria, better (and greater number of) diagnostic assessments, greater general awareness of autism etc.	Noted, thank you.
European Association for Behaviour Analysis	18.02	3.1b	These features need to be present by age three to receive a diagnosis of autism	Noted, thank you
European Association for Behaviour Analysis	18.03	3.1c	Adding a lower level of analysis during diagnosis/assessment of the prevalent behavioural features of the condition may be helpful to those that will be later involved in treatment and management. This could be achieved by ascertaining the absence/presence of key behavioural skills with functional relevance. For example, prevalent features of the condition (e.g., stereotyped mannerisms) may give access to certain kind of stimulation or effects in the environment that the individual cannot produce through more	This is very helpful. We will discuss this as part of the guideline development process

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			sophisticated repertoires (e.g., language, communication skills). When those more sophisticated repertoires are taught, other behavioural features of the condition may decrease. In other words diagnosis and assessment may be more helpful if they were to incorporate not only prevalent behaviours but the absence/presence of skills that are known to be necessary for the acquisition of more complex repertoires (e.g., eye contact, ability to repeat words). There is an extensive literature on these issues that would need to be reviewed in order to develop specific guidelines according to the rationale described above.	
European Association for Behaviour Analysis	18.04	3.1d	'Condition' versus 'disorder' potentially makes a distinction between an untreatable medical model and a transient and treatable set of problems. Such a distinction and reasoned debate ought to be had in the context of future guidelines on interventions.	We will be setting guidelines for symptoms with impact and thus 'disorder' but will discuss this point of view
European Association for Behaviour Analysis	18.05	3.1e	PDD-NOS is not atypical autism. One receives a diagnosis of PDD-NOS if some, but not all of the diagnostic criteria for autism are met. Rett Syndrome and Childhood Disintegrative Disorder are also in the Pervasive Developmental Disorders category but neither would be described as atypical autism.	We will be considering all these terms and liaising with colleagues developing DSM V and ICD11
European Association for Behaviour Analysis	18.06	3.2a	The use of the term 'biomedical investigation' implies that this is a valid and evidence-based assessment procedure for individuals with autism which it is not. Genetic counselling is only used to rule out other disorders (such as Fragile X syndrome). Diagnostic criteria rely solely on the behavioural deficits described in 3.1b,	Some underlying medical conditions have genetic implications and need to be investigated. We will be looking at guidelines for such tests. Clarification made in the scope text under 3.2d
European Association for Behaviour Analysis	18.07	3.2d	See comment 6 above.	Noted.
European Association for	18.08	3.3h	There is much debate about the value and biases	Thank you. This guideline is strictly limited to a

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Behaviour Analysis			inherent in the published clinical guidance related to intervention (e.g. Department of Education in Northern Ireland, 2001; Welsh Assembly Government, 2008; Schools Directorate Scottish Government, 2009). None of the published guidelines have mentioned the substantial and unequivocal evidence base for applied behaviour analytic interventions; none have involved any behaviour analysts as panel members (many of whom are world experts within the field of autism intervention/education); many have been reliant on the personal opinions and biases of panel members and misinformation about the effectiveness of specific interventions. If clinical guidance is mentioned, then this should be properly discussed and include a range of panel members representing their respective areas of expertise. It is a shame that these guidelines do not seek to address interventions and ongoing management of ASD (4.3.2d) as this is of crucial importance given 3.1a. If treatment guidelines were to be included, these would need to be based upon systematic review of the outcome and meta-analytic literature (e.g., Eldevik et al., 2009). As they stand, these guidelines will have treatment ramifications as diagnostic and referral practices ought to determine how promptly individuals have access to effective treatment, something that has been demonstrated to be a key factor in treatment outcome (Fenske et al., 1985; Harris & Handleman, 2000; Luiselli et al., 2000).	focus on recognition and diagnosis and does not address intervention.
European Association for Behaviour Analysis	18.09	4.2b	It is almost universally agreed, notwithstanding the debate about the evidence-base (see comment 8 above), that education is the most effective intervention for individuals with autism. This section, therefore, ought to carry more weight that the	Noted, text change has been made to clarify and strengthen this point.

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			involvement of primary, secondary and tertiary care by healthcare professionals (4.2a).	
European Association for Behaviour Analysis	18.10	4.3.1d	It is not clear why there should be focus on non evidence-based investigations (such as many described in this section) given that first, diagnosis is made on the basis of the presence of specific behavioural deficits and second, given the importance of agreeing and disseminating the evidence-base for effective interventions.	Thank you. We have proceeded on the basis that it is important to make recommendations on which investigations have no evidence base as to identify those with a sound evidence base
European Association for Behaviour Analysis	18.11	4.3.1f	It is not clear what is meant by 'reasonable steps'. One would hope that the guidelines development group review the evidence-base using established procedures (such as those employed by the National Standards Project of the National Autism Centre in the US) and make recommendation based on these findings rather than 'robust and credible recommendations'.	Thank you. This unhelpful statement has been removed.
European Association for Behaviour Analysis	18.12	4.3.2a	There are many early markers that would mean that early screening and surveillance would result in faster diagnosis and earlier intervention. It would be a shame to omit this issue.	If evidence is identified in our literature search on the signs and symptoms clinical question on early markers then this will be considered by the GDG for incorporation into the recommendations.
European Association for Behaviour Analysis	18.13	4.3.2c	This issue is crucial and is a serious omission for such important clinical guidelines.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
European Association for Behaviour Analysis	18.14	4.3.2d	See comment 13 above.	The remit is strictly limited to recognition and diagnosis.
European Association for Behaviour Analysis	18.15	4.4b	See comment 10 above.	Thank you. See response to comment 10 above also
European Association for	18.16	4.4d	QALYs are difficult to operationalise, measure and	We agree that QALYs are difficult to operationalise

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Behaviour Analysis			report. Outcomes ought to include some psychometric assessment measures such as adaptive behaviour and direct observational measures related to the primary behavioural deficits.	in this context. Intermediate health outcomes are also not fully satisfactory since they do not allow comparison across different diseases. We will have to take a pragmatic approach to addressing these issues in the guideline
European Association for Behaviour Analysis	18.17	4.5	4.3.2 suggests that issues related to interventions will not be covered so how can developers make recommendations about interventions? Also see comment 16 above.	Thank you, this has now been clarified in the text of the scope
European Association for Behaviour Analysis	18.18	4.6.1	The timeline for consultation is very short. Perhaps it could be extended?	This is the standard timescale for a scope consultation and cannot be extended.
European Association for Behaviour Analysis	18.19	General	In addition to the specific comments made, please note that we are very concerned about the omissions in the document, particularly with regard to treatment/intervention. We would like you to include treatment/intervention guidelines within these guidelines and that would probably necessitate extending the consultation period. If there is to be no other reference to treatment in the guidelines other than section 3.3h then there is a danger that this section could become the default reference and sole source of information on treatment for ASD within the UK. At the very least this section ought to include additional and influential reports such as the New York State Department of health report (1999), the National Standards Project of the National Autism Centre report (when it becomes available next month) and there are others. If the addition of other reports to this section becomes too unwieldy, perhaps the guidelines could include a clinical guidance reference section that could list all relevant reports, with new reports to be added to this reference list as they became available?	We are limited in our remit to recognition, referral and diagnosis. The text in section 3.3h has been changed to clarify that we are referring to clinical guidance for diagnosis and not for treatment/ management. Thank you for pointing this out.
Greenland Road CAMHS	19.01	4.3.1 a	Signs and symptoms….. there is a growing body of	Thank you. It is intended that the review of signs

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			work dealing with identifying early signs of autism in babies – 'red flags'. Such signs may be identified in the infant- parent relationship, eg babies who avert their gaze from mother's face. They may also be in abnormal patterns of motor movement. This guideline could sketch out the desirability of training health visitors and other primary care workers to look out for early signs of autism in infants in order that early intervention for babies and families may be provided. 'initiate referral for further assessment'. Useful to specify whether this further assessment should be multi-disciplinary/multi-agency at this point or whether there might be an intermediary stage, eg a Paediatric screen/SALT assessment?	and symptoms will cover early signs To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
Greenland Road CAMHS	19.02	4.3.1 c	Assessment of mental health is likely to be a component part of the assessment. It is therefore likely that a CAMHS professional will be involved in the assessment. However it is also important that the assessment has a qualitative aspect to it, i.e. that someone should be thinking about the family's attitude towards and response to the assessment as it proceeds. This is often done well by a CAMHS professional, particularly one with a therapeutic stance, rather than only a diagnostic stance. Assessment and diagnosis can be a distressing experience for families and there needs to be an awareness of this and a way of working with it, otherwise it can become part of the trauma.	Thank you for this comment. The GDG will consider tools and methods of the core components of a clinically and cost effective diagnostic process for the assessment of Autism.
Greenland Road CAMHS	19.03	4.3.1d	Clinical and cost effectiveness of biomedical	NICE guidelines include a cost impact assessment

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			investigations….. It would be useful to have clinical and cost effectiveness of all the autism specific investigations and not only the biomedical ones. It would be very useful to cost out the whole assessment, and its component parts, including ADOS, ADI-R, SALT assessment, CAMHS assessment, etc. so commissioners have an idea of what a good assessment costs when developing services.	which is developed after guideline recommendations have been agreed to support commissioners in planning for and delivering services.
Greenland Road CAMHS	19.04	4.4	a) Length of time to correct diagnosis: define carefully from when. Is it from when the initial concerns are raised, when first seen for a screen-type appointment, or when first seen by the m/d team.	Noted, thank you. We are limited by the evidence available to us in this regard, but will be mindful of differences in reporting this data.
Greenland Road CAMHS	19.05	4.5	Economic aspects A review of the economic evidence needs to be multi-agency. Eg if a child attends a special school for autistic children, there may well be savings to CAMHS. Costs to health and education needs to be thought about together if at all possible.	We strongly agree with this point, thank you for raising it.
Greenland Road CAMHS	19.06	General	Need a section on reliability of standardised assessment tools, ADOS and ADI-R.	The effectiveness of these diagnostic assessment tools will be covered in the guideline
Imperial Healthcare	20.01	3.2 f	It would be interesting to see where the evidence comes from that "children with learning difficulties (LD) are misdiagnosed as autism. evidence that I have seen indicates that LD needs to be very profound to confuse LD with autism and the relationship is rather inverse as in 3.1 f: Autism is likely to be under-diagnosed in a LD population. In addition in my experience depression in people with ASD is often under-diagnosed	We agree that there is underdiagnosis in LD and will clarify this in the scope, and seek to address it in the guideline recommendations There is further clarification of diagnostic overshadowing added to the scope. Children and young people with an intellectual disability are a specified group because it may be

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				necessary to undertake additional components of assessment or do an assessment differently because of the disability. ther groups are also underdiagnosed but the components of the diagnostic assessment may or may not be t different because of this.
Imperial Healthcare	20.02	4.3.1 a,b	I would recommend you look into the role that questionnaires could play such as the M-CHAT, It has good sensitivity and specificity and can be used as guidance for staff. Alternatively there are algorithms that may help staff decide whether or not to refer. The other issue is the discussion between referrer and family about the purpose of the assessment-it needs to be explained to the family why the child is referred and that social communication including autism is one of the concerns. Many families come to the assessment convinced they have been referred for delayed speech. however full consent and understanding about the purpose and possible endpoint of the assessment is absolutely crucial for an SCD assessment to proceed	The effectiveness of these diagnostic assessment tools will be covered in the guideline Information needs for the individual and wider family will be addressed in the guideline
Imperial Healthcare	20.03	4.31.c	There is a need for more detail in this section. role of physical signs on examination, i.e. Need to measure Head circumference to exclude predisposing medical conditions, need(choice and value) of developmental tests and psychometric testing, Speech therapy testing- any formal test needed. Occupational therapy for sensory integration disorder, dietetics for eating disorder(screening test for eating problems) Parenting stress index and screen for sleeping disorders	We will review the evidence of the effectiveness of the main components of the diagnostic assessment. The guideline development group's role is to prioritise which components we should search for evidence for
Imperial Healthcare	20.04	3.1.e	Important to comment on concepts such as	Thank you, we will be discussing these descriptions

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			pathological demand avoidance or schizotypal disorder as these essentially fall under ASD(at least this is would most clinicians would argue) but are often misunderstood	in the guideline development process
Imperial Healthcare	20.05	General	There is some literature available about <u>prevention of autism</u> in at risk children(for instance siblings of children with ASD) To my knowledge there has been no appraisal of evidence in these (often mother child psychoanalysis) interventions. In my view they would come well under the remit "initial recognition, referral and diagnosis" as this happens before diagnosis.	Unfortunately this is beyond the remit of this clinical guideline
Institute of Psychiatry	21.01	3.1.a	Prevalence as such has not risen – numbers of cases diagnosed has	Noted, thank you
Institute of Psychiatry	21.02	3.1.b	These are NOT the DSM/ICD criteria but are based on clinical descriptions of Wing & Gould. It would be preferable to use the formal classification criteria (i.e. Communication deficits, Social impairments and Repetitive & Restricted patterns of behaviour/interests) as in ICD/DSM.	Thank you. The DSM IV criteria are now added to the scope
Institute of Psychiatry	21.03	4.1.1 b	Other groups in whom ASD is less likely to be recognised include children with sensory impairments (deaf; blind etc) and children with other genetic disorders (e.g. Down's syndrome; Cornelia de Lange syndrome in which rates of autism are raised, but differential diagnosis can give rise to many problems)	Noted, thank you. Individuals with an intellectual disability may have specific problems in undertaking a diagnostic assessment. Other populations are also less likely to be recognised but the process of diagnostic assessment may or may not be the same. We fully recognise the specific needs of these groups and will ensure their needs are addressed by highlighting them as part of our conclusions. .
Institute of Psychiatry	21.04	4.3.2 b-e	Why are these issues not covered? It seems a lost opportunity to focus on guidelines for diagnosis without making any recommendations for at least general guidelines on intervention, models of service delivery and other routine assessments.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as

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				that will differ around the country depending on current service configuration and resources.
National Autistic Society	22.01	General	The NAS welcomes the development of the clinical guideline for recognition, referral and diagnosis of autism spectrum disorders in children and young people. The NAS further recognises that NICE must respond to the remit given by the Department of Health, which refers to guidelines for 'children and adolescents'. However, the NAS would argue that a guideline restricted to the ages of 0-18 fails to recognise the reality that diagnostic services are currently also failing adults with ASD. The NAS' *I Exist* survey (2008) found that under half (48%) of primary care trusts do not have an autism specialist diagnosis service for adults or an identified person who can undertake assessment within their boundary. Furthermore, 54% of local authorities believe that adults with autism who have a diagnosis are more likely to receive support than those without one. For these reasons, the NAS feels strongly that it would be a significant opportunity missed if these guidelines were not developed to cover adults as well as children and adolescents, and urges NICE to extend the guidelines to include adults. If this is not a possibility, the NAS still believes that the age range does not acknowledge that transition to adulthood for young people with ASD is a process rather than an event. Although health services may continue to operate a rigid cut-off point at 18, many other elements of the Transition Support Process, including social care support, will provide discrete services for young people aged 16-24 or beyond. The NAS would therefore urge NICE to take a broad interpretation of the remit given by the Department and, if it is not possible to include all ages, at least	Thank you for your comments. We are strictly limited to the age cut-off set out in the scope which we recognise has important limitations. We would urge you to make a case for a guideline that did cover this important age group in a future NICE guideline which can be done via the Topic Selection Process on the NICE website.

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			extend the age range for these guidelines from 18 to 24.	
National Autistic Society	22.02	General	The NAS continues to support and endorse both the National Autism Plan for Children (NAP-C) and the Scottish Intercollegiate Guidelines Network (SIGN) ASD guidelines, and would urge the developers to work from these well-evidenced documents in taking forward the NICE clinical guidelines.	Thank you, we fully intend to develop a compatible guideline to these important documents by reviewing the updated evidence base .
National Autistic Society	22.03	1 - Title	The guideline title refers to 'recognition, referral and diagnosis'. Parents continue to stress to the NAS the importance of ensuring that a care assessment flows directly from the diagnostic process. Parents need to know that the diagnosis of an ASD will lead directly to a process from which they should receive appropriate services and support. This is a meaningful benefit to families from any functioning multi-agency process. While it may not be for NICE to set out in detail a multi-agency assessment process, which in any event is already specified in statutory guidance, the routes in to that process are a proper subject for these clinical guidelines. The NAS would therefore argue that the title should be amended to read as follows: Autism spectrum disorders in children and young people: recognition, referral, diagnosis and assessment. At the same time, the guidelines need to recognise the importance of emotional support for parents immediately post-diagnosis and the need for a sensitive progression from diagnosis to care assessment.	Our guideline does cover diagnostic assessment which includes aspects of assessment which will impact on how an individual child or young person is cared for immediately afterwards. We fully recognise the importance of rapid access to appropriate care once a diagnostic assessment has been undertaken. However, it is beyond our very strict remit to also do this as part of this current guideline. The guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country. The guideline will review information and support for children, families and carers that have been shown to be beneficial but will not look at the evidence of the effectiveness of therapeutic support and treatment during diagnosis.
National Autistic Society	22.04	3.1(a)	The Draft Scope is a little unclear here as to the prevalence figures that the developers will be working from. The current consensus is that ASD in	Thank you. This was taken from a rapid review of the prevalent literature. We will undertake a more detailed search and review for the guideline.

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			children affect at least 100 in 10,000 children. See for example Baron-Cohen S, Scott FJ, Allison C, Williams J, Bolton P, Matthews FE and Brayne C (2009) Prevalence of autism-spectrum conditions: UK school-based population study, British Journal of Psychiatry, 194: 500-509, a study which found a prevalence rate of 1 in 64 amongst primary school children in Cambridgeshire using three different methods of case ascertainment. In the same study, the number of children with a formal diagnosis was 94 in 10,000. The NAS therefore recommends that the draft scope is amended to refer to the prevalence of ASD as 'around 100 in 10,000 children'.	
National Autistic Society	22.05	3.1(d)	While we would agree that the impact of ASD on an individual can range from 'minimal to severe', it is important to note that this impact does not correlate with IQ or type of diagnosis. It is sometimes wrongly assumed that the impact of high functioning autism or Asperger syndrome on an individual will be less severe than the impact of autism with an additional learning disability.	This is an important point to make clear. Thank you for pointing this out.
National Autistic Society	22.06	3.2(b)	The Draft Scope suggests that 'Healthcare professionals usually make the diagnosis of ASD in a child or young person by working jointly with social care and educational professionals to agree on a diagnosis and plan for future management' (emphasis added). While the NAS would agree that this is the approach advocated in NAP-C, the Children's NSF and other policy documents, there is little evidence that this is yet happening 'usually', or indeed even in the majority of the cases. The NAS would suggest that the Draft Scope is amended to reflect the current gap between policy and practice, perhaps changing 'usually' to 'should'.	Clarification has been made to the text of the scope.

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National Autistic Society	22.07	3.2(e)	While the Draft Scope is correct to suggest that children's social circumstances impact on how quickly ASD is diagnosed, we would suggest that 'their parents' ability to advocate for the child' is one of the major determinants and specific reference should be made to this. Effective diagnostic pathways need to ensure that awareness that some children (not just those formally looked-after) will not have parents who are able to be sufficiently 'pushy' to make the current system work for them.	Noted, thank you.
National Autistic Society	22.08	3.2(f)	While the NAS accepts that there may be some children who are wrongly diagnosed with autism, our experience is that the greater problem remains children being wrongly diagnosed with a mental illness, or in some instances as suffering from abuse or neglect, and then finally getting an ASD diagnosis. We would strongly urge NICE to amend this paragraph to present a more balanced picture here.	Thank you, this point has been added to the scope.
National Autistic Society	22.09	3.2(h)	The National Audit Office ASD study has now published and can be found on the NAO website. The NAS would urge the developers to consider this study carefully in conducting any cost benefit analyses of different approaches to diagnosis.	The NAO has undertaken a cost impact analysis comparing current service use against a new scenario with more specialist support. NICE takes a different approach to economic evaluation by comparing the costs and benefits of specific interventions to assess whether additional resources are a good use of public money compared with the alternative. This analysis is undertaken to support decisions about which recommendations to make about service provision. There is a clearly defined methodology for this approach which we will follow. In additional, NICE produces a cost analysis after draft publication of the recommendations to assess the likely financial consequences of implementing the recommendations.
National Autistic Society	22.10	3.2(i)	While the NAS would agree that this is generally a	We are strictly limited in our remit to focus on the

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			helpful summary of the purpose of the guidelines, we would suggest that they should not seek simply to 'enable planning for future care' but should ensure that there is a seamless referral process for children from diagnosis to care assessment.	clinical pathway until the point of diagnosis. We recognise that this is the point where seamless referral should take place, but we cannot cover referral in this guideline.
National Autistic Society	22.11	4.1.1(a)	The NAS reiterates that it wishes to see the age limit for the guidelines extended to include adults (see point 1). Alternatively, it must extend from 18 to 24, to reflect the realities of health, education and social care service delivery. See for example the government's Transition Support Process, a central component of the Aiming High for Disabled Children programme.	This point is duly noted, please see response given above.
National Autistic Society	22.12	4.1.1(b)	There are distinct challenges associated with identifying and diagnosing ASD in children with and without learning disabilities. A great many children with high functioning autism or Asperger syndrome reach adulthood without being diagnosed – having above-average intelligence can prove to be a significant barrier to recognition and diagnosis. It should not be assumed that recognition is harder or less likely in children with a learning disability.	Noted, thank you
National Autistic Society	22.13	4.1.2(a)	As above, the NAS suggests that the cut off point between 'children' and 'adults' should be 24, not 18.	This point is duly noted, please see response given above.
National Autistic Society	22.14	4.2(a)	The NAS would want the reference to professionals who 'make decisions concerning' the care of children and young people to include commissioners, both at a strategic level and those commissioning individual care packages.	The role of commissioners will be considered throughout the guideline, but the specific point being made here is about those professionals in settings where they have day to day contact with children and young people in order to recognise the features of ASD
National Autistic Society	22.15	4.2(b)	In the context of children's trusts, to be set on a statutory footing through the current Apprenticeships, Children, Skills and Learners Bill, the suggestion that the guidelines will not 'cover the practice' of educational and social care professionals	Change has been made to 4.2b to address this concern

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			seems to fly in the face of current government policy. NAP-C recommends a multi-agency assessment conducted by a multi-disciplinary team, whose core members should be available locally and include an educational specialist and a family support worker. The assessment should include an assessment of the needs and strengths of all family members, thus a professional with a social care background would be most appropriate. The NAS believes that the Draft Scope should be amended to make it clear that the guidelines will apply to all those professionals involved in the care of children. The guidelines need to consider further the ongoing challenge of identifying effective key working arrangements to ensure proper co-ordination of diagnosis and assessment around the child and family.	
National Autistic Society	22.16	4.3.1	The NAS recommends that 'effective methods for engagement of children, young people and families' should be one of the clinical issues within the scope of the guidance, and should therefore be added to this section (given this is listed as one of the 'main outcomes', see 4.4(e)). Further, the training needs of professionals should be added as another critical clinical issue for the guidelines. The National Audit Office's study into ASD found that 80% of GPs felt that they needed they need additional guidance and training to manage patients with autism more effectively. The Royal College of Psychiatrists, in their report "Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic Spectrum Disorders" (2006), recommend appropriate competence and training levels for psychiatrists dealing with ASD at different levels. The NAS recommends that the training needs of	This is a very interesting recommendation but we will not be able to add to our list of clinical questions without taking something away. All of the clinical issues currently in the scope are seen as priorities. However, the issues you raise about effective engagement will be at the forefront of the GDG group in developing a guideline for children and young people that is fit for purpose. Training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will address the specific needs of vulnerable groups going through diagnostic assessment

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			these and other relevant professionals are given full consideration within the scope.	
National Autistic Society	22.17	4.3.2(e)	The NAS is not clear about the reasons why reassessment and review of diagnosis would be excluded from the scope of these Guidelines, and would welcome clarification on this point.	We are strictly limited to end the guideline at the point of initial diagnosis. The guideline will focus on specific areas where there is wide consensus that the most good can be done to make a real difference to service provision. Many of the issues covered in this guideline around diagnosis may be pertinent to reassessment and review and should be read widely not only by those involved in initial assessment.
National Autistic Society	22.18	4.5	The NAS would urge the developers of the guidelines to pay careful attention to the recent National Audit Office study in considering the economic aspects of the guidelines.	Noted, thank you. See the response to 22.09
Northumberland Tyne & Wear Trust	23.01	3.1.b	The international classifications include a requirement that the unusual features in development have been evident before 3 years of age.	Noted, thank you.
Northumberland Tyne & Wear Trust	23.02	4.1.1 b	Only children with intellectual disability are listed as groups where ASD is less likely to be recognised. There are other groups where ASD is common, and assessment expertise is needed, such as children with hearing impairment, and epilepsy, etc that the guideline should consider.	Noted, thank you. Individuals with an intellectual disability may have specific problems in undertaking a diagnostic assessment. Other populations are also less likely to be recognised but the process of diagnostic assessment may or may not be the same. We recognise the specific needs of this group and will ensure their needs considered as the recommendations are drafted
Northumberland Tyne & Wear Trust	23.03	4.2 b	Education staff such as educational psychologists are commonly involved in diagnostic assessment. Therefore the guideline is relevant to their practice when they are contributing to a multi-agency assessment. The scope of the guideline as written may act against multiagency working.	Multidisciplinary working underpins the ethos of the entire guideline. To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country.

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				Changes have been made to the text of the scope to clarify the status of recommendations in the educational field.
Northumberland Tyne & Wear Trust	23.04	4.3.1 c	Identification of any co-existing conditions is actually complex and requires more detailed consideration in the scope. The conditions include language disorder, dyspraxia, dyslexia, ADHD, common mental health problems such as anxiety, sleep disorders, etc. Therefore the full assessment has implications for the availability of expertise from professionals such as occupational therapists, and mental health specialists who may not be part of the core team.	A more detailed clinical question to run a literature search for the evidence will be developed with the help of the guideline development group. This list is very helpful, thank you.
Northumberland Tyne & Wear Trust	23.05	4.4 d	It is not clear why or how the guideline would include health-related quality of life, calculated as QALYs. This is a developmental disorder so children change markedly in their functioning over time; for young children the family quality of life is of prime importance to consider; quality of life is a subjective phenomenon and many children and young people with autism would not be able to self-report. This would require a large and new research project.	All NICE clinical guidelines must consider clinical and cost-effectiveness and the currency used to report cost-effectiveness analysis is the QALY. All clinical guidelines face methodological challenges in using a health related quality of life approach and this guideline is no different. There are specific issues in the use of health related quality of life in diagnostic guidelines but the issue of children's ability to self report well-being is a global problem not confined to the QALY.
Parents Protecting Children UK	24.01	GENERAL – terms of reference / long & short titles / remit 1, 1.1, 2.	At the scoping day I pointed out that the term AUTISTIC SPECTRUM is widely used in England to include ADHD, ADD, OCD, Dyspraxia, Semantic Pragmatic Disorder etc etc and yet NICE were interpreting the Govt brief on Autism / Autistic Spectrum to include only Autism & Asperger's Syndrome **I felt at the time that NICE needed to go back to**	Thank you for raising this important issue again. The guideline will provide a detailed statement on what is and what is not included in the terms autism spectrum condition and autism spectrum disorders. This will be discussed at length by the guideline development group and a clear consensus will need to be reached and is seen as a workable and useful definition for the NHS and its partners.

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			the Govt for clarification. Recently someone sent me the link below to the Govt Lamb Inquiry on Special Ed Needs http://www.dcsf.gov.uk/lambinquiry/evidence.shtml I started to work through the Parents questionnaire... and (as I suggested at the NICE scoping workshop....) in Q5 Lamb USES THE TERM "AUTIS**TIC** SPECTRUM" TO INCLUDE ADHD & OTHER CONDITIONS - it must do, as these conditions are so prevalent & there is no other category in the questionnaire into which they would possibly fit... It would be totally confusing to the general public (and professionals - especially in education) to have the Lamb Inquiry & NICE producing reports at around the same time but with totally conflicting definitions The term "Autism Spectrum" (as used in the Scottish & Australian documents) DOES NOT HAVE A CLEAR MEANING IN ENGLAND - parents, voluntary groups & people in Special Educational Needs in England say "Autistic Spectrum" and include in that term ADHD, ADD, OCD, Dyspraxia, Semantic Pragmatic Disorder etc etc **I AM CONVINCED THAT THE NICE GUIDELINES NEED TO SAY EITHER :** **"AUTISM & ASPERGER'S SYNDROME". (full**	

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			stop) – this is what I think you actually mean. Or it should say <u>"AUTISTIC</u> SPECTRUM DISORDERS" and include in that ADHD, ADD, OCD, Dyspraxia, Semantic Pragmatic Disorder etc etc - but as you have recently done work on ADHD I suspect that this is NOT what you are talking about in this case.	
Parents Protecting Children UK	24.02	3.1 b & c	I suspect that most parents / carers would probably see SENSORY ISSUES as a higher priority than it appears here.	Noted, thank you.
Parents Protecting Children UK	24.03	4 .1.1 .b & c	I think that many high IQ Asperger's Syndrome Children are undiagnosed & unsupported with consequent educational, social & mental health consequences. There is a need to look in more detail at the gifted & talented who also have Autistic Spectrum Disorders.	Noted, thank you. We are confined by the remit of the scope to look at recognition and diagnosis. Asperger's is one of the conditions that falls into our remit, so diagnosis and support for these children and young people are covered.
Parents Protecting Children UK	24.04	4.2.b	It is in the educational & social work spheres that most mistakes & misunderstandings & consequent devastating misrepresentations occur. It is therefore vital that these new NICE guidelines fully intermesh with procedure & practice in education & social work etc – HENCE THE IMPORTANCE OF NO CONTRADICTIONS BETWEEN LAMB & NICE – please see my point 1 above & look at the online documents concerning the LAMB INQUIRY. http://www.dcsf.gov.uk/lambinquiry/terms.shtml	Thank you. We will review the terminology used in the guideline as part of the guideline development process.
Parents Protecting Children UK	24.05	4.3.2.b	**This seems an enormous mistake** as this is where most cases of Asperger's Syndrome are missed – and because it has been missed medically then Education & Social Services don't believe it can exist. I think it is VITAL to provide guidance to medics to make sure that fewer cases of A.S. are missed at the stage where support could be most effective & many later problems could be avoided.	To clarify, the guideline will not review the evidence for what should be in a standard paediatric assessment but will focus on the aspects of assessment relevant to children with a possible diagnosis of ASD, that is, what additional information should be asked for and what assessments should be undertaken when a child with signs and or symptoms of ASD is referred for an assessment

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Parents Protecting Children UK	24.06	4.3.2.d & 4.4.e	This may be a contradiction. I'm not sure that you can separate intervention (support) and involvement / feedback in this way – eliciting the feedback implies intervention & support..	The guideline will review the types of information giving and support that have been shown to be beneficial to children, young people, families and carers but will not look at the evidence of the effectiveness of therapeutic support and treatment during diagnosis since this is beyond the specific remit of the guideline. This cut-off is necessary to keep the guideline to a manageable size.
Queen's University of Belfast	25.01	3.1.	It is my understanding that the areas of functioning have to be affected for a prolonged time, it would be useful to mention this	Noted – thank you
Queen's University of Belfast	25.02	3.1 d	The issue of calling it disorder vs. condition would need further discussion, this is not explained well here, e.g., if there is no impact on functioning, should there still be a diagnosis when the definition is that functioning is affected?	Thank you for raising this important point of clarification. We are developing a guideline for situations where the condition causes an impact on a person's quality of life and well-being (and on their family and carers). We will be clarifying the use of these terms in the development of the guideline
Queen's University of Belfast	25.03	3.2. f	This is a very valid and important point	Noted – thank you
Queen's University of Belfast	25.04	3.2. h	These guidelines were generally written without the expert input from a Board Certified Behavior Analyst (BCBA; cf. www.bacb.com) and thus all of them entail varying degrees of mistakes with regard to recommendations of ABA. The cry 'nothing about us without us" should therefore also be applied to the writing of expert guidelines; i.e,, nothing about ABA without a BCBA.	Noted – thank you
Royal College of Nursing	26.01	General	The Royal College of Nursing welcomes proposals to develop this guideline. It is timely.	We welcome your comments.
Royal College of Nursing	26.02	3.2.b	Multi-agency working is not well co-ordinated and without close working of these agencies, the systems will fail. How would health services be able to influence these other systems effectively? This should be fully explored.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as

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				that will differ around the country
Royal College of Nursing	26.03	3.2.b	Waiting times of up to 2 years reported anecdotally – this needs to improve as children and young people risk getting worse while waiting for diagnosis to be confirmed and often families are also unable to access the much required educational and social care support without a confirmed diagnosis.	Noted, thank you.
Royal College of Nursing	26.04	3.2. b	Observations need to be carried out in more than one environment.	This is now clarified in the text – thank you
Royal College of Nursing	26.05	3.2. b	In practice, certainly in Northern Ireland, a diagnosis of ASD in children & young people is made by healthcare professionals, usually a trained Paediatrician and Specialist Speech & Language Therapist. We are also aware that in some trusts in England, Child and Adolescent Psychiatrists are involved in this. The reality is that, post-diagnosis, there appears to be little by way of support, other than for those children and young people who also have a diagnosis of a severe learning disability, and therefore are eligible to input from both Clinical Psychology and Children's Disability Social Work Teams. We would suggest that the opening sentence in this section might therefore be split into two distinct parts to reflect this: 1. Healthcare professionals usually make the diagnosis of ASD in a child or young person; 2. By working jointly with social care and educational professionals, healthcare professionals can share information	Thank you, suggested changes to the text for clarification made to 3.2b. However, we need to be careful on to pre-empt the guideline by suggesting what ought to be done in terms of joint working before the guideline is developed

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			regarding the diagnosis and ideally, to begin to agree on a plan for future support and/ or intervention for each individual child or young person.	
Royal College of Nursing	26.06	3.2.c	What are the competencies required by the multidisciplinary team when assessing for ASD? Equally what are the competencies needed at primary care to recognise difficulties with social development?	We recognise the very important role of the multidisciplinary team and this ethos will underpin all the recommendations in the guideline. We recognise that many different professionals can contribute to making a diagnosis and we will not be defining which professionals should be undertaking which roles since this may differ around the country. The key message of the guideline will be that the process of diagnosis is multidisciplinary and that different professionals play different roles around the country. Individual competencies are outside the scope.
Royal College of Nursing	26.07	3.2.c	Appropriate referrals could be speeded up by first line health professionals being adequately trained. School nurses, Health Visitors, GPs, Practice Nurses – protocol needed for identifying those in need of assessment, and referral pathways. Delay in diagnosis or wrong diagnosis can lead to behaviour deterioration, family stress increase, reduced educational attainment.	Training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will address the specific needs of vulnerable groups going through diagnostic assessment.
Royal College of Nursing	26.08	3.2.e	Children with other conditions for example Learning disabilities may not have autism recognised, or may	This issue has been clarified in the scope, thank you for raising it.

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			be misdiagnosed. LD behaviour could be due to physical illness not being diagnosed correctly. LD nurse skills are vital in this, also views of parent/carer re physical symptoms interpretation. Treating the physical condition may result in behaviour of LD being 'normalised'. LAC children especially disadvantaged – behaviour may be inappropriately classed as 'awkward' but this could be undiagnosed autism.	
Royal College of Nursing	26.09	3.2.g	Family/carer support – it is essential they are fully informed and supported regarding how to best help the child	This is covered in the guideline, thank you
Royal College of Nursing	26.10	3.2.g	Pathways should be in place for post diagnostic support and advice.	The guideline will include an algorithm/ clinical care pathway.
Royal College of Nursing	26.11	3.2.h	The DHSSPSNI launched the Autism Spectrum Disorder (ASD) Strategic Action Plan (2008/9 – 2010/11) on 29th June 2009. This action plan is aimed at delivering significant improvements in services for people of all ages affected by autism, their families and carers and follows an independent review of ASD services. The RCN Northern Ireland Board contributed to this document.	Thank you, we will be mindful of this document
Royal College of Nursing	26.12	4.1.1 and 4.1.2	CAMHS goes up to 18th birthday according to the National Service Framework (NSF). It is unclear where the cut off age for this guideline will be as in sections 4.1.1 and 4.1.2 it says up to 19 years of age. Can this be made clearer?	Thank you, this is now clarified in the scope. The age cut off is 18 years up to the 19th birthday.
Royal College of Nursing	26.13	4.2	Links with other agencies and the third sector is necessary.	This has been clarified in the scope under 4.2b
Royal College of Nursing	26.14	4.2.b	Consideration should be given to the introduction of	Noted, thank you.

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			joint guidelines.	
Royal College of Nursing	26.15	4.3.1.f	It is really important that interventions should be evidence-based as far as possible. Identify those treatments which are simply 'opinion' but lacking scientific evaluation. It is unethical for parents/carers to be misled.	Yes, this is the essence of the clinical guideline
Royal College of Paediatrics and Child Health	27.01	General	The scope aims to address key issues in recognition and diagnosis and its general aims are welcomed. It is well designed, well written and comprehensive.	Thank you.
Royal College of Paediatrics and Child Health	27.02	General	Specialist practice, diagnostic thresholds are a main challenge. Occasionally, independent 'specialists' giving a single professional view, and private diagnoses that are at odds with multi professional opinions can create confusion and dilemmas. Therefore it would be helpful to bear this in mind and define best practice in guidance on the diagnostic process.	Noted, thank you.
Royal College of Paediatrics and Child Health	27.03	General	Further clarity is needed in the definition of 'The broader spectrum'." It is unclear if the definition includes for example; ASC /D, Autism, high functioning etc.	The guideline will provide a detailed statement on what is and what is not included in the terms autism spectrum condition and autism spectrum disorders. This will be discussed at length by the guideline development group and a clear consensus will need to be reached that satisfies the majority and is seen as a workable and useful definition for the NHS and its partners.
Royal College of Paediatrics and Child Health	27.04	General	Epilepsy is not mentioned under one of the coexisting conditions throughout the draft. Epilepsy, in particular temporal lobe epilepsy has association with increased incidence of ASD and ASDs themselves are associated with higher incidence of epilepsy. It should be clarified whether the guideline will cover management of ASD in children with epilepsy, particularly recommendations for resources for such	Thank you for raising this. We will specifically consider epilepsy in the diagnostic discussion.

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			children.	
Royal College of Paediatrics and Child Health	27.05	General	Adequate distinction needs to be made about having 'features' of ASD as opposed to impairment which requires input from services etc. This distinction would need to be made clear to all involved especially teachers etc to prevent an influx of inappropriate referrals.	Thank you. Impairment and the impact of symptoms will be an important issue to discuss in the guideline development group.
Royal College of Paediatrics and Child Health	27.06	3.1c	Other features; obsessions, selective restrictive eating disorders, perseveration and invasion of personal space.	Thank you, all the important features of ASD will be included in a longer introduction to the clinical guideline once it is written. The scope does not provide the definitive list, but thank you very much for the suggestions of other features we could include
Royal College of Paediatrics and Child Health	27.07	3.1f	Children with visual impairments are another group where ASD is likely to be under-diagnosed (see the work by Alison Salt et al ICH).*NB the consultee who made this comment needs to provide full ref or remove*	Noted. We are aware that other groups may also be under diagnosed with autism and where evidence is found, this will be identified and specific recommendations made if a different process of assessment is required.
Royal College of Paediatrics and Child Health	27.08	3.2 a	It would be beneficial to consider the roles of individual health disciplines such as Medical (paediatrician/child psychiatrist), Speech and language therapist, Occupational therapist, Clinical Psychologist, Psychotherapist and how they work together.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country. However the components of an effective assessment will be addressed.
Royal College of Paediatrics and Child Health	27.09	3.2 b	The word 'usually' should be replaced with 'often' as many services do not routinely collaborate with both education and social care. A waiting list of 2 years is unacceptable in the life of a young child. An 18 week deadline is often imposed on health services.	Thank you, there is now clarification of this issue in the scope.

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Royal College of Paediatrics and Child Health	27.10	4.1.1 (b)	Additional subgroups of children in whom the diagnosis of ASD is less likely to be recognised include: (i) Children in whom an intellectual disability is diagnosed. (ii) Children presenting with symptoms of ADHD. (iii) Children presenting primarily with aggression or behavioural problems, or symptoms of Oppositional Defiant Disorder or Conduct Disorder. (iv) Children diagnosed with severe visual impairment.	Noted, thank you. Individuals with an intellectual disability have been identified due to specific problems in undertaking a diagnostic assessment. Other sub-groups are also less likely to be recognised. We recognise the specific needs of this group and will ensure their needs are addressed by considering them when we make draft recommendations.
Royal College of Paediatrics and Child Health	27.11	4.2	The process of assessing and diagnosing children and young people with an ASD can be made much quicker and significantly more efficient if a multi – disciplinary/ multi-agency approach is adopted. That means involving colleagues from the Education departments from very early on. This has already been made mandatory for children 0-5 years through the implementation of the Early Support Program, which is already a reality in many areas. Within the ESP framework, children with developmental disorders (including suspected ASDs) are referred to a multi-agency team composed of professionals from Health and Education and Social Care. Very often both colleagues from Education and Health conduct parallel assessments, which allow for a speedier and more accurate diagnosis or assessment of need. This area should be addressed within the guidance. It may be worth exploring working models such as for School aged children, established agreements	The status of recommendations for education has been clarified in the scope. See above response re: multidisciplinary approach to the guideline. This is very helpful, thank you.

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			with Education colleagues (SENCOs and Specialist teaching Teams) by which they conduct some initial assessments prior to referral to Health services. This potentially makes the diagnostic process quicker, and more efficient with considerable savings of time and resources for heath services.	
Royal College of Paediatrics and Child Health	27.12	4.3.2 a	We note that screening is outside the Scope of this exercise; however there are some instruments that can be used for screening but are also felt to have a place in a diagnostic (second tier) setting, e.g. M-CHAT. It would be beneficial if these could be evaluated in this guidance. Paragraph 2 Remit refers to initial recognition of ASD which implies that use of structured tools such as this may be appropriate in some circumstances when ASD is suspected	M-Chat will be one of the components of a diagnostic assessment covered by this guideline.
Royal College of Speech and Language Therapists	28.01	General	The RCSLT welcomes the draft scope for autism spectrum disorders in children and young people. We look forward to the development of this guideline and the opportunity to contribute to its development.	We welcome your comments.
Royal College of Speech and Language Therapists	28.02	General	The draft scope refers to ASD however the Department of Health draft strategy for adults with autism labels it ASC. We recommend that there is consistency between the two documents.	The guideline will provide a detailed statement on what is and what is not included in the terms autism spectrum condition and autism spectrum disorders. This will be discussed at length by the guideline development group and a clear consensus will need to be reached that satisfies the majority and is seen as a workable and useful definition for the NHS and its partners.
Royal College of Speech and Language Therapists	28.03	3.1	The guideline needs to reflect that the features and severity of ASD also interact with language difficulties or disorder and intellectual ability, and which are not necessarily interdependent.	Noted, thank you.
Royal College of Speech and Language Therapists	28.04	3.1 a	To validate these statistics the RCSLT recommends that comprehensive references are added.	It is not NICE policy to add references to the scope. However a more detailed review with references will be included in the guideline

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Royal College of Speech and Language Therapists	28.05	3.1 a	More recent studies estimate that the prevalence of ASD is closer to 91 per 100,000. The current statistics used indicate too greater degree of uncertainty in judging the prevalence.	Noted, thank you.
Royal College of Speech and Language Therapists	28.06	3.1. a	The RCSLT recommends that the three areas on childhood autism, ASD and Asperger's syndrome are separated into individual groups.	See response to 28.02 above
Royal College of Speech and Language Therapists	28.07	3.1.b Bullet one	Expressive language is often affected by underlying problems related to ASD, including a very literal understanding of language which needs to be reflected in the main areas of functioning affecting people with ASD.	Noted, thank you
Royal College of Speech and Language Therapists	28.08	3.1 c	Anxiety is such a frequent associated feature of ASD that the RCSLT strongly recommends that this is included in this section on other features.	We agree with this point which is implied in emotional and behavioural problems.
Royal College of Speech and Language Therapists	28.09	3.1 d	ASD affects people differently. It is important to recognise that ASD may have minimal or little impact on a few [very] cognitively high functioning individuals who use their special skills in the work place.	Noted, thank you.
Royal College of Speech and Language Therapists	28.10	3.1.f	We recommend that the evidence stating that ASD has a link to associated increased mental health difficulties is added. Anecdotally we agree that there may be an increased risk of anxiety or depression however we are concerned that that there is limited research on this subject.	We agree with this point and will reference any evidence we use on this issue in the full guideline.
Royal College of Speech and Language Therapists	28.11	3.1.f	We recommend that examples of co-morbid developmental disorders are added to this section. Failing to do this makes it appear that someone with ASD (which is in itself a developmental disorder) may have a developmental disorder which is confusing.	Thank you for raising this. We have made changes to the text to clarify this point.
Royal College of Speech	28.12	3.2 b	Our therapists believed that in practice this	We have made changes to 3.2bt to clarify that the

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and Language Therapists			statement to be inaccurate. They stated that health care professionals usually make the diagnosis of ASD by working jointly with education and in some cases with social care particularly if the child or young person has learning difficulties or is a looked after child. However the relationship with social care and more able children particularly those with Asperger's syndrome is more fragile.	emphasis is on joint working.
Royal College of Speech and Language Therapists	28.13	3.2 f	It is important that the scope recognises that the features which define ASD may also feature in other disorders [and visa versa]. As a consequence children may be misdiagnosed unless assessments are conducted by specialist teams who have experience and knowledge of a wide range of co morbid psychiatric disorders. Behaviours can often disguise or impact on the presentation of ASD which results in under or over diagnosis.	Thank you. We have made changes to the text to clarify this point.
Royal College of Speech and Language Therapists	28.14	4.1.1.b	We recommend that to the current statement you add …"children diagnosed with an intellectual disability and high functioning young people with co-morbid conditions like ADHD etc".	Noted, thank you. Individuals with an intellectual disability have been identified due to specific problems in undertaking a diagnostic assessment. Other sub-groups are also less likely to be recognised but the process of diagnostic assessment may or may not be the same. We recognise the specific needs of this group and will ensure their needs are addressed by highlighting them as recommendations are drafted.
Royal College of Speech and Language Therapists	28.15	4.3.1	The RCSLT recommends that particular attention is paid to the differential diagnosis of ASD from other language and communication difficulties in very young children (for example Specific Language Impairment verses ASD).	Noted, thank you.
Royal College of Speech	28.16	4.3.1	The diagnostic sub-group of high functioning autism	We cannot include this as a separate sub group in

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and Language Therapists			currently causes confusion and we recommend that this is considered by NICE.	the scope but will be mindful of this group during the development of the guideline
Royal College of Speech and Language Therapists	28.17	4.3.1 and 4.3.2	Although the international diagnostic standards for ASD are ICD 10 and DSM 4, some of our clinicians work in multi-disciplinary team's and use Gillberg's criteria and state that this is an extremely helpful tool. We are therefore disappointed that the methods of diagnosis are not to be reviewed.	Methods of diagnosis are included in the scope under 4.3.1 c
Royal College of Speech and Language Therapists	28.18	4.3.2 d	We are disappointed that interventions and ongoing management of ASD are not to be covered by the guidelines.	We confirm this is outside the scope.
Royal College of Surgeons	29.01	4.4 d)	It is extremely important to measure outcome in terms of quality of life. The measure should be broader than health-related and maybe could be broadened to look at well-being and resilience. Both of these will be impacted on by health issues and as such health-related quality of life would be included but not the entire issue. Using QALYs allows comparison of outputs for various actions, allowing for a value related to cost to be made for that action. However, it also allows for this comparison to be made across various groups and always carries a risk of being used to make the case that interventions are not worthwhile on the basis of cost because a greater QALY value can be achieved by putting that same effort and financial investment into, for example, early cardiac surgery for children with Down's Syndrome. There are many measures of quality of life and well-being available that offer a robust measure of change. I would caution against the use of QALYs.	When used correctly, the use of QALYs is a robust means of comparing across interventions within and between disease groups – this is the purpose and essence of cost-effectiveness analysis on which NICE guidelines are based. It allows for decisions to be made explicitly about where finite NHS resources should be used to maximise health gain. In a resource constrained health care system, comparing between interventions for ASD and Downs Syndrome is a legitimate and necessary activity. QALYs do assess quality of life in the broadest terms taking into account physical, social and psychological well-being. The problems in using QALYs are different from but not greater than those found in the use of any other generic outcome measures.
Royal Society of Medicine	30.01	General	The Scope is well designed and written and	Thank you.

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			comprehensive	
Royal Society of Medicine	30.02	3.2 a	It would be useful to look at the roles of individual health disciplines such as Medical (paediatrician/child psychiatrist), Speech and language therapist, Occupational therapist, Clinical psychologist, Psychotherapist and how they work together	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country
Royal Society of Medicine	30.03	3.2 b	I would replace the word 'usually' with 'often' as my understanding is that many services do not routinely collaborate with both education and social care. A waiting list of 2 years is unacceptable (is it correct?) in the life of a young child. An 18 week deadline is (quite rightly) often imposed on health services	This has been clarified in the scope.
Royal Society of Medicine	30.04	4.3.2 a	I agree that Screening is probably outside the Scope of this exercise. However there are some instruments that can be used for screening but also have a place in a diagnostic (second tier) setting, e.g. M-CHAT. Para 2 Remit refers to initial recognition of ASD which implies that use of structured tools such as this may be appropriate in some circumstances when ASD is suspected	M-Chat will be one of the components of a diagnostic assessment covered by this guideline.
South Staffordshire & Shropshire NHS Foundation Trust	31.01	3.1 and 4.3.2	Could there be mention of the developmental nature of ASD and the changing pattern of presentation over time and in response to different circumstances? This will have a bearing on identification and assessment but appears to fall outside the stated scope i.e. re-assessment. For example, a child may meet ICD-10 criteria for Childhood Autism at age 5 years but be better described and served by a diagnosis of Asperger Syndrome when in his teens.	Very helpful, thank you, text now added to 3.1a
St Andrew's Healthcare	32.01	4	The scope should include the criminal justice system	Thank you this is also helpful

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			to ensure that adolescents with an offending history that are held inappropriately in prison or in a non-specialist mental health service can benefit from the initial recognition, referral and diagnosis of any autistic spectrum disorder that they may suffer from. Youth offending teams are the people most likely to recommend disposal to prison or a mental health service; these should be considered in the scope alongside education and social services and the voluntary sector as the professionals working with young people who are most likely to identify signs and symptoms of ASD.	
St Andrew's Healthcare	32.02	4.3.2	The primary concerns of St Andrew's Healthcare in regards to the guideline are that people with autism have their condition diagnosed and that they are treated in services that are specifically provided to meet their needs. It is therefore disappointing that the guideline coverage will include referral for diagnosis but not include referral on diagnosis or models of service delivery.	We are restricted in our remit to cover recognition, diagnosis and referral but we have had clarification that while we will take a multidisciplinary approach to underpin the ethos of the guideline, we will not be asking an additional clinical question on models of service delivery. To clarify, we will consider the evidence on signs and symptoms, diagnostic investigations and information and support needs and from this, make recommendations on how to diagnose ASD in a multiprofessional way. But we are not reviewing the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
St Andrew's Healthcare	32.03	4.4	Providing guidance to help identify people with ASD may not necessarily mean that they are treated in appropriate placements. Non-specialised services are very unlikely to meet the needs of people with ASD, or make an impact on the risks they pose to themselves and others. Subsequently health-related quality of life may not be an appropriate	We agree that it will be a challenge to undertake cost-effective analysis when the guideline does not cover intervention and management.

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			outcome if the guideline does not follow diagnosis through to treatment (or at least referral once ASD has been diagnosed).	
Sussex Partnership NHS Trust	33.01	1	The guideline title should include '……*and intervention planning'*	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.02	3.1.2 c	'…*and emotional dysregulation'* should be added	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.03	3.2 a	' There is wide variation in rates of *identification* & referral…'(add italics)	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.04	3.2 c	'..variable time frame *involving* (not requiring) different competencies…'	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.05	3.2 f	'..such as acute trauma, long term illness and *acquired brain injury*..'(add italics)	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.06	3.2 g	'..information for the family *while awaiting diagnosis* and immediately after diagnosis…'(add italics)	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.07	3.2 i	'…process of diagnostic assessment *and resulting care plan* to enable *longer term* future care..' (add italics)	Thank you, this has been noted and text changes made
Sussex Partnership NHS Trust	33.08	4.3.2 a	Although the process of intervention and management of ASD is not covered by the guideline, the guideline needs to state the importance of the diagnostic process leading to/resulting in a subsequent care plan, not just ending at the point that a diagnostic label is or is not given.	We cannot directly address care planning in this guideline although during development the GDG will be continually mindful of this step along the clinical pathway. Text changes have been made.
TreeHouse	34.01	3.1.a	We do not find the distinction between "autism" and "autism spectrum disorder" helpful. We do not accept that there is clear evidence to make this distinction. Hence the quoted epidemiological figures for "autism" of 20-40 per 10,000; and 60 per 10,000 to over 100 per 10,000 are confusing or even misleading.	See response above
TreeHouse	34.02	3.1.(b)	underlined words need to be added: Social communication (understanding **and expressing** verbal and non-verbal language)	Words have been added, thank you.
TreeHouse	34.03	3.1.d	The distinction between "disorder" and "condition" is	Thank you for raising this point. We will be using

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			misleading and too vague to be meaningful. We would urge NICE to adopt the now-accepted generic term "autism spectrum" throughout this guideline development. Autism is a lifelong neurological condition, the expression of which in individuals will differ at different stages of their lives and in response to interventions, e.g., appropriate education. We do not accept that the presence of features of autism will have no impact on a person's ability to function in the world. In order to get the diagnosis of 'autistic features' these difficulties need to have an impact on an individual's daily functioning. In young people, the onset of puberty or a change in circumstances, such as the move from primary to secondary schooling, may bring about a change in the ability of an individual to interact with his or her surroundings and thus a change in behaviour. What might have been regarded as a "condition" suddenly becomes a "disorder", despite there being no underlying change in the neuropathology. Hence we would propose that "AS" is used throughout.	'impact' linked to diagnosis as a working definition of autism spectrum conditions as defined as a 'disorder' as opposed to a 'condition'. We have removed "no impact" in the text – thank you. We have added recognition of autism as a life long condition in 3.1. The guideline will provide a detailed statement on what is and what is not included in the terms autism spectrum condition and autism spectrum disorders. This will be discussed at length by the guideline development group and a clear consensus will need to be reached that satisfies the majority and is seen as a workable and useful definition for the NHS and its partners.
TreeHouse	34.04	3.1 (f)	The diagnosis of Asperger's Syndrome or High Functioning Autism is known to be more difficult and we suggest that this should be a focus of this study.	Noted. Thank you. The focus of the guideline will be on the spectrum of Autism
TreeHouse	34.05	3.2 (f)	Along with misdiagnosis, there is also a risk of confusing autism for signs of abuse which can cause many difficulties for parents. Health professionals or social workers/education professionals may think a child is in a high risk group of abuse when in fact the child exhibits behaviour that defines AS. It may be worthwhile having this aspect of misdiagnosis considered in better diagnosis. This	Noted, thank you. We will be mindful of the content and approach taken by the NICE clinical guideline published on maltreatment in July 2009 in the development of this guideline, so that they complement each other.

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			issue will be raised in the coming year when there will be much greater focus on safeguarding vulnerable children and stronger regulation of home education. With further regulation planned, many parents are already worried about their children's autism being mistaken.	
TreeHouse	34.06	4.1.1 (b)	In line with 3.1 (f) – if it is accepted that Asperger's / HFA are more difficult to identify this group could be specified here.	Noted, thank you. Other populations are also less likely to be recognised but the process of diagnostic assessment may or may not be the same. We recognise the specific needs of the Asperger's / HFA group and will ensure their needs are considered when drafting recommendations.
TreeHouse	34.07	4.1.2 (a)	We would question why the age limit is 18 for the guidelines. As those with learning difficulties will come under legislation up to the age of 25, we would like the scope of the guidelines to be extended to 25.	Thank you for your comments. We are strictly limited to the age cut-off set out in the scope which we recognise has important limitations. To expand it further would necessitate a far wider review of the evidence than can be undertaken in one clinical guideline. We would urge you to make a case for a guideline that did cover this important age group in a future NICE guideline which can be done via the Topic Selection Process on the NICE website.
TreeHouse	34.08	4.1 (b)	As diagnosis often starts in education or social services and moves to health, the place that other agencies hold in this process is extremely important and we would urge that this is reflected in the guidelines.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country
TreeHouse	34.09	4.3.1.(c)	We would strongly urge these guidelines to be based on strongest available research evidence. The methods for assessing AS or diagnostic thresholds are difficult questions and what evidence such assessments are based on will be very important.	This will underpin the entire methodological approach to the guideline

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TreeHouse	34.10	4.3.2 (e)	We would like to see reassessment and review of diagnosis as an important part of the review, particularly as there is acknowledgement of the problems with misdiagnosis. Reassessment and review of diagnosis is very important to parents and families and should be considered.	Review and reassessment following a confirmed diagnosis are outside the scope of the guideline.
TreeHouse	34.11	4.5	The document says "developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions", however elsewhere the draft scope clearly states that one of the issues that will <u>not</u> be covered is interventions and ongoing management of ASD (4.3.2.d).	Thank you for raising this, the meaning of the sentence has been clarified in the scope
UNITE THE UNION-CPHVA	35.01	4.1.1a	CPHVA recognises the importance of early diagnosis, therefore welcomes the proposed age-range. However would this exclude children with ASD so far undetected and still at school at 19yrs?	Yes, strictly it would exclude them, but there is no reason why recommendations from this guideline should not also be applied to this group.
UNITE THE UNION-CPHVA	35.02	4.1.1b	Children (later diagnosed) with ASD present with behavioural difficulties both at school and at home and are referred to "behaviour management" clinics. However Tier Two work is often under-resourced. Will the scope consider the extra resources necessary to support the skills required for practitioners at this level EG Training and Clinical supervision?	NICE guidelines include a cost impact assessment which is developed after guideline recommendations have been agreed to support commissioners in planning for and delivering services.
UNITE THE UNION-CPHVA	35.03	4.3.1a	Early recognition of signs and symptoms is essential to referring on for assessment, diagnosis and treatment. At a time when the health visiting service to the under 5s is under review and many families are receiving the minimum of a universal service who will see the children and start the referral process?	This is an important point . However, we will be considering initial signs and symptoms rather than who observes them.
UNITE THE UNION-CPHVA	35.04	4.3.1b	If children are diagnosed with ASD early what support services are going to be in place for the families involved? Considering the increase in	The guideline will review information and support for children, families and carers that have been shown to be beneficial but will not look at the evidence of

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			prevalence would more resources be made available to assist parents in developing their parenting skills in order to meet the child's needs?	the effectiveness of therapeutic support and treatment during diagnosis since this is beyond the specific remit of the guideline.
UNITE THE UNION-CPHVA	35.05	4.3.1c	A standardised method of assessing ASD would be useful, although a rigid approach may fail to capture the subtleties of this condition. It would be important to include a multi-modal and multi-disciplinary approach to assessment. Using a more holistic approach would help to address some of the co-existing conditions.	The guideline will focus on the core components of diagnosis and assessment of ASD. It will include a clinical algorithm or pathway which will take into account the need for flexibility and recognise the limitations of a "one size fits all" approach to diagnosis.
UNITE THE UNION-CPHVA	35.06	4.3.1e	Parents often require more support during the assessment process and following diagnosis. Information should be available in a variety of mediums made available to professionals working in the NHS and not solely via voluntary organisations, for example printed information.	See response to 35.04 above
UNITE THE UNION-CPHVA	35.07	4.3.1e	Parents and carers often request respite care; will parents/carers be consulted so that their expressed needs might be considered?	This important issue is outside the remit of the guideline
UNITE THE UNION-CPHVA	35.08	4.3.1e	Siblings report that their needs are often over-looked; will the needs of all family members be considered?	Yes, in part, they will be under the clinical question on information and support
UNITE THE UNION-CPHVA	35.09	4.3.1e	School children with undiagnosed ASD often present with behavioural difficulties which become the focus of attention This can lead to exclusion for many young people. Would the scope seek to identify the education and training needs of professionals working in schools so as to improve liaison between healthcare and education, and improve outcomes for children with ASD through greater understanding.	Yes, the scope expands on this point now to make this point more clearly (4.2b). However training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will address the specific needs of vulnerable groups going through diagnostic assessment.

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UNITE THE UNION-CPHVA	35.10	General	• Early identification is important but often parents are reluctant to accept that their child may have difficulties. Therefore it is important that parents are given time to build up a good rapport with professionals involved in order to work in partnership. • Children with ASD often present with behavioural issues or other adaptive difficulties in the school setting which can often be missed or misinterpreted. Schools and healthcare need to work more closely together in assessing the individual needs of children. • A clear and easy-to understand pathway is required. • A multi-disciplinary approach to assessment should be established but a reduction in overlap is needed. • Many professionals in Tier Two services are already under-resourced. Secure funding should be available to cope with the development of a quality service to meet the growing needs of this group. • Agreed outcome measures are required. Can the guidelines incorporate this? • Help should be available to carers and parents • User-involvement is paramount. How will young people be consulted and involved in the guidelines development? • Some children with ASD have great gifts and talents. Would consideration be given to developing a range of services to nurture these and enable greater independence for	We agree with all these points. A clinical pathway will be developed based on the recommendations in the guideline. Multidisciplinary working underpins the ethos of the guideline. Cost implications of recommendations are assessed after recommendations have been drafted based on clinical and cost effectiveness evidence. Outcomes are specified in the scope under 4.4. Information and support for parents and carers is included in the scope. Lay members are important contributors to all of our GDGs. Services and interventions are unfortunately outside the scope of this guideline. You may refer new topics for NICE clinical guidelines through the Topic Selection Process via the NICE website.

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			those children and young people?	
United Kingdom Council on Psychotherapy	36.01	3.1 General	UKCP PCC welcomes this accessible clear formulation of the autistic spectrum disorders & associated conditions	We welcome your views
United Kingdom Council on Psychotherapy	36.02	3.1.f	The related occurrence of associated mental health problems, developmental disorders & adaptive impairments, as well as intellectual disability, are noted by UKCP PCC as indicative of the need for complex, rigorous & often long-term services for young people experiencing ASD & their families & carers.	Noted, thank you
United Kingdom Council on Psychotherapy	36.03	3.2.a	UKCP PCC recognises that many young people & their families receive variable responses including delays in both referral for diagnosis, & formal diagnosis itself, UKCP PCC deplores the delays in provision of appropriate responsive service, recognising this often causes great distress & difficulty to young people & their families.	Noted, thank you
United Kingdom Council on Psychotherapy	36.04	3.2.b	UKCP PCC welcomes the recognition that multi-disciplinary work is so crucial in the provision & development of timely effective services for young people experiencing ASD & their families. As an umbrella organisation representing all the modalities of psychotherapy we value the diversity of input from a range of specialist professions & particularly welcome the stakeholder proposals on moving away from a 'one-size-fits-all' pathway & evidencing the value of a multi-disciplinary approach.	Noted, thank you
United Kingdom Council on Psychotherapy	36.05	3.2.c	UKCP PCC recognises that the complexity of diagnosis may require a range of specialist competencies with a degree of flexibility within a variable time-frame. In taking seriously the needs for an individualised response to the needs of the young person & their family we would stress the need for	Training issues are not directly addressed in clinical guidelines as these come under the remit of the professional bodies that set the standards for registration and continuing professional development. However, the guideline is based on an ethos of multidisciplinary working and will

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			clinicians trained at specialist levels who can proceed at a pace & depth that suits the unique needs of the client.	address the specific needs of vulnerable groups going through diagnostic assessment.
United Kingdom Council on Psychotherapy	36.06	3.2.d	While welcoming any evidence-based investigation & diagnostic procedures UKCP PCC also recognises that ASD & related conditions present a level of complexity where skilled interpersonal assessment & the experience of family & carers is of great value.	To clarify, the guideline will make recommendations on how to diagnose ASD in a multiprofessional way. But we will not review the role of different personnel or local models of service or the competencies needed to deliver a diagnostic service nor the specific means by which it should be delivered as that will differ around the country depending on current service configuration and resources.
United Kingdom Council on Psychotherapy	36.07	3.2.e	Given the complexity & variability of ASD diagnostic & assessment procedures, UKCP PCC would stress the value of substantial interpersonal contact such as psychotherapies assessments, which allow for the interplay of factors such as social circumstances or personal experience (e.g. with children 'looked after') to be observed & taken into account. We note that the stakeholders workshop raised such variables as equalities issues & support that position.	The components of a multidisciplinary diagnostic assessment will be reviewed and recommendations made based n the best available evidence of effectiveness
United Kingdom Council on Psychotherapy	36.08	3.2.f	UKCP PCC considers these to be key points in considering the complexities of ASD diagnosis. In the interests of the young person it is not only necessary that clinicians be trained in recognition & assessment of ASD, but that clinicians with experience & knowledge of how other disorders, disabilities & childhood experiences such as trauma may impact on the young person & affect their presentation & communication also be available within the multidisciplinary team to inform judgement & decisions. We recognise that some children may be misdiagnosed, & believe this is less likely to	Noted, thank you

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			occur when a full range of experienced specialist professionals familiar with complexity of presentation are involved in assessment.	
United Kingdom Council on Psychotherapy	36.09	3.2.g	UKCP PCC standards stress as a requirement for all psychotherapists of any modality working with children that they be constantly mindful of the importance of timely & appropriate information-sharing & consideration of the impact of major life-events such as ASD diagnosis on parents, carers, siblings & family members.	Noted thank you
United Kingdom Council on Psychotherapy	36.10	3.2.h	UKCP PCC standards stress all psychotherapists working with children are aware of the benefits of interagency cooperation in supporting the child to be healthy, stay safe, enjoy & achieve, & make a positive contribution. The experience of our registrants is that young people diagnosed with ASD & their families will experience a range of needs & difficulties of varying complexity at different times throughout life. The stakeholder comments on the variable nature of the disorder & how this may impact on assessment & diagnosis are valuable. Thus the network of care needs to be able to work together to appropriately offer a range of different tailored responses, including brief focussed interventions & more substantial complex input. Transition is a key point in any young person's life & in the family life-cycle, & psychotherapists of all modalities are mindful of the significance of such transitions. The UKCP PCC also welcomes the recognition of under-provision of services for adults with ASD diagnoses & our registrants working with adults look forward to contributing to similar reviews of good practice for ASD in the future.	Please see response to 36.06 above Transition to adult services is outside the scope as are adult services
United Kingdom Council	36.11	3.2.i	UKCP PCC welcomes the creation of such a	Thank you

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on Psychotherapy			guideline, stressing the importance of individualised tailored response & a range of specialist provision to adequately meet the needs of young people & their families living with ASD.	
United Kingdom Council on Psychotherapy	36.12	4.1.b	UKCP PCC welcomes this recognition that some groups of young people, particularly those with intellectual disability, may not access appropriate services due to failures to recognise the coexistence of ASD with other conditions.	Thank you
United Kingdom Council on Psychotherapy	36.13	4.3.1 General	UKCP PCC supports this clinical management strategy overall.	Thank you
United Kingdom Council on Psychotherapy	36.14	4.3.1.e	UKCP PCC stresses the importance of support for young people, & their carers or families during the process of referral, assessment & diagnosis, recognising the profound emotional & psychological impact & distress this process can involve.	Support and information sharing will be included in the guideline. However, the guideline will not consider management interventions
United Kingdom Council on Psychotherapy	36.15	4.3.f	UKCP PCC entirely supports a rigorous approach to identifying ineffective interventions & approaches to ASD, recognising the complexity of these conditions.	Thank you
United Kingdom Council on Psychotherapy	36.16	4.4.d	UKCP PCC entirely welcomes the recognition that quality of life for young people & their families or carers may be profoundly impacted by the complex & ongoing impact of ASD, practically & emotionally as well as in terms of mental wellbeing.	Thank you
United Kingdom Council on Psychotherapy	36.17	4.4.e	UKCP PCC entirely supports the inclusion of the views of children, young people, their families & carers in the guidance & sees this as a welcome improvement in the creation of good practice guidelines.	Thank you
United Kingdom Council on Psychotherapy	36.18	4.5	UKCP PCC welcomes the recognition of effectiveness of services in terms of quality of life, & stresses the importance for young people their families & carers during assessment & diagnosis that recognition of their emotional & mental well-being will be taken into account when planning &	Thank you,

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			provisioning services, & evaluating good practice.	
United Kingdom Council on Psychotherapy	36.19	General	UKCP PCC welcomes the recognition of the complexity of ASD assessment & diagnosis & the profound impact this has on the lives of young people, their families & carers. We support the creation of guidelines which emphasise clinical rigour, recognition of the unique needs of each child & family, & provision of a specialist network trained to work at such levels of complexity to support each young person in enjoying a healthy, fulfilling, safe, constructive life where they are able to achieve & thrive. We welcome recognition that the emotional & mental wellbeing needs of young people & their families & carers are central to such good practice.	Thank you
Whitstone Head School (NMSS-BESD)	37.01	3.2.(f)	My comments are as follows. Childhood attachment disorders (ICD-10) should be included in the list of conditions that have behaviours that define ASD, especially given the shared commonalities with Asperger's/HFA presentations which can necessitate skilled differential diagnosis to avoid misdiagnosis.	Thank you for raising this point, we will be making recommendations that cover differential diagnosis for the major commonalities
Whitstone Head School (NMSS-BESD)	37.02	3.2.(h)	My comments are as follows. In line 4 please change '[SIGN]' to '[SIGN 98]' to enable readers to identify the appropriate Scottish Intermediate Guidelines.	Text changed, thank you
Whitstone Head School (NMSS-BESD)	37.03	General	My comments are as follows. A list of references and reference sources at the end of the draft scope would be beneficial for readers, especially those who may wish to contribute further to the consultation process.	It is not NICE house style to include references in the scope as this is based on a first, high level search of the evidence. However, a full list fop references will be included in the main guideline.