National Institute for Health and Clinical Excellence

Autism in adults
Guideline Consultation Comments Table
2nd Dec 2011 – 27 January 2012

No.	Stakeholder	Order No	Document	Section No	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group				General		Good to see acknowledgement of the role and the impact of the social and physical environment as we know the environment in which individuals with ASD function can be a barrier to adult functioning. In particular the sensory features of the environment are frequently under recognised. This is acknowledged in the Guidelines.	Thank you for your comments. We agree this can have a great impact on people with autism.
2.	Association Directors of Adult Social Services	25	Both		General		Recognition of the scope of the spectrum of Autism needs to be clearly defined when using recommendation examples where focusing on a specific group of people and not the broader spectrum. There is a specific focus on Intellectual disability and clarification should be given as a reference to the new classification or reference to LD – in order to minimise the Risk of Autism being perceived as a LD.	Thank you for your comment. We have reviewed all recommendations to ensure they are clear on whether they all apply to all or some people with autism and amended where necessary. We have also reverted to use of the term learning disability.
3.	Association Directors of Adult Social Services	27	Both		General		There is an omission to mention meeting siblings needs, and those of young people as carers needs to be clearly addressed within 4.3.11 (pg 73) and 6.3.5 (pg 133).	Thank you for your comments, the GDG believes this adequately dealt with by the reference throughout the document to families, and in particular recommendation 1.1.13 which highlights the importance of offering a carer's assessment.
4.	Association Directors of Adult Social Services	28	Both		General		There is a general omission to identify the statutory entitlement to a Care Needs Assessment by the Local Authority where such needs are identified and an Autism diagnosis made.	Thank you for your comments. In recommendations 1.1.13 and 1.1.14 we refer directly to the importance of informing carer's about their right to a formal assessment and recommended helping them to access this.

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5.	Association Directors of Adult Social Services	29	Both		General		Social Care professionals should be referred to if the guidance is to be used as a guidance tool. This needs to be in conjunction with the Autism Strategy with the focus of promoting the independence and opportunities of individuals with Autism to live independently with the appropriate care and treatment required This needs to be inclusive of reasonable adjustments in communication in order to fully include the individual and their Family Members / Carers. Links to Pg 9 in referencing Social Workers as contributors, need to reflect the whole system and social care in the wider document. Including Wider Universal services and Eligibility Criteria. Promoting independence, independence and control of their lives needs to be more prevalent in the guidance particularly in the promotion of aspirations for young people development of social skills and coping, working etc. The focus on care does not provide the guidance across the spectrum and is not reflective of the wider needs of individuals who are higher functioning.	Thank you, NICE guidelines do not, unless absolutely necessary, refer to specific professional groups. However, we have added a section on social care to the full guideline. The purpose of the guideline is to provide advice on the most effective interventions and not to provide advice on the development/implementation of the Autism Strategy or, for example, eligibility criteria. We have reviewed and revised our recommendations on families and carers in light of your and other comments.
6.	Association for Family Therapy and Systemic Practice	1	Both	General			It would be helpful to include partners as well as 'families and carers' in recommendations for providing information and support. For instance, the partner's autism may only become explored and identified after their child's diagnosis of autism, so it is about understanding relationship issues, as well as finding ways to manage responses.	Thank you for your comment. We have now included partners along with families and carers.
7.	Autism NI	7	Full				Overall this is a very good document.	Thank you for your comments, they are appreciated.
8.	Royal College of Psychiatrists	12	Full				Unused.	
9.	NHS Direct	1	Full				NHS Direct welcome the guidance and have no comment on its content.	Thank you.

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10.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 6	Full				It is considered that clear description that an informant is necessary in order both to give a developmental history and to give an objective account of the individuals presentation is required as part of the assessment	Thank you for your comment. A developmental history is always desirable but the GDG view is that where no “informant” is available to provide a developmental history, this should not be a barrier to receiving a diagnosis, and that the best available information should be used to make the diagnosis. This might include school reports, and ultimately self-report.
11.	Calderstones Partnership NHS Foundation Trust	7	Full				Our diagnostic team prefer the Diagnostic Interview for Social and Communication Disorders (DISCO) as we feel it is more comprehensive than the ADI-R, and is more helpful when diagnosing individuals with learning disabilities who have no family informants and limited developmental history.	Thank you for your comment. We have revised our recommendations about assessment and included the DISCO as a possible method for structuring an assessment.
12.	Hertfordshire Partnership NHS foundation Trust	6	Full		-	-	Overall, the Guidelines are very comprehensive and will be extremely helpful.	Thank you very much for your comments.
13.	NCCMH expert reviewer	1 1	Full		168	1	Section 7 Psychosocial interventions. This is a very important part of the guide. In general I have little else to say by way of comment. I welcome the approach taken. I cannot comment on whether good studies have been overlooked or omitted. This could be very helpful for commissioners and is likely to be welcomed by service users, carers and their advocates.	Thank you for your comments.
14.	NCCMH expert reviewer	1	Full		21	4	In general I am quite impressed with the full and short versions of the consultation guideline. I'm particularly pleased, as set out in the full version, that NICE found evidence they could recommend on psychosocial interventions given the limited benefit over risk of biomedical interventions. In general what NICE propose to say about biomedical interventions lines up with the Cochrane ASD intervention reviews and with what has been flagging up on the NAS Research Autism website on what does/does not work (I should declare that I am a member of the Research Autism scientific committee): http://www.researchautism.net/pages/welcome/home.ikml I would remind the reader that at the request of NICE I prepared and updated the preliminary brief on a potential adult guideline in 2009. At that time I felt there was very little literature on effective interventions but a good deal of clinical	Thank you very much for your comments.

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							experience and some degree of consensus to build upon in a review and recommendations. I am delighted that NICE was commissioned to undertake this review and guideline and that more evidence for interventions was found than I had expected. Therefore I shall focus my comments on a small number of important technical issues about which I am concerned.	
15.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full		General		Behaviour Section It appears no certified Board Behaviour Analyst was involved in this review. This happened with the SIGN work, resulting in an erroneous section having to be withdrawn later. 'Applied behavioural analysis' is not a term used by behaviour analysts - it should be 'applied behaviour analysis'.	Thank you. Individuals are selected for their expertise and to ensure that the GDG can properly address the scope of the guideline. In this regard, their professional backgrounds are of secondary importance.
16.	Institute of Psychiatry, Kings College London	6	Full		general		In terms of research recommendations, in the light of the general recommendations I wonder if I could suggest that research as to establish the optimum content and methods of a training package for health and social care professionals to become conversant with ASC as suggested by the guidelines would be of benefit.	Thank you for your comment, we did consider this but training is outside of the scope of the guideline and therefore we did not take up your suggestion, but we agree it is an important area.
17.	Institute of Psychiatry, Kings College London	7	Full		general		I wonder as there have been such few systematic treatment studies considering the effectiveness for individual CBT for anxiety and depression is lacking, and that there has only been 1 (and now a 2nd study, both focused on OCD), that in addition to recommending research in self-help for anxiety and depression, that the guidelines might recommend research into therapist delivered individual CBT for anxiety and depression in adults with Autism Spectrum Conditions (these treatment are 1st line in the general population and should be considered in people with ASD)	Thank you for your comment. We have included a new research recommendation in light of your comments.
18.	Queen's University Belfast,	1	Full		general		Again, no Board Certified Behaviour Analyst was involved in the review, therefore not surprisingly there are a number of problems (we addressed some of these in the attached papers). Eg 'applied behavioural analysis' is not a term used by behaviour analysts, it should be 'applied behaviour analysis' The term 'operant conditioning theory' is also not a term you would find in a book on behaviour analysis.	Thank you. Individuals are selected for their expertise and to ensure that the GDG can properly address the scope of the guideline. In this regard, their professional backgrounds are of secondary importance. We do not agree with you that 'applied behavioural analysis' is an incorrect term. In fact 'applied behavioural analysis' and 'applied behaviour analysis' are used interchangeably in the literature. Review of

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							Basically it is very difficult to know where to start. If you are really serious about getting this right you would need to include a Board Certified Behaviour Analyst (www.bacb.com) in the writing team. This would prevent the necessity of the major rewrite that is now going to be necessary. Alternatively you could get a team of BCBAs to rewrite this, as was the case in New Zealand. I attach a couple of papers to indicate the extent of basics that are wrong in this document. Put simply, if this was a student essay, it would be marked a fail and the student would be required to rewrite under the guidance of a professional qualified to guide her/him.	the literature also confirms that the interventions are based on the principles of 'operant conditioning theory'. Therefore, we do not feel that the suggested terminology changes are necessary.
19.	European Association for Behaviour Analysis	1	Full		Ge ner al		No behaviour analysts included within the guidelines development group?	Thank you. Individuals are selected for their expertise and to ensure that the GDG can properly address the scope of the guideline. In this regard, their professional backgrounds are of secondary importance.
20.	Sussex Partnership NHS Foundation Trust	1	Full		Ge ner al		We are extremely impressed by the hard work of the committee in putting together this document and covering so much evidence	Thank you for your comments.
21.	Sheffield Asperger Syndrome Service	1	Full		Ge ner al		The document does not covey the complexity of the disorder and heterogeneity of the disorder and its outcome, particularly the fluctuations in response to life experience and environment and the notion of significant improvement or "losing the diagnosis".	Thank you for your comment. The guideline has been amended to stress the breadth of the spectrum and mentions that symptoms can change over time (in both directions) and at times of stress.
22.	Sheffield Asperger Syndrome Service	2	Full		Ge ner al		The impact of the disorder on the presentation and management of co-morbid psychiatric condition is not sufficiently addressed. Reliance on NICE guidance on the management of such conditions could be unsatisfactory.	Thank you for your comment. Where there was sufficient evidence on autism-specific modifications to the treatment of coexisting conditions this was used to inform the recommendations, for instance, see section 7.5.3 in then full guideline on CBT for treating coexisting OCD in autism and recommendation 7.5.7.3 and see section 8.9.3 and recommendation 8.9.7.1 on the use of stimulants for treating coexisting hyperactivity in autism

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23.	Sheffield Asperger Syndrome Service	3	Full		General		The guidance gives the impression that people with the disorder could always manage their behaviour if they are offered an intervention, while changing the environment or educating other might be more crucial.	Thank you for your comment. We agree that modifications to the environment can be a crucial element in the management and treatment of adults with autism. Please see recommendations 1.7.1-1.7.5 in the full guideline, where a detailed functional analysis of behaviour is recommended, including assessment and modification of the environment where it is found to trigger or maintain challenging behaviour.
24.	Sheffield Asperger Syndrome Service	4	Full		General		There is very limited mention of forensic aspects or people in secure care.	Thank you for your comments, this guideline has not reviewed the evidence for prison populations, although the recommendations may be relevant to those working within prison/forensic services, and is unfortunately outside the scope of this guideline.
25.	Sheffield Asperger Syndrome Service	5	Full		General		Women with the disorder are considered as “special group”, while they are about half of the population.	Thank you for your comment. We agree that women should not be considered as a ‘special group’. However, we wanted to retain the emphasis that women might have specific needs with regards to accessing services, given the suggestion in the literature that women may be under-diagnosed. Therefore, the title of section 5.3.9 in the full guideline has been amended from ‘Case identification in *special* populations’ to ‘Case identification in populations *with specific needs’* and the wording in recommendation 1.9.3 in the full guideline has been amended with ‘The autism strategy group should develop local care pathways that promote access to services for all adults with autism, including *for people from certain groups such as…women’* replaced by ‘The autism strategy group should develop local care pathways that promote access to services for all adults with autism, including *the following…women’*
26.	Sheffield Asperger Syndrome Service	6	Full		Gener		No clear reference to cognitive problems of people with ASD, which are occasionally the reason for presenting to services	Thank you for your comment. We have revised the text in the introductory chapter to

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					al		and the focus of management plans e.g. Dysexecutive syndrome.	make reference to the wide range of comorbid reasons for presentation.
27.	Sheffield Asperger Syndrome Service	10	Full		General		The Care Pathway is not included. This needs to take account of many of the previous points (complexity, heterogeneity, IQ, impact on presentation and management of co-morbid conditions, interaction of the disorder with the environment and life circumstances, forensic issues…etc).	Thank you for your comment. The NICE care pathway is under development and will integrate adult and child guidelines – it is published on the NICE website as a separate document.
28.	Sheffield Asperger Syndrome Service	11	Full		General		While the document talks about follow up and support, it does not specifically mention "post-diagnostic support" sessions. The Children guidance recommend one session. Diagnosis in adults is considered a life changing event, and the implications for adults are enormous (employment, education, relationships, parenthood…etc). We routinely offer 3 sessions, other services offer 4-6 sessions.	Thank you for your comment. We have included an additional recommendation in light of your comment
29.	Sheffield Asperger Syndrome Service	13	Full		General		Greater recognition of the following issue is required: too many high-functioning adults who are extremely intelligent and who have huge potential struggle to find and keep employment matching their level of ability (e.g. an individual with a 1st Class Hons degree working filling shelves in a supermarket for years). For some employment support agencies, the person described in the previous hypothetical example would not meet their inclusion criteria for support because they are deemed as 'in employment', regardless of how unsuitable.	Thank you for your comment, we agree this is a significant issue and have made specific recommendations about employment.
30.	Sheffield Asperger Syndrome Service	19	FULL		General		We are increasingly seeing deterioration in mental health among adults struggling to cope with the process involved in accessing financial support and benefits. There does not seem to be enough recognition and consistency in the assessment of high-functioning adults and there is a lack of clear support for adults struggling with the system. This is a significant and growing issue which should be recognised in the NICE guidelines.	Thank you for your comment, please see the recommendations on assessment in which this issue is addressed.
31.	Sheffield Asperger Syndrome Service	20	FULL		General		There needs to be greater acknowledgment of the fact ASCs are pervasive and lifelong and that for many "time-limited" support, as typically offered by CMHTs, is insufficient. Instead there should be greater emphasis on low-level, proactive/preventative interventions which are ongoing or can be accessed when required. This would frequently prevent crises from developing which have numerous financial implications for families, employers, individuals and the NHS.	Thank you for your comment. We have revised the introduction in light of your comment We have mentioned in several places that autism is lifelong and that care pathways need to allow the person to come in and out of them to access services when they need them. We will stress the need that the care pathway is not just there for crisis

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								management but for crisis prevention. Unfortunately the evidence for the prevention of problems in autism is very limited and therefore limits the recommendations we can make in this area.
32.	Sheffield Asperger Syndrome Service	2 1	FULL		Ge ner al		There needs to be greater recognition of the way in which sensory needs can massively impact the everyday life of adults with ASCs – there is no mention of appropriate interventions or disciplines which can help with this e.g. sensory integration and OT input.	Thank you for your comment. The GDG feel that, within the limitations of the available evidence that we have addressed this issue – for example in the recommendations about assessment, delivery of the interventions and the physical environment.
33.	Sheffield Asperger Syndrome Service	2 2	FULL		Ge ner al		There should be mention somewhere of the importance of considering specific ASC traits when assessing risk (e.g. self-harm, suicide) in adults on the Autistic Spectrum: e.g. 'black and white thinking', 'attention to detail', difficulties communicating intentions/thoughts/feelings. The way in which risk is assessed should be adapted, as well as the way in which it is managed.	This is an important point. We have revised the introduction to will mention that black and white thinking ("If life is not working, then I may as well end it") and empathy difficulties ("My family will be better off without me") can be a risk for suicide. Thank you for raising this.
34.	Berkshire Autistic Society	1	FULL		Ge ner al		'We support the NICE guidance. In particular, the focus on working WITH the person with autism and/or their family and support the General Principles of Care as proposed.'	Thank you for your comments.
35.	NCCMH Expert Reviewer	1	Full		gen eral		I think this guideline is an impressive piece of work. In completing it, I have no doubt that Guideline Development Group (GDG) have moved the agenda as regards ASD in adults onto a significantly more informed level which will help clinicians, families and adults with autism in a fundamental way. As Chair of the SIGN guideline in ASD for children and young people (SIGN 98) I know how much team effort is required to achieve work of this standard and I therefore offer you my congratulations and thanks for the hard work that you have put in. I will now contribute some specific and more focussed general comments that hopefully will be of interest to the GDG.	Thank you very much for your comments.
36.	NCCMH Expert Reviewer	2	Full		gen eral		I think chapter 2 is a very well written piece of work. It provides an elegant summary of complex issues that is easy to understand.	Thank you.
37.	NCCMH Expert Reviewer	3	Full		gen eral		In SIGN 98 we were concerned about the issue of how ASD was diagnosed (and how the assessment process was explained) in terms of the subjects recruited for research	Thank you for your comment. The diagnostic criteria according to which participants in intervention studies were diagnosed are

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							studies. In short, how confident could we be that subjects the researchers claimed had autism actually did have autism? The SIGN 98 GDG therefore developed a sliding scale of criteria for assessing the reporting of the diagnosis of ASD in the literature (see Annex 1; SIGN 98; page 45). Having read through the whole of this draft guideline for adults, I have looked for information to explain that the GDG considered this important issue. I couldn't find any, but it may be that I have missed this. Could you comment on this please?	recorded in the study characteristics tables in Appendix 14. Most participants were diagnosed according to DSM/ICD criteria and where this was not the case, the GDG considered the diagnostic procedure and were satisfied with the assessment process.
38.	NCCMH Expert Reviewer	7	Full		gen eral		The chapter on assessment and diagnosis of autism in adults will provide an important steer for services. I wonder if you could make it clearer which assessment instruments are used for what purpose? In SIGN 98, in Chapter 3 (page 10 onwards) we explained the sequential components of assessment: history taking; clinical observation/assessment; contextual and functional information. We considered the specific instruments for the first 2 of these sections. It seems to be important, for example, to explain clearly that ADOS is an instrument for clinical observation only and that DISCO or ADI-R are instruments for history taking. The draft NICE adult guideline does provide this information in the text, but I would prefer it to be more obvious, as I think it is a simple but important concept for people to grasp. In addition, the fact that the GDG has not found sufficient evidence to support the use of DISCO, 3di, ADI-R and other history taking instruments is very significant for clinicians, many of whom may be concerned about this. I think the GDG should consider offering advice as to what components of an autism specific developmental history should be obtained by the clinician, to bolster clinical practice in history taking. I also think the GDG should consider what the adult equivalent of contextual and functional information in clinical assessment should be. For example, what is the adult equivalent of a school observation or a school report? As a clinician regularly assessing children and young people for the possibility of ASD, I know how valuable, even crucial this third aspect of assessment can be. It would be very helpful if the GDG could come up with 'expert opinion' advice on this, if there is no	Thank you for your comment. In light of your observations, and other comments, we have amended the recommendations to provide greater clarity. The assessment and diagnosis recommendation is now split into two separate recommendations. The first recommendation concerns using a formal assessment tool to aid more complex diagnosis and assessment for adults with possible autism. This recommendation includes using the assessment instruments for which we have sensitivity, specificity and psychometric data as an aid to diagnosis (see recommendation 1.2.8 in the NICE guideline). The second recommendation concerns using assessment tools to help to structure a more complex assessment for adults with possible autism but for which we have no diagnostic accuracy data, such as the DISCO (see recommendation 1.2.8 in the NICE guideline).

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							evidence for it.	
39.	AUTISM ALLIANCE UK	1	Full		gen eral		Our major comment on the generally excellent NICE draft guideline is the lack of inclusion of expert providers in the two major groups set out in the guideline: the local multi-agency strategy group and the specialist community-based multidisciplinary autism team. We do not see how these groups can work effectively without including specialist providers. Without labouring the point too far, the generally very strong draft guideline is self-evidently weakest in Section 6: Principles and practice for the effective organisation and delivery of care. This is partly because of the acknowledged lack of outcome-based evidence, but partly, we would suggest, because of the low representation of specialist providers in the guideline development group. The draft guideline states on two occasions that the group contains “a representative from a service organisation”. That is not in any sense to criticise the representative or the service organisation, but it does indicate a less than comprehensive understanding of the practical aspects of specialist care. Section 6 acknowledges the weak evidence base from settings of care for adults with autism. The decision was taken to extrapolate from (again quite limited) data from settings for adults with intellectual disabilities. This approach is, of course, fraught with danger: people with autism, by definition, are not neurotypical, and data from non-specialist autism settings may have little relevance and may be misleading. The dangers manifest themselves strongly on page 166, in section 6.5.8 at lines 21-23. The evidence, as noted, is exclusively based on populations with intellectual disabilities, rather than on people with autism. The comment is then made that “it should be noted that a significant proportion, if not the majority, of individuals with autism who live in residential accommodation will have intellectual disabilities”. The logic here has self-evidently gone seriously wrong: • many people with autism in residential accommodation do not have intellectual difficulties • even if, as stated, the majority of people with autism in residential accommodation have intellectual difficulties, the	Thank you for your comments. The GDG are content with the membership of these groups. At a local level additional staff from a range of organisation may be appointed in addition to the core group we recommend, but this is more appropriate as a local decision and not one for the GDG.

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							converse does not apply: i.e. it is not the case that the majority of people with intellectual difficulties in residential accommodation have autism, and it is therefore misleading to extrapolate from a larger population to the much more specific autism population • the primary purpose of the Guideline is, we suggest, to concentrate on autism and on what works for people with autism. In this section, the decision has been taken to use a flawed proxy for autism (intellectual disability) as a basis for recommendation. This is logically and in practical terms a serious error. The approach should be based on outcomes for people with autism, some but not all of whom will have intellectual difficulties, rather than on outcomes for people with intellectual difficulties, some of whom will have autism. • more specifically, the evidence summary, explicitly and startlingly, does not include evidence from ANY specialist autism service. This makes any recommendations of limited - and perhaps negative - value. We see the recommendations on page 167 [6.5.10 Recommendations] as seriously flawed because they do not recognise the heterogeneous nature of autism. It is not clear from the recommendations that a residential environment as described goes far enough in enabling and developing the skills of the person with autism. We also question the unevidenced preference for small community-based units. Our experience is that the key factor in successful outcomes is skilled staff in a caring environment. It is possible to have a caring environment with good outcomes in services caring for 20 residents. Conversely, it is possible to have very bad outcomes in services caring for four or five residents. Size is one factor, but is not a conclusive factor. We would recommend a complete review of these recommendations and would be happy to give more detailed views in any revision process. Another major concern is the assumption that the Care Quality	The guideline states that there was *a representative from a service user organisation* and not a service provider organisation. In extrapolating from different populations other than those with autism we took care to ensure that the extrapolation was valid (see chapter 3 for further explanation of methods). We accept that not all people in residential care have learning disabilities but a significant proportion do (see for example the review by Emerson and Baines S. Learning Disabilities Observatory, 2011). Please see our previous response. We have not extrapolated from data on learning disability populations to determine all our recommendations. The intention is to inform GDG decision-making. The extrapolated evidence – where used - serves to inform, but did not determine the recommendations.

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							Commission (CQC) will monitor the effective implementation of the guideline. CQC has a vast and multi-faceted remit, and therefore it is not a criticism to state, as is the case, that CQC has not demonstrated significant knowledge or capability in the field of autism; and nor is it, at least at present, able to demonstrate expertise in reviewing organisational structures or the implementation of complex proposals across different agencies. The proposal to add the review of the guideline to CQC's already massive remit would take it into areas which are beyond its capability. We would therefore recommend the National Audit Office (NAO) as a better choice of monitor. The NAO has the intellectual grasp and the ability to see both the wood and the trees to carry out this task, and has also demonstrated substantial knowledge and understanding of autism. The NAO will presumably wish, in any event, to review the way in which the guideline is being implemented, and therefore work done by CQC might duplicate work by NAO at unnecessary cost to public funds. Our final concern relates to the practice – unfortunately widespread – of so-called "Fund-dodging". This practice involves moving people with autism from one publicly funded budget to another publicly funded budget. A typical example would be moving someone with autism from an adult social care budget to a mental health budget. There may be no benefit to public funds (and there may well be a detriment). There may be no benefit to the person with autism (and there may well be a detriment). We think it of prime importance that budgets should be pooled. Unless budgets are pooled, these practices are likely to continue for the short-term advantage of individual budgets, rather than concentrating on the welfare of the person with autism and on the overall cost to public funds. Our main additional recommendation is that research needs to be carried out on outcomes for people with autism. This is difficult to structure, because of the varying nature of autism and the highly variable needs of the different client groups within the spectrum. Nonetheless, it should be possible to identify cohorts and conduct longitudinal studies identifying progress, or lack of progress, in increases/decreases in	Please see our previous comment and do note the GDG included members with considerable experience of working with residential services. We accept that good outcomes may be obtained in large units but the GDG took the view that it was more likely to be the case that good outcomes would be obtained in smaller units. The GDG noted that there was no evidence to support the provision of larger units specifically for people with autism and in their expert opinion smaller units were to be preferred. We have revised the evidence to recommendations section to more fully reflect these issues. The CQC has a formal role in the monitoring of all care settings – it is not within the remit of the guideline to suggest a revision of this role.

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							medication, increases/decreases in episodes of challenging behaviour; and the extent to which adults who have previously been sectioned are able to live outside secure accommodation or are sectioned again. These are (in one sense) elementary numerical measures. However, they should be guides to the efficacy of practice in different care/support environments. In other words, they will help to show what works.	Thank you, but this issue if outside the scope of the guideline. Thank you, we will consider this comment when developing our research recommendations but what you set out is a broad strategy for research and does not fit with a specific research recommendation. All of our research recommendations have been explicit about the focus on outcomes.
40.	Autism West Midlands	1	Full		gen eral		Autism West Midlands welcomes the NICE Guideline and the opportunity it provides to reinforce the Autism Act 2009, the subsequent Autism Strategy and the Statutory Guidance. Autism West Midlands is a member of the Autism Alliance UK: this is the largest grouping of specialist autism charities in the UK. We have read the Alliance response to this consultation and were closely engaged in its drafting. We endorse the whole of the Alliance response. Rather than repeat the Alliance response here, our own response concentrates on issues at a more detailed level. We also, in preparing this response, held a lengthy workshop session with adults with autism, at which the main points from	Thank you very much for your comments.

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							the shorter NICE version were discussed – together and in separate groups. The comments from this Autism Consultation Work Group (referred to in this response as ACWG) inform this response.	
41.	Autism West Midlands	2	Full		gen eral		The relationship between Implementing fulfilling and rewarding lives and the NICE FULL Version Implementing fulfilling and rewarding lives directly refers to the NICE clinical guideline (DH, 2010: 14; 16). We recommend that the NICE FULL Version has a section on how the NICE guideline should be used in conjunction with the Statutory Guidance in order to 'diminish unacceptable variations in the provision and quality of care'. Discussion of the interaction between these two documents would help to reinforce their effective implementation.	Thank you for your comment. This is an implementation issue which is outside the scope of the guideline - the NICE guideline and the DH guideline are intentionally independent of each other.
42.	Autism West Midlands	3	Full		gen eral		Additional point which should be covered by the guideline: community care assessments We recommend that the guideline should include advice about making adjustments to community care assessments under the Department of Health's Guidance - Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care (2010). Community care assessments are an important interface between health and social care services; and adults with autism often experience a significant barrier to accessing the services they need because the assessments do not take account of their autism. Implementing fulfilling and rewarding lives (DH, 2010) goes some way towards improving the likelihood of a more effective assessment, because of its stipulation that people carrying out these assessments should have specialist training. Nonetheless, it would be hugely beneficial for NICE to include in the guideline some guiding principles on conducting community care assessments of adults with autism. Adults with autism often experience high levels of anxiety and stress which mean that the more anxious the individual with autism, the 'less likely they [are] able to cope' with 'change, anticipation, sensory stimuli and unpleasant events' (Gillett et al, 2007). Advice on how to ensure that these assessments reflect the variable and fluctuating nature of autism would therefore be highly valuable.	Thank you for your comment and for raising this important issue. Unfortunately to make recommendations in this area is outside the scope of the guideline, but we do think our general recommendations regarding assessment will be of value in addressing the concerns your raise.

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							Individuals on the spectrum often present as 'normal' during assessments, with their answers to assessment questions indicating that they are coping. However, this is largely due to the tendency towards literal interpretation by individuals on the spectrum (Happe, 1993). Guiding principles on conducting community care assessments should recommend how the assessor can elicit answers which capture the actual needs of the person with autism.	
43.	Autism West Midlands	4	Full		gen eral		Additional point which should be covered by the guideline: Individuals on the autistic spectrum often need specialist advice and guidance in relation to sexual health. People with autism are often unable to understand euphemisms, do not automatically pick up on the social norms surrounding sexual etiquette and may not comprehend the inappropriateness of displaying sexual behaviour in public (see Hatton and Tector, 2010). Many individuals on the spectrum have, quite unnecessarily, ended up in the criminal justice system because these issues have not been dealt with properly (Allen et al, 2007). As a result of the problems individuals with autism have with social imagination and social communication (Wing 1981) they are frequently unable to predict other people's behaviour and intentions; this can make them extremely vulnerable to sexual attack (Allen et al, ibid). Adults with autism therefore need specialist advice within mainstream services: merely providing access to mainstream services is not enough. Furthermore, professionals who are supporting these individuals in developing their relationships and maintaining their sexual health, need specialist autism knowledge. One example of good practice is the specialist service provided at the Moseley Day Centre in Birmingham. Our residential services have found this service extremely useful in supporting service users and we would recommend that this service is used as an example of good practice. The Centre runs a 12 week Personal Development Programme dealing with social and personal relationships, friendship and intimate sexual relationships, in 12 half day sessions, primarily for people with learning disabilities. Although skills training in sex education is briefly mentioned in the NICE FULL Version (NICE, 2011a: 157, line 1), we believe	Thank you for your comment. We have added a recommendation regarding sexuality.

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							that this area could be more comprehensively covered in the guideline.	
44.	Autism West Midlands	5	Full		gen eral		Additional point which should be covered by the guideline: interventions on section orders and the interface between forensic and mental health placements and aftercare in the community Appendices 1-13 cover healthcare settings which include prisons and forensic services (see NICE, 2011c: 6, section 4.2) but the NICE FULL Version makes no mention of the management of adults with autism who have been sectioned under Section 1, 2, 3 or 37 of the Mental Health Act 1983. Nor does the NICE FULL Version make any recommendations about the discharge of adults with autism from sectioning orders under Section 117 of the 1983 Act and their subsequent aftercare. As the NICE FULL Version itself recognises, some interventions such as Cognitive Behavioural Therapy used on a sectioning order may be inappropriate or may need to be adapted for adults with autism (NICE, 2011b: 188; see Howlin, 2010; (Anderson & Morris, 2006). We suggest that recommendations about the management of adults with autism on sectioning orders should be included in the final draft of the NICE guideline. Adults with autism may experience delayed discharge from hospital and inadequate aftercare provision as a result of their complex needs and the failure of local authority social services departments to assess patients leaving hospital with ongoing community care needs and provide appropriate care packages (see Lewis and Glasby, 2006). As a result, careful multidisciplinary working is vital to ensure individuals get the right support as they move from one system to another. This will help to prevent crisis and promote successful enablement of service users. We recommend that the final draft of the NICE FULL Version provides more specific guidance about the interface between forensic /mental health ward placements and appropriate aftercare on discharge under Section 117 of the Mental Health Act 1983.	Thank you for your comment, we agree that this is an important issue but it is generally outside of the guideline scope to comment. The issues to which you refer are in significant part covered by relevant aspects of the Mental Health Act and in particular its implementation. A number of the issues you raise are addressed in Mental Health Act and in the Code of Practice. We carefully considered your comments about the interface between forensic and mental health ward placements but did not think it appropriate to comment on this in the guideline as we had no evidence that related directly to this issue. The Lewis and Glassy study makes only a very brief single reference to autism and as such does not provide significant evidence on the care of people with autism.

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45.	South London and Maudsley NHS Trust	2 4	Full		Ge ner al		This is a great set of evidence based reviews. However, I am really concerned about the advice with respect to diagnostic procedure (see above) and some aspects of the diagnostic/care pathway (see above), which I think will disadvantage people with autism.	Thank you for your comment, we have revised the recommendations in light of your and others' comments.
46.	Northumberland, Tyne & Wear NHS Trust		Full		gen eral		Massage therapy - was the study by Silva et al included in the review? Silva, L. M. T., Schalock, M. & Gabrielsen, K. (2011) Early Intervention for Autism With a Parent-Delivered Qigong Massage Program: A Randomized Controlled Trial. American Journal of Occupational Therapy, 65, 550-559.	Thank you for your comment. However, the Silva et al. (2011) study was not included as the mean age of participants was under 18 years of age.
47.	Northumberland, Tyne & Wear NHS Trust		Full		gen eral		The comprehensive nature of the a priori search protocols for qualitative and quantitative research appears reassuring.	Thank you for your comments.
48.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full		gen eral		Guidance for adults with Autism Spectrum Disorder is welcome. The Welsh Government launched its Strategic Action Plan for Wales in 2008; amongst the recommendations of a subsequent task and finish group for addressing the needs of adults was the establishment of a national clinical network for assessment and diagnosis together with pre and post-assessment counselling. This network was set up in 2011 and is hosted by Betsi Cadwaladr University Health Board. The Network has been involved in developing and implementing a standards-based assessment pathway in all the Welsh Health Boards through the education and training of relevant clinicians, the development of teams of local expertise and the support of experts at a national level. Though the NICE guidelines are applicable to England and Wales, There is no reference in the guidance to these Welsh developments nor obvious Welsh perspective/involvement in the development of the guidance. There needs to be more acknowledgement that there are distinct needs for the different clients groups – those with and without a learning disability have significantly different pressures re housing, employment interests and difficulties accessing benefits. Interventions and support needs to recognise the support required for those with more classical autism, and those with a higher IQ.	Thank you for your comments. Please accept our apologies for omitting mention of the Welsh Strategy Action Plan. We have revised the introduction in order to take account of your comments. Thank you for your comments. The recommendations have been amended to make the differences between these groups more distinct.

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							Will there be a version accessible for clients with a learning disability?	
49.	British Dietetic Association		Full		gen eral		The role of dietitians is barely mentioned in this document. Many of the following statements attempt to address this. Dietitians in Autism are a national group of dietitians whose work includes or affects children and adults on the autistic spectrum. Their roles are often multi-facetted to include clinical nutrition assessment and advice, behavioural management of eating and feeding problems, training of other staff, advising on food provision in institutions, and research. Individuals with ASD have many different dietary issues for which they or their carers seek help from dietitians – over or underweight (sometimes related to medications), nutrient deficiencies, allergies, a general imbalanced diet, diet-related constipation, diarrhoea or irritable bowel syndrome, food fads or phobias, and trial of dietary interventions that may improve problematic behaviours. Dietetic input is incredibly cost effective - reducing or eliminating the need for medications in the management of constipation and other gut problems, preventing medical problems that can result in increased need for medical care for example in weight management, malnutrition and allergies, and improvements in nutrition that can promote an individual's learning and development and so reduce their need for support in the future. For effective and joined up working dietitians should have access to the full training and support of being an integral part of multidisciplinary teams involved in providing services to adults on the autistic spectrum. It is known that specialist services have been set up with absolutely no dietetic service attached. Non-specialist dietetic departments don't always have the capacity or expertise to provide effective support. It is the experience of the writer that dietetic input to individuals with ASD is being reduced in different areas of the country, and specialist dietitians are being	Thank you for your comments. Our primary concern in the guideline was with the care and treatment of autism and dietary interventions targeting core autism symptoms – we have made recommendations in this area. We have however amended a recommendation to draw attention to the importance of broader dietary issues. Thank you, we think this level of planning will be for commissioning groups to determine when considering implementation of the guideline.

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							reassigned to other specialities**. We strongly stress the importance of highlighting the inclusion of specialist dietitians in service planning and provision in this document to prevent inequity of care, and the undermining and deskilling of the profession in this important area.**	
50.	Royal College of Nursing	1 2	Full		gen eral		Existing conditions are often over looked. Often managing the autism is not necessarily the problem for families but having to deal with the co-morbidities is where they need most support.	Thank you for your comment. Where there was sufficient evidence on autism-specific modifications to the treatment of coexisting conditions this was used to inform the recommendations, for instance, see section 7.5.3 in the full guideline on CBT for treating coexisting OCD in autism and recommendation 7.5.7.3 and see section 8.9.3 and recommendation 8.9.7.1 on the use of stimulants for treating coexisting hyperactivity in autism
51.	Association Directors of Adult Social Services	1 5	FULL		Ge ner al		The guidance could be presented in different versions to support the application and practice with a reduced research trails focus and epidemiology, particularly where the recommendations are not a significant direct outcome of the text of the research.. Dependant on its use it could be perceived as repetitive and too lengthy as guidance or a reference document.	Thank you for your comments. The full guideline documents how each recommendation was made by presenting all the evidence reviewed and showing how decisions were made during the development process. The NICE guideline should be used by clinicians as a reference document in practice. Once published there will also be a document for service users and carers called ‘Understanding NICE guidance’, as well as an electronic pathway which displays the recommendations on the NICE website.
52.	The Royal College of Psychiatrists, Learning Disability Faculty	1 0	Full		Ge ner al		In general the guideline is extremely welcome. It is clear, comprehensive and based on the available evidence.	Thank you for your comments.
53.	The Royal College of Psychiatrists, Learning Disability Faculty	1 1	Full		Ge ner al		Throughout the guidance there is a most welcome emphasis on consideration being given to sensory difficulties (both hypo- and hypersensitivities) in all aspects of assessment and support. There is also a focus on necessary environmental adaptations being made. This emphasis has been conspicuous by its absence in some key past guidance and legislation, and the fact that the importance of sensory issues is highlighted here is very encouraging.	Thank you for your comments.

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54.	The Royal College of Psychiatrists, Learning Disability Faculty	12	Full		General		It is slightly disappointing that given the unique nature of this client group, the working group was not able to adopt a more flexible approach to the use and status of evidence. Autism is a field where much useful evidence is anecdotal, due to ethical and other difficulties in carrying out clinical trials. Also, there is a wealth of good clinical information in books rather than journals/published studies, and especially in first-person accounts of the experience of having autism. These sources of evidence may have been under-utilised. Many clinicians will find it particularly mystifying that the group were unable to recommend some commonly used interventions, including SSRI's to reduce autistic anxiety, and Melatonin for sleep. The lack of RCT's does not dissuade practitioners from using safe interventions that they know to be effective from clinical experience. There is also very good anecdotal evidence that dietary interventions may help a small subset of individuals with autism, and blanket statements that interventions should not be used may lead to interventions that have already proved to be useful being withdrawn for some clients.	Thank you for your comment. NICE guidelines consider evidence according to an established hierarchy of study types and well-conducted randomised controlled trials (RCTs) are at the top of this hierarchy. This is because RCTs provide the greatest degree of certainty that can be attributed to the conclusions drawn from the study. Personal accounts published in peer-reviewed journals were considered for experience of care but not for intervention efficacy reviews due to the high risk of bias inherent in such study types. Given that there was only one trial of moderate quality for the use of SSRIs in targeting core symptoms in adults with autism the GDG concluded that further research examining the efficacy and safety of fluvoxamine and other potent and selective serotonin uptake inhibitors was necessary in order to provide evidence for clinically important treatment effects. No recommendation could be made with regards to melatonin due to the lack of evidence for melatonin in people with autism and sleep related problems. Finally, there was insufficient evidence to recommend the use of diets to treat core symptoms in autism given that the evidence considered was of low quality and indirect.
55.	The Royal College of Psychiatrists, Learning Disability Faculty	13	Full		General		The 50 page NICE document is an accurate summary of the main document, and is the right size to be user-friendly and widely read.	Thank you for your comments, NICE will also publish an 'Understanding NICE guidance' document aimed at service users, and their families and carers.
56.	The Royal College of Psychiatrists, Learning Disability	14	Full		General		Overall the guidance was welcomed particularly as it goes beyond diagnosis to give guidance on the provision and delivery of care.	Thank you for your comments.

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	Faculty							
57.	The Royal College of Psychiatrists, Learning Disability Faculty	8 5	FULL		Ge ner al		Massage therapy - was the study by Silva et al included in the review? **Silva, L. M. T., Schalock, M. & Gabrielsen, K. (2011)** Early Intervention for Autism With a Parent-Delivered Qigong Massage Program: A Randomized Controlled Trial. *American Journal of Occupational Therapy*, **65**, 550-559.	Thank you for your comment. However, the Silva et al. (2011) study was not included as the mean age of participants was under 18 years of age.
58.	Autism Cymru	1	Full		Ge ner al		Autism Cymru endorses the responses given by the Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network, and the Welsh Government; especially in relation to the progress that has been made in Wales with the development of the All-Wales diagnostic and pre and post diagnosis counselling network and also the general and specific impact made by the ASD Strategic Action Plan for Wales since 2008. The critical need to establish a clear knowledge of ASD within MH services is emphasised. In policy terms the Welsh context is very different to England. We therefore ask you to withdraw the falsehood implicit in the Guidelines that the autism act adults (2009) and the autism strategy for adults (2010) apply beyond England to Wales. Indeed we would ask you refer to the Welsh policy context in the final Guidelines. We also draw attention to the response from the Autism Alliance UK which emphasises the social context in which services to adults with autism should be planned and delivered from the point of diagnosis; and this should include the active engagement and participation with specialist providers during these critical and formative periods.	Thank you for your comments. We have amended the introduction in light of your comments. We have included an additional recommendation regarding post diagnostic discussion.
59.	The College of Social Work	1	Full		Ge ner al		What evidence is there for the widespread adoption of Multi-agency Specialist Autism Teams and how will they be funded?	Thank you, the recommendation for the autism team was based on a number of factors – the NAO report and assessment of the potential cost-effectiveness' of such teams, and the expert opinion of the GDG that a number of the recommendations, for example the assessment recommendations would be best provided in the context of a specialist team. Funding arrangements are an implementation issue for the NHS and related services to

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								determine.
60.	The College of Social Work	2	Full		General		What safeguards would be put in place to avoid a specialist team only being approached for the most complex/ high risk cases, including those in crisis? Some adults with autism may only require low level support to have an improved quality of life, avoid greater service dependence or crisis. Preventative work within statutory, voluntary and community groups and 'mainstream' public services needs to continue – Social Workers as a professional group are very well place to be involved in this. Best practice examples of preventative work should be shared.	Thank you for your comment. It is not specified by the guideline that interventions are delivered by clinicians, but rather health or social care professionals. Chapter 5 makes recommendations that assessment should be individualised and ensure the level of interventions is tailored to each person.
61.	The College of Social Work	3	Full		General		Specialist adult social work skills and knowledge [e.g. in autism] need to be valued and maintained whilst recognising that they must not become too 'isolated' or rarefied. Opportunities to forge links and build capacity for the future should be encouraged e.g. providing autism related social work placements or acting as an advisor/ speaker for social work degree courses.	Thank you for your comments. We agree this is an important issue.
62.	The College of Social Work	4	Full		General		Participation in different levels of autism training/ education, as a learner or as an educator, could provide a good example of professional development in the Professional Capabilities Framework.	Thank you for your comments. We agree this is an important issue.
63.	The College of Social Work	5	Full		General		A lone social worker in a predominately health based multi-agency team could feel isolated. There may also be limited opportunities to informally share learning and build capacity and confidence with other social workers. The College's mentoring scheme and the possible development of an autism-focussed Community of Practice could assist with this.	Thank you for your comments. We agree this is an important implementation issue.
64.	ADRC	1	Full		General		ADRC welcomes the NICE guidelines as a positive step forward for people with autism who, to date, have not had access to a service designed specifically to meet their needs.	Thank you for your comments.
65.	ADRC	2	Full		General		The guidelines should specify which criteria (ICD-10, DSM-IV) should be used to make a formal diagnosis. This is vital for validity, consistency and replication.	Thank you for your comment. We have amended the introduction to stress that ICD-10 are the current European/UK criteria.
66.	ADRC	3	Full		General		ADRC welcomes the recognition that people with autism may have hypo- and/or hyper-sensitivity and that these need to be assessed, documented and taken into consideration.	Thank you for your comments.
67.	ADRC	4	Full		General		ADRC has some concern regarding the words 'care' and 'treatment'. Many people with autism do not need 'care' but 'habilitation' (referred to in Asperger's original work). Although	Thank you for your comments. We did consider this issue but in the interest of consistency, and to facilitate general

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							coexisting conditions may be amenable to treatment there is no 'treatment' for autism.	understanding in the world of health and social care we decided to stay with the existing terminology, but we have tended to favour the use of interventions over care and treatment in the revised guideline.
68.	ADRC	5	Full		Ge ner al		Throughout the guidelines there does seem to be more emphasis on people with autism and an intellectual disability. About 50% of people with autism do not have an intellectual disability (i.e. IQ<70) [*Supporting people with autism through adulthood*. NAO,2009]	Thank you for your comments. This is in part correct but reflects the greater need for care and intervention of this group but the recommendations apply to all people with autism.
69.	ADRC	6	Full		Ge ner al		It is important to recognise that coexisting mental disorders may be transient, and are often a consequence of the social isolation experienced by people with autism. Mental health problems therefore need to be treated in the context of the primary diagnosis of autism.	Thank you for your comments. We agree that this may be the case and we believe this is reflected in our recommendations for assessment and treatment in this area.
70.	ADRC	1 3	Full		Ge ner al		Although not diagnostic, formal, standardised measures of social perception, executive functioning and speed of processing can be extremely useful, especially when making recommendations for habilitation.	Thank you for your comments. We could find no strong evidence to support recommendations to use these measures. It will be for individual professionals to determine if there is a use for such measures.
71.	Welsh Government		Full		gen eral		Guidance for adults with Autism Spectrum Disorder is welcome. The Welsh Government launched its Strategic Action Plan for Wales in 2008; amongst the recommendations of a subsequent task and finish group for addressing the needs of adults was the establishment of a national clinical network for assessment and diagnosis together with pre and post-assessment counselling. This network was set up in 2011 and is hosted by Betsi Cadwaladr University Health Board. The Network has been involved in developing and implementing a standards-based assessment pathway in all the Welsh Health Boards through the education and training of relevant clinicians, the development of teams of local expertise and the support of experts at a national level. Though the NICE guidelines are applicable to England and Wales, There is no reference in the guidance to these Welsh developments nor obvious Welsh perspective/involvement in the development of the guidance. There needs to be more acknowledgement that there are distinct needs for the different clients groups – those with and	Thank you for your comments. Please accept our apologies for omitting mention of the Welsh Strategy Action Plan. We have revised the introduction in order to take account of your comments.

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							without a learning disability have significantly different pressures re housing, employment interests and difficulties accessing benefits. Interventions and support needs to recognise the support required for those with more classical autism, and those with a higher IQ. Will there be a version accessible for clients with a learning disability?	Thank you for your comments. The recommendations have been amended to make the differences between these groups more distinct.
72.	London Borough of Tower Hamlets	2	Full		General		Identification and diagnostic assessment for autism are appropriately given prominence. It appears that all individual psychosocial interventions proposed need more research re efficacy and effectiveness.	Thank you for your comments.
73.	London Borough of Tower Hamlets	3	Full		General		Welcome that individual supported employment programmes appear very important as do interventions for and support to families and carers.	Thank you for your comments.
74.	London Borough of Tower Hamlets	4	Full		General		There could be more emphasis on intimate relationship difficulties (including sexual) experienced by autistic people and the support that is needed. There is no mention of the 's' word anywhere so it seems that there is still a barrier in peoples minds to the notion that autistic people have the same range of needs as non-spectrum people.	Thank you for your comment and for raising this important issue. We have now included a recommendation to address sexuality.
75.	London Borough of Tower Hamlets	5	Full		General		When the guideline refers to 'families and carers' it would be useful to specifically state "including spouses or partners" so that people can begin to recognise these relationships more.	Thank you for your comment. We have now included partners with families and carers.
76.	London Borough of Tower Hamlets	6	Full		General		In general the guideline is extremely welcome. It is clear, comprehensive and based on the available evidence.	Thank you for your comments, they are appreciated.
77.	Brain-in-Hand Ltd	1	Full		General		Brain-in-Hand Ltd welcomes the NICE guidelines as a positive step forward for people with autism many of whom, have not had access to a service designed specifically to meet their needs – especially those who do not have a learning disability.	Thank you for your comments, they are appreciated.
78.	Brain-in-Hand Ltd	6	Full		General		The term "behavioural principles" is used a lot. This term may mean different things to different people. A clear definition would help.	Thank you for your comments. We have now included a glossary.
79.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full		General		Overall these guidelines for adults are very comprehensive and no areas of recognition, referral, diagnosis or management seems to have been neglected.	Thank you for your comments, they are appreciated.
80.	Cochrane		Full		Ge		Good to see acknowledgement of the needs of parents/carers	Thank you for your comments.

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	Collaboration Developmental, Psychosocial and Learning Problems Group				neral		given the long-term burden of care when people are adults and parents themselves are ageing. Recommendations relevant to families are sound based on the limited research evidence to date in Section 8.	
81.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full		General		Good to see recommendation of assessment of adult's level of personal, social, occupational and educational functioning in determining a care plan.	Thank you for your comments.
82.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full		General		The issue of consent to having an assessment undertaken is often problematic for adults (as is the cost of assessment, access etc) but probably beyond the scope of these guidelines.	Thank you for your comments. You are correct, this is beyond the scope of our document, however we have added to the recommendations a need for professionals to be aware of the implications of the Mental Capacity Act.
83.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full		General		How does this adult guidance connect with the CG128 NICE children's guidance 2011? When does adulthood start in this doc? 16. How do adult services actively receive new adolescent referrals etc? Transitions may be much later/fragmented due to developmental delay. Which service will take the lead? Integrated children's services dissolve into disparate hard-to-reach (enhanced eligibility criteria) silo services for adults. Where is the lifespan management approach in this document? Towards independence?	Thank you for your comments. The issue of transition will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents, and the age at which this guideline starts (18yrs).
84.	Ambitious about Autism	1	Full		general		The scope of the guidelines covers 'interface with other services such as...education services' and 'economic aspects'. Whilst education services are mentioned in a couple of places in the draft guideline, we feel the guideline could do much more to ensure people with autism get access to education and training they need to fulfil their ambitions and become active members of their communities. Evidence, such as that collected in our 'Finished at School' campaign report (Ambitious about Autism, 2011) points to the economic benefits of ensuring people with autism are able to continue their education beyond school. Developing independence skills reduces pressure on both health and social care budgets. Developing career prospects also reduces pressure on these (as well as on welfare) budgets. We know the focus of the	Thank you for your comments. We have reviewed this report but unfortunately it does not include any economic evaluation about provision of education services; it concludes that "a well-planned personalised process can improve quality of life as well as being highly cost effective" which is based on case studies. However, we do make a number of recommendations about ensuring individuals' educational needs are met such as recommendations 1.1.11, 1.1.13, 1.2.2 and 1.2.7 (revised recommendation numbers).

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							guidelines is on health professionals, but we believe health services can often be a gateway through which people with autism can access education or other support, and would like to see the guidelines better reflect this role.	
85.	Ambitious about Autism	2	Full		gen eral		The guideline mentions the need to improve transition from childrens to adults services, but we believe it could be more robust on this point. Firstly, it should reference the need for strong links with childrens services and dedicated transition support staff. Secondly it could helpfully recommend the use of data from children's services to help inform strategic planning of services for adults coming through the system.	Thank you for your comments. The issue of transition will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
86.	National Autistic Society	1	Full		Ge ner al	G e n er al	The National Autistic Society (NAS) warmly welcomes the work that NICE and the Guideline Development Group (GDG) have put into making such a comprehensive guideline. This guideline has the potential to substantially improve clinical knowledge, patient experience and the nature of support offered to adults with autism. We are acutely aware of the difficulties faced by the GDG because of the lack of clinical evidence and believe that praise is due for producing such a useful document. The diagnosis and management of autism is a controversial area. Too often individuals with autism are let down by a health service that fails to recognise their autism, a social care system that refuses - or is unable - to offer support to those that need it and a general population who are ill-informed and ill-equipped to make adjustments for individuals with autism and their family/carers. These problems and the fact that not enough research has been done into autism, have led to a number of radical therapies, treatments and even 'cures' being bandied around as the 'answer'. To take just one example[1] of the impact this has, one quote is particularly telling about the need for more information and clinically proven guidelines:	Thank you for your comment. We have set out in our recommendations the principle by which a pathway can be developed - the implementation will be for local services to determine. Separately NICE will also produce an integrated pathway linking all 3 guideline s- we hope this will address your concerns.

[1] As part of the NAS response to this consultation we asked our supporters what their experience has been in getting support.

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							“We didn’t really grasp that autism is a lifelong condition and probably didn’t want to believe it. We wasted time looking for “cures” when there are none. We could have better directed our energies to try to get half decent support for his needs.” **Parent of person with autism** The NAS is committed to ensuring that we improve knowledge of autism, that more research is conducted and that practices change based on this research. Too often we have seen desperate parents, or ill-advised adults, being sold a ‘treatment’ for autism, when what they need is information, advice and advocacy from someone or an organisation that they can trust. This guideline goes some way to addressing many of these questions and creating a point of consensus, so that we can move forward and ensure that adults with autism receive the support they need. Hopefully, this will mean we no longer hear stories like this: *“[My son] gets no autism specific support which is what he has always needed. We bought [My son] a small house to try to help him become independent but he comes to us daily. He has 10 hrs/week carer support - the carers, whilst well intentioned, are not particularly well versed in autism and we are the experts who have to deal with him daily. Support is grudgingly given and always against a background of limited resources. It’s almost as if we have to be made to feel guilty for simply asking for help. We have had to fight every step of the way and we have been exhausted by the process. We are his main support and we are now in our sixties.”* ***Parent of adult with autism*** We therefore fully support the development of the guideline. Nonetheless we do raise a number of points in this response that we believe will make the guideline clearer and more relevant. Our major concerns with the guideline relate to: • The need to place the guideline in the wider context of the adult autism strategy and statutory guidance • Screening and diagnosis tools • The need for greater clarity of some of the recommendations made; and	

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							• A greater emphasis on prevention and post-diagnostic support Before moving on to these concerns, the NAS would strongly recommend that the GDG do all it can to ensure that this guideline – and the shorter NICE version – are as systematic and clear as they can be in outlining what an ideal pathway for diagnosis and support could be. The adult autism strategy[2] states: *"the second strand of our strategy is to develop a clear, consistent pathway for diagnosis of autism across the country. To support this, NICE is developing a clinical guideline which will include diagnostic processes. Our aim is to increase capacity around diagnosis so that in every area of the country people have easier access to diagnosis if they want it"* We strongly support the model advocated in this guideline of having multidisciplinary teams, but sometimes the guideline is not as clear as we would have hoped about the whole pathway. Setting out examples of existing pathways could help in this regard.	
87.	National Autistic Society	2	Full		General	General	As the guideline states, adults with autism have for too long been overlooked in terms of identification and support services. This persistent failure was a key driver for the passing of the Autism Act (2009). This historic piece of legislation, and the subsequent strategy[3] and statutory[4] guidance, has been a major force in ensuring that local authorities and the NHS in England support adults with autism better. Because of this, local authorities and the NHS have to do numerous things, including: • Appoint a senior manager/commissioner to be an autism	Thank you for your comment. We understand your arguments for a closer integration of the guideline and the strategy but this is not possible. We do not, in NICE guideline recommendations refer/make specific links to policy documents or even reference such documents as an evidence source. However, the introduction has been revised to ensure the relationship between the Act, strategy and this guideline is clearer.

[2] Department of Health (2010) *Fulfilling and rewarding lives: the strategy for adults with autism in England.* London http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369
[3] *ibid*
[4] Department of Health (2010) *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy.* London http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847

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							lead • Appoint a diagnostic lead • Review their diagnostic pathway by 2013 • Produce a commissioning plan • Ensure that services are commissioned based on accurate population data and include adults with autism in standard data collection – such as the Joint Strategic Needs Assessment • Provide basic training to all staff – usually as part of standard equality and diversity training • Ensure key staff – such as GPs and community care assessors – have access to specialist training • Involve adults with autism and their families/carers in planning usually through a autism partnership board There is clear overlap between some of the recommendations in this guideline and the actions being taken forward as a result of the Autism Act. As such, this guideline is inherently linked to the Act, strategy and statutory guidance and the NAS believe that these links need to be clearly identified in the guideline. This will be particularly helpful for practitioners. Clearly, numerous references are made in the full guideline, but we believe that more references could be made in the recommendations themselves and, in particular, in the shorter 'NICE' version. To look at just three examples (training is discussed later on)[5] the interaction between autism planning groups (6.4.7.6), leads responsible for these pathways (6.4.7.6 line 2) and care pathways (6.4.7.5), recommended in this guideline and the commissioning plans, autism leads and autism partnership boards recommended in the strategy, should be highlighted and explained. To take what the statutory guidance sets out, under the guidance local authorities and the NHS are under a duty to	

[5] One point that is not mentioned, when the Government produced the adult autism strategy it commissioned £500,000 of training materials. It would be helpful to ensure that professionals using this guideline are aware of these. More information can be found http://www.dh.gov.uk/health/2011/12/autism-training-resources/

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							ensure they involve adults with autism and their families/carers and it is suggested they do this through autism partnership boards – which are to be attended by professionals from health, social care, criminal justice etc. Many authorities have these groups and they have been effective drivers for change in many areas. We would fully expect that in many areas these partnership boards could take on the role outlined for the planning groups in the guideline or at the very least it will be vital to ensure that any local planning group developed as a result of the guideline is linked to these partnership boards. Secondly, according to the statutory guidance: *"Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. This named commissioner should participate in relevant local and regional strategic planning groups and partnership boards, to ensure that the needs of adults with autism are being addressed."* (p.24) It also states that: *"Each local authority should appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area." (p.18)* These leads will also be in a strong position to become the lead in overseeing the development of a local pathway, a role outlined in the guideline. Finally, the statutory guidance also recommends that: *"Local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually."* (p.24) Although not all areas have finalised these plans, many are in process of producing them. These plans are by their very nature linked to an individual's care pathway and recognition of this should be made in this guideline. As you can see, the above are necessarily linked to this guideline and in order to avoid potential confusion, we would suggest that the links are made explicitly clear in the	

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							recommendations, shorter NICE version and materials produced when this guideline is published in July. The NAS would happily aid the GDG or NICE to ensure that the links are made as clear as possible.	
88.	The National Autistic Society	13	Full		General	General	Discussed above is the need for better diagnostic services, however, another important issue concerns post-diagnostic support. Our consultation exercise suggested that when adults are diagnosed they receive very different post-diagnostic support: *"We had to tell them what little we knew about autism. No help after diagnosis."* **Adult with autism** *"They did not tell me anything about autism. I was told that my partner would be sent information about Asperger's. They sent a printout of a webpage from patient.co.uk several months later."* **Adult with autism** *"So the main problem I had was coming to terms with the diagnosis, and understanding and accessing the sources of help in an orderly sequence."* **Adult with autism** *"Professionals gave us no advice - everything has been learned through family research helped by the fact I am a nurse."* **Parent of person with autism** *"I did my own research and read books written by other people with ASD - I have Asperger's. I also find the discussions on the Asperger's awareness page on Facebook particularly helpful. I specifically joined FB to participate in these nightly discussions - sometimes just to read about others experiences and sometimes to comment."* **Adult with autism** *"I was told that I had a form of autism called Asperger Syndrome and it was on the spectrum of Autism and that my frontal lobes of my brain were part of the Asperger Syndrome and that I was born with Asperger Syndrome and that I was to really get to understand Asperger Syndrome for myself and not in anyway let it be a hindrance to me."* **Adult with autism** *"After diagnosis, Aspergers was explained to me in quite full detail. I was given suggestions and information about what support my son/I could expect locally, particularly now a diagnosis had been made."* **Parent of adult with autism** *"Not sure what other information would have helped. Autism is so specific and I understood it so clearly that any reading about life patterns made sense anyway."* **Adult with autism**	Thank you for your comment, in light of your and others' comments we have added a recommendation regarding post-diagnostic support.

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							At worst these quotes highlight the need for extra post - diagnostic support and at best they show that good practice is out there, but not available to everyone. The NAS, therefore, believe this guideline should consider adopting the post-diagnostic support model recommended in the child guideline.[6] The child guideline, amongst other things, recommends: • Sharing information, including the written report of the diagnostic assessment, with the GP • Techniques of how best to tell individuals/families/carers once the diagnosis has been confirmed • Appropriate post-diagnostic information which gives more detail regarding autism and about potential support available. This should include contact details for: ➢ local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people) ➢ organisations that can provide advice on welfare benefits ➢ organisations that can provide information on educational support and social care • A follow-up appointment 6 weeks after diagnosis with the multidisciplinary team[7] • Referral to other services – such as mental health teams – if required Much of this could easily be adopted by this guideline, at very least we would suggest that providing information which is appropriate – and accessible - for the individual.[8] At very least, the NAS believe recommendations should be	

[6] Clearly some elements will have to be adapted, such as a referral to for a community care assessment – as per the statutory guidance.
[7] We realise that for adult diagnostic teams who are extremely hard pressed at the moment this would be a very ambitious target to set. We are also aware that by NICE recommending this follow-up appointment and with very few – if any services – able to offer it, it could make adults with autism very anxious about not receiving the level of support.
[8] Clearly, it is recommended in this guideline that the care pathway – and autism strategy group – should look at what information is needed and at what points in the pathway. Nonetheless, in the NAS's opinion, when we have workable suggestions from the child guideline, we should as far as possible mirror these to avoid confusion.

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							made by the GDG concerning: • post-diagnostic information • post-diagnostic follow-up • referral to other statutory services	
89.	The National Autistic Society	22	Full		General	General	Transition is a key time for individuals with autism and one where we consistently see problems occurring. With this in mind, we believe that the adult guideline should – so to ensure consistency – mirror the child guideline as much as possible. For instance, in the child guideline it is recommended that: 1.1.10 If young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability. It would be helpful if this – or something similar - was included in the adult guideline.	Thank you for your comments. The issue of transition will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents. All three of these guidelines will also be also be in one care pathway on the NICE website which will display these links in a clear way.
90.	Nottinghamshire Healthcare NHS Trust	73	Full		General		Issue of differential diagnosis between Personality Disorder and Autistic Spectrum Conditions is portrayed as simple. In reality, (particularly in the Criminal Justice System) it is very complex. Particularly given that there may be limited early history and complex history of other diagnoses.	Thank you for your comment. We agree this is not simple. We have mentioned in the Introduction that personality disorder is differentiated from autism by the absence of obsessional behaviour in childhood. It is however outside our scope to deal in detail with this – it is more an issue for training and assessment manuals.
91.	Nottinghamshire Healthcare NHS Trust	74	Full		General		Would have valued guidance/research on best practice for those with diagnosed Autistic Spectrum Condition within the CJS e.g. reducing risk directly related to core autistic behaviours e.g. as with section on anger management.	Thank you for your comment. The guideline applies to people in the health care system including this on specialist forensic services and the prison health care system but not to the wider CJS. We did not identify any evidence specifically for forensic setting and it will be for individual clinicians to judge the relevance of our recommendations for use in such settings.
92.	Association Directors of Adult Social Services	1	FULL	1	6	14	Including Professional not just clinicians and family support not just carers	Thank you for your comment, this has been amended.
93.	Association Directors of Adult Social Services	3	FULL	1.1	7	26-3	Reads as not specific to the priority identified. Generic standard statement of such guidance. Needs to include the recognition that within this particular subject matter there is a	Thank you for your comment, the purpose of this section is to give a background and understanding of how evidence based

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						1	requirement for an assessed applied intervention that takes into consideration the reasonable adjustments of the delivery of the holistic support plan inclusive of treatment (needs to be explicit of the treatment focus). For example building in the rituals and routines sensitivities as an individual – person centred with identified outcomes.	guidelines should be used and is not specific to the condition the guideline relates to. For further information of how people with autism should be specifically treated, please see chapter 2 onwards.
94.	Association Directors of Adult Social Services	2	FULL	1.1.3	7	3 7	Inclusion of Partner Agencies, I not just Health Care, consideration of Social Care, Housing, employment etc as per Autism Strategy	Thank you for your comment. NICE gives advice specifically to the NHS, although recommendations may be relevant to social care situations.
95.	AUTISM ALLIANCE UK	2	Full	1.1.6	8	3 4	The guideline states that the Care Quality Commission will monitor the extent to which Primary Care Trusts, trusts responsible for mental health and social care, and Health Authorities have implemented these guidelines. As noted in the previous comment, CQC has not demonstrated significant knowledge or understanding of autism, and nor is CQC equipped to carry out this complex monitoring task. The National Audit Office has the ability to monitor implementation more effectively, and has demonstrated high interest in and understanding of autism.	Thank you for your comments. The CQC has a formal role in the monitoring of all care settings – it is not within the remit of the guideline to suggest a revision of this role.
96.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	1.1.6	8	3 0	The absence of a Welsh perspective is clear in this section which refers to CQC monitoring implementation through Primary Care Trusts, Health Authorities etc. These are not structures relevant to Wales since the NHS re-organisation in 2010. The Welsh structures have a significant impact on the way in which health care is delivered, planned and co-ordinated and there should be further consultation with the Welsh Government, Public Health, Health Boards to clarify not only how NICE guidance is implemented and monitored but to consider some of the potential advantages of the different structures in Wales in delivering and developing best practice.	Thank you for this comment. We have made some revisions to the introduction in light of this and similar comments. We will also draw the matter to the attention of NICE.
97.	Welsh Government		Full	1.1.6	8	3 0	The absence of a Welsh perspective is clear in this section which refers to CQC monitoring implementation through Primary Care Trusts, Health Authorities etc. These are not structures relevant to Wales since the NHS re-organisation in 2010. The Welsh structures have a significant impact on the way in which health care is delivered, planned and co-ordinated and there should be further consultation with the Welsh Government, Public Health, Health Boards to clarify not only how NICE guidance is implemented and monitored but to	Thank you for this comment. We have made some revisions to the introduction in light of this and similar comments. We will also draw the matter to the attention of NICE.

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							consider some of the potential advantages of the different structures in Wales in delivering and developing best practice.	
98.	Royal College of Nursing	2	Full	1.2.1	8	2 0	This requires resources to support personnel, expertise and skills of the professional or it is never going to be implemented	Thank you for your comment. NICE provides costing and implementation tools for services to prepare for guideline implementation that are separate from the guideline. It is not within the remit of the guideline to determine how recommendations will be financed locally.
99.	Association Directors of Adult Social Services	4	FULL	1.2.2	9	2 4 /3 3	Although does not cover practice of Social Services it should recognise the interdependencies, as unlikely to be working in isolation. Particularly when examining Psychosocial interventions	Thank you for your comments. We think the guideline already does this with a strong emphasis on multi-disciplinary approach.
100.	Calderstones Partnership NHS Foundation Trust	1	Full	1.2.3	9	3 7	There is a word missing: '*treatment and management of ? in adults'.*	Thank you for pointing this out, it has been amended.
101.	Association Directors of Adult Social Services	5	FULL	1.2	10		Include the Application of the intervention including Communication.	Thank you for your comment, this section broadly sets out the areas in which evidence will be looked at and therefore it is not appropriate to include specific interventions.
102.	WaASP		Full	2.1.1	11	6	Originally Kanner defined people with AU as having LD which is interpreted in UK as IQ of less than 70. The higher functioning Asperger's group is deemed not to fall within the LD service. In general however people with AU and a LD are better served in terms of service because they better ' fit' what is on offer. It is unrealistic to lump all autistic disorders into a single category. At a time of budgetary constraint administrators will take the cheap and easy option of delivering a single service based on a single speciality or skill. If that skill is LD-based the damage done to an Asperger's patient by lack of appropriate treatment can be lasting and severe.	Thank you, but we do not agree that treated autism as a single category. We have responded in our recommendations to the range of needs and do, where appropriate take into account differing levels of intellectual ability.
103.	Nottinghamshire Healthcare NHS Trust	3	Full	2.1.1	11	3 4	It would be helpful to add in the Brugha et al. (2011) UK adult households survey reference here as it relates specification to adult UK population.	Thank you for your comment. We have amended the introduction to include reference to the Brugha et al. (2012) 'Estimating the Prevalence of Autism

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								Spectrum Conditions in Adults' study.
104.	South London and Maudsley NHS Trust	1	Full	2.1.1	11	3 7	Should be stated that the draft of ICD11 (what most clinicians and researchers outside the States use) does not do this and allows for autism, atypical autism, Asperger's syndrome, PDD unspecified etc). We still have an extant version of ICD10 – not even mentioned. Please do not give priority to the ASA DSMV classification as it will lead to confusion and limit the specificity available to clinicians and researchers. Inappropriate priority to DSMV is currently implied by the wording here.	Thank you for your comment. We have amended the introduction to stress that ICD-10 are the current European/UK criteria. However, we should point out that although the GDG made recommendations on the basis of identified patient need taking into account factors such as intellectual disability, social and cognitive impairments we are not able to find high quality evidence that would support specific recommendations for the various categories you list in your comment.
105.	Royal College of Speech and Language Therapists	1.	Full	2.1.1	12	3	The triad of impairments refers to "social imagination" not "imagination". The experience of speech and language therapists shows that their clinical experience is that people with AS have huge difficulties in 'social imagination' and this is not the same of 'imagination' generally, e.g. drawing a picture.	Thank you for your comment, this has been amended.
106.	Caldedstones Partnership NHS Foundation Trust	2	Full	2.1.1	12	4 0	It states *'comes follows'*. One of these words needs to be removed.	Thank you for pointing this out, it has been amended.
107.	South London and Maudsley NHS Trust	2	Full	2.1.2	12	2 4	As above – it seems that the emphasis of this entire section is in accord with the members of the panel's own perspectives which I do not think represent the perspectives of the majority of the clinicians and researchers in the UK. I can not see why else there is no mention of the extant ICD10 – there's an alpha draft of ICD11 and it is not mentioned. At least as much emphasis should be put of ICD10 and the alpha draft of ICD11 as on DSMV.	Thank you for your comment. We have amended the introduction to stress that ICD-10 are the current European/UK criteria.
108.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.1.2	12	3 6	The document sets out talking about Autism Spectrum Condition yet at this point states it is going to use the term "the autism spectrum" – it would be less confusing if this were stated at the very beginning	Thank you for your comment. We have revised the guideline to use the simpler term 'autism' to cover the entire autism spectrum.
109.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.1.2	12	3 9- 4 3	As pointed out in the general point above – whilst you refer to the Autism Act and Autism Strategy from the DoH there is no mention of the Welsh Strategy which predates these	Thank you for your comments, again please accept our apologies that this was omitted. The guideline has been amended to include the Welsh Strategy.
110.	Welsh Government		Full	2.1.2	12	3	The document sets out talking about Autism Spectrum	Thank you for your comment. We have

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						6	Condition yet at this point states it is going to use the term “the autism spectrum” – it would be less confusing if this were stated at the very beginning	revised the guideline to use the simpler term ‘autism’ to cover the entire autism spectrum.
111.	Welsh Government		Full	2.1.2	12	39-43	As pointed out in the general point above – whilst you refer to the Autism Act and Autism Strategy from the DoH there is no mention of the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales which predates these	Thank you for your comments, again please accept our apologies that this was omitted. The guideline has been amended to include the Welsh Strategy.
112.	Nottinghamshire Healthcare NHS Trust	5	Full	2.1.3	13	40	We would advise that sensory sensitivities should be included in this list. Issues with praxis or motor coordination could also usefully be included here.	Thank you for your comment. The guideline has been amended to mention sensory sensitivity in many places throughout the guideline.
113.	Nottinghamshire Healthcare NHS Trust	4	Full	2.1.3	13	39	It would be useful here to add that some individuals with autism display apparent skills in these areas which they have learnt through observation and structure, rather than being an innate skill.	Thank you for your comment. The guideline has been amended to mention that difficulties can be masked by learnt strategies.
114.	Tees, Esk & Wear Valleys NHS Foundation Trust	3	Full	2.1	14-15		It is recommended that there is greater explanation of the nature of the disorder and the wide variation in presentation and how this can fluctuate in settings/ circumstances	Thank you for your comment. We have stressed the variability of symptoms.
115.	Tees, Esk & Wear Valleys NHS Foundation Trust	5	Full	2.1	15		Other disorders - include DCD, Catatonia. Catatonia is important to explain given the misinterpretation of this being a schizophrenic illness rather than presenting as part of the autism	Thank you for your comment. The guideline has been amended to mention catatonia. Thank you for raising this.
116.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.1	15	9-18	This presents a negative picture of ASD – giving no account of how people can live successful and fulfilling lives and tends to reinforce stereotypes e.g. “this person cannot have Asperger syndrome because he is married and has a job”.	Thank you we have amended the guideline in order to take account of your comment.
117.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.1	15	29-31	There are also a number of genetic syndromes associated with autism (tuberous sclerosis, Fragile X, Angelmann syndrome, Rett syndrome, Turner syndrome etc)	Thank you for your comment. We have revised the guideline to list the syndromic forms of autism. Thank you for highlighting this omission.
118.	Nottinghamshire Healthcare NHS Trust	1	Full	2.1.1	General		We may have missed this in the document, but from what age does this guideline refer? And how does it dovetail with the NICE guideline for children and young people? (NICE clinical guideline 128).	Thank you for your comment. The guideline is aimed at people 18 and older, which is included in the scope however this has been added to the Preface to make it clearer. The NICE guideline for children and young people includes up to the 19th birthday so there is some overlap to ensure continuity.
119.	Nottinghamshire	2	Full	2.1.3	Ge		We are aware that the group did not include members from	Thank you for your comment. We have

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	Healthcare NHS Trust				ner al		professions such as speech and language therapy and occupational therapy. The guideline rightly makes reference to clinical areas these professional groups specialise in, such as communication, and sensory issues. There are potentially important gaps in the literature reviewed from these clinical areas, and perhaps consultation, for example, with the Royal College of Speech and Language Therapy if not already undertaken would be useful. In the guideline, where there has not been research evidence, the group has made its own recommendation, and again, this could have usefully incorporated the views of representatives from speech and language therapy and occupational therapy.	commented do a number of areas where the evidence supported it – for example facilitated communication. We have also stressed the role of speech and language therapists have a greater role in helping children with autism, rather than adults, but that they form an important professional group for adults too.
120.	Nottinghamshire Healthcare NHS Trust	6	Full	2.1.3	14	5	We would suggest that 'tantrums' is not an appropriate word to describe adults – perhaps stating a change in behaviour, or distressed behaviour, would be more appropriate, and would reflect a more diverse range of behaviours.	Thank you for your comment, we agree this is not appropriate and have amended the guideline.
121.	British Psychological Society		Full	2.1.3	14	1 3	It is helpful that specific examples of some of the difficulties experienced by people with autism are outlined (p.13, line 44 to p.14, line 12). Some people with autism present as excessively passive, seemingly because they find it hard to think of things to do if a narrow interest is not available to / initiated for them. This presentation can be overlooked or misdiagnosed (e.g. as a symptom of depression). It would therefore be helpful to include it as a specific example here such as: • *Being extremely passive if an activity of interest is not available / initiated by someone else.*	Thank you for your comment. We have added this to the guideline.
122.	South London and Maudsley NHS Trust	3	Full	2.1.3	14	1 1	Could you use a word other than obsessional? Your phrase may give rise to the mistaken view that egodystonic and resisted (as in OCD) thoughts/behaviours are a 'normal' part of autism, as opposed to (as far as we currently conceptualise them) a co-morbid disorder. The phrase implies that obsessional thoughts are a core feature of ASD when they are not. Presumably this is why ICD10 chooses to (in my view appropriately) use the phrase 'restricted, repetitive patterns of interests and activities'. People with ASDs have suffered a lot from clinicians and others	Thank you for your comment. We have amended the bullet point under section 2.3 from "Development of *obsessional* interests'" to "Development of '*fixated* interests'".

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							thinking that 'obsessionality' is a core feature of ASDs, because it has meant that they haven't looked for OCD, so they haven't been treated. OCD is common in ASD, but absence of a diagnosis of OCD means absence of treatment means continued distress. There is very limited evidence regarding the absence of 'treatability' of apparently classical OCD in the context of autism, and some evidence (including in your review) that it may be at least partially responsive to psychological and pharmacological treatments.	
123.	South London and Maudsley NHS Trust	4	Full	2.1.3	14	2 1	What's going on with the DSMIV/V emphasis and absence of reference to the WHO instruments? Seems very odd.	Thank you for your comment. We have amended the introduction to stress that ICD-10 are the current European/UK criteria.
124.	Association Directors of Adult Social Services	6	FULL	2.1.3	14	1 3	Should be explicit that it is a spectrum condition of which an individual will have some of the traits identified but not necessarily all coupled with their individual likes and dislikes. Needs to have a person centred approach to understand how it effects as an individual.	Thank you for your comment. We have stressed autism is a spectrum (see section 2.1.1).
125.	Association Directors of Adult Social Services	7	FULL	2.1.3	14	2 2	Caution needs to be given so not to label people with Autism as having a LD. Must be based on the presenting need not the diagnosis. Diagnosis – Impact of the Welfare reform on individual's consideration.	Thank you for your comment. We make this very clear in setting out a number of recommendations the assessment section.
126.	Association Directors of Adult Social Services	8	FULL	2.1.3	14	5	Change Tantrums to behaviours (reinforces a childlike and inappropriate perceptions)	Thank you for your comment, we agree this is not appropriate and have amended the guideline.
127.	WaASP		Full	2.1.3	14	2 1	The DSM-V plan is only a plan. The effective abolition of Asperger's as a diagnosable condition is strongly opposed by the American Psychologists' Association and by European bodies. It is opposed by every British psychologist with whom we have contact. There is no need to assume that DSM-V will be clinically implemented in UK and it not helpful for this guideline potentially to marginalise still further, people with Asperger's.	Thank you for this comment. The section you refer to points out that it is the intention to establish a broad autism category. It does not indicate GDG support for this and there is no recommendation to this effect in the guideline. The guideline does however provide advice on the assessment of the full range of people with autistic spectrum conditions including those with a current diagnosis of Asperger's.
128.	Calderstones Partnership NHS Foundation Trust	3	Full	2.1.3	14	1 7, 1	An IQ below the average range is a learning 'disability', not learning *'difficulty'.*	Thank you for your comments, this has been amended.

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						8, 2 0.		
129.	WaASP		Full	2.1.4	14	3 0	You refer to Asperger's syndrome because there is a need so to do in the interest of categorising and differentiating symptoms in order to structure a clear social and clinical pathway – see our point 2 above.	Thank you for this comment. Please see our previous response and do note that our recommendations on the development of care pathways stress that that they should be based on a proper assessment of need and a regular review of the outcome of any care provided. .
130.	Northumberland, Tyne & Wear NHS Trust		Full	2.1.4	14-15		2.1.4 While the detail does give some indication of the complexity of autism it perhaps needs to make an over- arching statement about the heterogeneity of autism and its dependence on circumstances and systems. There is debate in our group regarding whether autism is best conceived as a life-long condition or vulnerability.	Thank you for your comment. We acknowledge the heterogeneity in the Guideline. We use the terms life-long simply because for most people with the diagnosis, they need the diagnosis at different points in their life, and they remain vulnerable at different points in their life. We make the point that with the right support, crises can be prevented making the autism less evident and making the person less vulnerable.
131.	The Royal College of Psychiatrists, Learning Disability Faculty	1 6	FULL	2.1.4	14-15		While the detail does give some indication of the complexity of autism it perhaps needs to make an over-arching statement about the heterogeneity of autism and its dependence on circumstances (which include both relationships and physical settings). It then might state explicitly that its presentation will vary with age and emotional state as well as ability and setting; that it often improves with maturation and that it is not necessarily a life-long disorder. The guidelines should draw attention to the difficulty of living with a condition that is so extensively amplified/minimised by circumstances and that a failure to appreciate this can compound an individual's difficulties	Thank you for your comment. We stress throughout the Guideline that environmental factors (including the social environment) can hugely reduce an individual's difficulties, or exacerbate them.
132.	Sheffield Asperger Syndrome Service	1 2	Full	2.1.4	15	1 0	There is not enough emphasis on the degree of difficulties many high-functioning adults face at college or university (e.g. mental health difficulties) and the challenges they face accessing adequate and timely support (especially if undiagnosed)	Thank you, we recognise this is an important issue and we have made reference to the importance of considering education in our recommendations for the assessment of people with autism, in the structure of the specialist teams, and in the training and knowledge of staff.
133.	Welsh Government		Full	2.1.4	15	9-	This present a negative picture of ASD – giving no account of	Thank you, we have amended the

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						18	how people can live successful and fulfilling lives and tends to reinforce stereotypes e.g. “this person cannot have Asperger Syndrome because he is married and has a job”.	introduction to take account of your comment.
134.	South London and Maudsley NHS Trust	5	Full	2.1.5	15	31	Not sure what the purpose of the ‘even’ is here. Suggest delete.	Thank you, we have amended the introduction to take account of your comment.
135.	Northumberland, Tyne & Wear NHS Trust		Full	2.1.5	15	28-31	Other disorders frequently present include Dysexecutive syndrome, Developmental Coordination Disorder and catatonia.	Thank you, we have amended the introduction to take account of your comment.
136.	Northumberland, Tyne & Wear NHS Trust		Full	2.1.5	15	28-31	The presentation of comorbid disorder will be modified by the autism affecting both its diagnosis and management, including the care pathway.	Thank you, this is acknowledged.
137.	The Royal College of Psychiatrists, Learning Disability Faculty	1	Full	2.1.5	15	35	There should be mention on both pages 15 and 17 of the likelihood of misdiagnosis as schizophrenia as well. This can often occur in general adult psychiatric services where clinicians are not familiar with autism, and core autistic symptoms can be misinterpreted as both positive and negative symptoms of schizophrenia.	Thank you, we have amended the introduction to take account of your comment.
138.	The Royal College of Psychiatrists, Learning Disability Faculty	20	FULL	2.1.5	15	28-31	Other disorders frequently present include Dysexecutive syndrome, Developmental Coordination Disorder and catatonia.	Thank you, we have amended the introduction to take account of your comment.
139.	Nottinghamshire Healthcare NHS Trust	7	Full	2.1.5	15	22	The term ‘socially clumsy’ – seems somewhat of a simplification and does not describe the significant difficulties experienced. We would suggest: ‘People who have significant social difficulties’.	Thank you, we have amended the introduction to take account of your comment.
140.	The Royal College of Psychiatrists, Learning Disability Faculty	21	Full	2.1.5	15	28-31	The presentation of comorbid disorder will be modified by the autism affecting both its diagnosis and management, including the care pathway.	Thank you, this is acknowledged.
141.	WaASP		Full	2.1.5	15	20	The width of the spectrum to which you refer reinforces our request that your maintain throughout the document, the differentiation of Kanner Autism and Asperger’s syndrome	Thank you, this point reiterates your earlier ones.
142.	South London and Maudsley NHS Trust	6	Full	2.1.6	15	40	Was this across the entire spectrum? If not, please state.	Thank you for your comment. This has been amended to specify the population the studies refer to.
143.	Welsh Health Boards ASD		Full	2.1.6	15	39	Specifically what sensory and gastro-intestinal issues?	Thank you for your comment, further exploration of gastro-intestinal issues

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	Assessment & Diagnosis (Adults) Network							appears in section 8.6 of the guideline.
144.	Welsh Government		Full	2.1.6	15	29-31	There are also a number of genetic syndromes associated with autism (tuberous sclerosis, Fragile X, Angelmann syndrome, Rett syndrome, Turner syndrome etc)	Thank you, we have amended the introduction to take account of your comment.
145.	Welsh Government		Full	2.1.6	15	39	Specifically what sensory and gastro-intestinal issues?	Thank you for your comment, further exploration of gastro-intestinal issues appears in section 8.6 of the guideline.
146.	Nottinghamshire Healthcare NHS Trust	8	Full	2.1.6	15	40	It would be more appropriate to reference the original research here: Leekham, S. et al (2007) Describing the sensory abnormalities of children and adults with autism. *Autism Developmental Disorders,* 37, 894-910.	Thank you, we have amended the introduction to take account of your comment.
147.	Sheffield Asperger Syndrome Service	14	Full	2.1.4	16	7	The term neurodiversity is used in the guidelines which is positive, but greater emphasis is required on the need for 'neurotypicals' to better understand and adjust, versus 'neuroatypicals' – there needs to be greater social awareness (with wider implications for education and the media)	Thank you for your comment. We make reference to this issue in the Experience of Care chapter.
148.	AUTISM ALLIANCE UK	3	Full	2.1.6	16	1	We endorse the whole of this paragraph, and would add that people with autism often fall through the gaps between medical and social care, especially if they do not present with an accompanying mental health issue or learning disability	Thank you, we have amended the introduction to take account of your comment.
149.	Association Directors of Adult Social Services	9	FULL	2.1.6	16	10	Incorporate awareness rising of communication, understanding and reasonable adjustments.	Thank you, we have amended the introduction to take account of your comment.
150.	Northumberland, Tyne & Wear NHS Trust		Full	2.2	16	18	'widening of the diagnostic criteria' – there should be mention of the adoption of Atypical Autism/PDD(NOS) as components of ASD.	Thank you, we have amended the introduction to take account of your comment.
151.	Tees, Esk & Wear Valleys NHS Foundation Trust	6	Full	2.2	16		'widening of the diagnostic criteria' It is considered that Atypical Autism/PDD(NOS) as components of ASD should be specifically mentioned This differences between obsessions and rituals of autism compared with the clinical presentation in OCD should be explained and the overlap It is considered there needs to be discussion of personality disorder and the mis-diagnosis die to specific presentations, with reference to the Royal College report	Thank you. We have amended this section to include Atypical Autism/PDD(NOS). We agree that personality disorders are possible examples of misdiagnosis of autism/AS. We have made mention of OCD but we should point out that this is an introduction to the guideline and as such cannot go into the level of diagnostic detail you suggest.
152.	The Royal College of Psychiatrists,	3	Full	2.2	16	16	Although it is a minority view, a significant number of clinicians feel there is evidence for some genuine increase in the	Thank you for your comment, the GDG decided that in the absence of any known

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	Learning Disability Faculty						prevalence of autism not associated with the listed factors. This alternative view should at least be recognised.	factor that might be causing the increase in prevalence, and to avoid raising public anxiety unnecessarily, we should simply refer to these less controversial reasons for the increase in prevalence.
153.	The Royal College of Psychiatrists, Learning Disability Faculty	2 2	Full	2.2	16	1 8	'widening of the diagnostic criteria' – there should be mention of the adoption of Atypical Autism/PDD(NOS) as components of ASD.	Thank you, we have amended the introduction to take account of your comment.
154.	British Psychological Society		Full	2.3	16	3 2	The guidance on differentiating autism from other conditions with which it may be confused, such as Obsessive-Compulsive Disorder (OCD), is helpful. However, the opening paragraph of Section 2.3 could be interpreted as saying that whenever a repetitive behaviour is associated with anxiety it should always be diagnosed as OCD. This is not the case (e.g. some people with autism may engage in repetitive behaviours specifically when they are anxious, such as at times of transition). The BPS therefore recommends that this be altered as follows: *Because Obsessive Compulsive Disorder (OCD) also involves unusually repetitive behaviour it is important to highlight some key differences between OCD and people on the autism spectrum:* • *social development is not necessarily atypical in childhood in people with OCD;* • *repetitive behaviours result in anxiety in people with OCD, so the absence of an anxiety response precludes OCD (but the presence of anxiety does not necessarily mean that someone must have OCD and not autism).* *Other possible distinguishing features of OCD are outlined in NICE Clinical Guideline 31 (National Collaborating Centre for Mental Health, 2006), including the person reporting intrusive thoughts that they perceive as "dangerous or immoral" and a belief that the person is "able to prevent harm occurring either to their self or a vulnerable person".*	Thank you. This is useful and all good suggestions. We have included these in the revised guideline.

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							A person can be co-morbidly diagnosed with autism and OCD.	
155.	Northumberland, Tyne & Wear NHS Trust		Full	2.3	16	32	This distinction, between obsessions and rituals of autism and those of OCD, although useful should be qualified by the statement that , in some, it may not be clear cut (particularly where the individual is unable to describe his thoughts clearly)	Thank you, We have made mention of the OCD in the guideline but we should point out that this is an introduction to the guideline and as such cannot go into the level of diagnostic detail you suggest.
156.	The Royal College of Psychiatrists, Learning Disability Faculty	23	Full	2.3	16	32	This distinction, between obsessions and rituals of autism and those of OCD, although useful should be qualified by the statement that , in some, it may not be clear cut (particularly where the individual is unable to describe his thoughts clearly)	Thank you, we have made mention of the OCD in the guideline but we should point out that this is an introduction to the guideline and as such cannot go into the level of diagnostic detail you suggest.
157.	Specialist Autism Services	5	Full	2.3	16	29	Adults, when approaching service providers often encounter different responses to whether the diagnosis was through standard NHS provision or privately paid diagnosis.	Thank you for your comment. We have not heard of this and this is clearly worrying. However, because we do not know how common this is, we cannot include this.
158.	Nottinghamshire Healthcare NHS Trust	68	Full	2.3	16	36	Presentation of different personality disorders vary widely (e.g. huge difference between schizoid to narcissistic). This suggests individuals with this diagnosis are a discrete group.	Thank you for your comment. We cannot go into detail on the personality disorders in this Guideline as it is outside our scope.
159.	Nottinghamshire Healthcare NHS Trust	69	Full	2.3	16	39	Part of the presentation for personality disorder is resistance to change – this is partly what makes them difficult to treat.	Thank you for your comment. We acknowledge that this is an overlap but have emphasized their difference to autism.
160.	Nottinghamshire Healthcare NHS Trust	70	Full	2.3	16	39	Individuals with personality disorder, particularly those who are institutionalised (Prison, Special Hospitals etc) may well show narrow or restricted interests and may have done so for some time.	Thank you, this is a good example where the differential diagnosis may be particularly difficult, but where early developmental history may have differentiated them.
161.	Nottinghamshire Healthcare NHS Trust	71	Full	2.3	16	42	A significant proportion of individuals with a diagnosis of personality disorder also have significant difficulty in 'theory of mind' and recognising what others think and feel. Number of studies conducted demonstrating processing difficulties in recognising others emotions from Non-verbal communication and facial expression (particularly negative emotion).	Thank you for this information we agree.
162.	Nottinghamshire Healthcare NHS Trust	72	Full	2.3	17	5	Talks about co-occurrence of other conditions, personality difficulties may be better presented as secondary to autism spectrum difficulties.	Thank you, but the GDG have considered this comment decided not to amend the guideline as there was not a consensus on this issue.
163.	Northumberland, Tyne & Wear NHS		Full	2.3	16-17		2.3 For greater clarity, this might use the term Dissocial PD (F60.2) rather than just 'antisocial' personality disorder.	Thank you for your comment, but we cannot go into the personality disorders in great

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	Trust						There should be some mention of other personality disorders – e.g. Schizoid & Borderline PD – as well as chronic, simple and catatonic schizophrenias? This might be a suitable point to note that severe anxiety may present as a psychotic reaction.	detail in this Guideline as it is outside the scope.
164.	The Royal College of Psychiatrists, Learning Disability Faculty	2 4	Full	2.3	16-17		For greater clarity, this might use the term Dissocial PD (F60.2) rather than just 'antisocial' personality disorder. There should be some mention of other personality disorders – e.g. Schizoid & Borderline PD – as well as chronic, simple and catatonic schizophrenias? This might be a suitable point to note that severe anxiety may present as a psychotic reaction.	Thank you for your comment, but we cannot go into the personality disorders in great detail in this Guideline as it is outside the scope.
165.	South London and Maudsley NHS Trust	7	Full	2.3	17	9	Don't like this. Complete supposition. How do you know it's not neurobiologically driven? Why not say 'in many cases this may be due to social difficulties due to autism, but may also be partly due to differences in the pattern of brain development' or similar?	Thank you for your comment, we are unable to find which section you are relating to as the page and line number do not correlate to your comments.
166.	Association Directors of Adult Social Services	1 0	FULL	2.3	17	1	Recognition needs to be given to the commissioning of advocate provision for people with autism by Adult Services.	Thank you for your comment, however NICE is independent of commissioning so cannot refer to this.
167.	Northumberland, Tyne & Wear NHS Trust		Full	2.4	17		Within our group some felt that there should be some mention "secondary" (acquired) autism syndrome whether as a behavioural phenotype (e.g. in Tuberose Sclerosis) as a consequence of meningitis or of extreme deprivation. Others felt that a primary-secondary dichotomy was less conceptually useful.	Thank you. We do not go into the concept of 'acquired autism' (secondary to deprivation, for example) because the main use of the term 'autism' refers to a congenital condition.
168.	Northumberland, Tyne & Wear NHS Trust		Full	2.4	17	1 9	The study by Hallmayer et al suggests that the range of heritability should be broadened to 40-90%. Hallmayer, J., Cleveland, S., Torres, A., et al (2011) Genetic Heritability and Shared Environmental Factors Among Twin Pairs With Autism. Archives Of General Psychiatry, 68, 1095-1102.	Thank you, we have amended the text.
169.	Tees, Esk & Wear Valleys NHS Foundation Trust	7	Full	2.4	17		It is considered that secondary autism should be explained as a phenotype in certain genetic disorders, but the useful nature of the additional diagnosis to inform management	Thank you. We do not use the term 'secondary autism' because it is not widely used. Rather we will refer to 'syndromic autism' that occurs in certain genetic conditions (e.g., Fragile X).
170.	The Royal College of Psychiatrists, Learning Disability Faculty	2	Full	2.4	17	2 9	As above	Thank you.
171.	The Royal College	2	Full	2.4	17		There should be some mention of the place of the secondary	Thank you. We do not use the term

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	of Psychiatrists, Learning Disability Faculty	5					(acquired) autism syndrome whether as a behavioural phenotype (e.g. in Tuberose Sclerosis) as a consequence of meningitis or of extreme deprivation.	'secondary autism' because it is not widely used. Rather we will refer to 'syndromic autism' that occurs in certain genetic conditions (e.g., Fragile X).
172.	The Royal College of Psychiatrists, Learning Disability Faculty	2 8	Full	2.4	17	1 9	The study by Hallmayer et al suggests that the range of heritability should be broadened to 40-90%. **Hallmayer, J., Cleveland, S., Torres, A.,** ***et al*** **(2011)** Genetic Heritability and Shared Environmental Factors Among Twin Pairs With Autism. *Archives Of General Psychiatry*, **68**, 1095-1102.	Thank you, we have amended the text.
173.	Nottinghamshire Healthcare NHS Trust	9	Full	2.5	17	1 2	It may be useful to add in here research by Bishop et al on individuals diagnosed in childhood as having language disorder, but later diagnosed as ASD in adulthood. Bishop, D.Whitehouse, A. Watt, H. and Line, E. (2008) Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder DOI: 10.1111/j.1469-8749.2008.02057.x Published online 31st March 2008	Thank you, this has been included.
174.	Hertfordshire Partnership NHS foundation Trust	4	Full	2.5	17	4 2	A typical diagnostic assessment may take at least 2 hours in carefully documenting the developmental history, in order to make the differential diagnoses…. Complex assessments may take much longer. Whilst appreciating that 2 hours may be an average, and also that the figure is qualified by the term "at least", it would be helpful for the purposes of conversations with commissioners and managers to highlight that the process may take considerably longer, particularly when taking into account in situ observations of the person themselves, talking to families and carers, writing up the assessment etc.	Thank you. We are mindful that autism diagnosis already takes a long time and thus costs the NHS a lot of money. We settled on the phrase "at least 2 hours" to indicate that for the most part GPs can't just diagnosis autism in 5 minutes and that a specialist clinic is needed. However, we wanted to strike the balance of not suggesting a diagnosis of autism takes all day which is likely to be unaffordable. We acknowledge that report writing and family liaison takes additional time that is outside of the diagnostic session.
175.	AUTISM ALLIANCE UK	4	Full	2.5	17	3 6	We endorse the whole of this section, in particular the need for specialist assessment and diagnostic services	Thank you for your comments.
176.	Royal College of Speech and Language Therapists	2.	Full	2.5	17	4 3	We would argue that it takes longer than 2-hours to complete an assessment. The ADI assessment takes 3 one-hour sessions, the ADOS takes one–hour and the DISCO similarly takes at least three-hours. Following the assessment there is also the paperwork and report to complete. With adults it can take further assessments to form an accurate	Thank you. We are mindful that autism diagnosis already takes a long time and thus costs the NHS a lot of money. We settled on the phrase "at least 2 hours" to indicate that for the most part GPs can't just diagnosis autism in 5 minutes and that a specialist clinic is needed. However, we wanted to strike the balance of not suggesting a diagnosis of

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							differential diagnosis, e.g. psychiatry assessment and other screeners, e.g. GAD-4	autism takes all day which is likely to be unaffordable. We acknowledge that report writing and family liaison takes additional time that is outside of the diagnostic session. We agree use of the SADOS or DISCO would significantly lengthen the assessment but the use of these instruments is optional.
177.	The Royal College of Psychiatrists, Learning Disability Faculty	4	Full	2.5	17	4 3	2 hours seems to be a major underestimate of the time required to carry out a thorough diagnostic assessment	Thank you. We are mindful that autism diagnosis already takes a long time and thus costs the NHS a lot of money. We settled on the phrase “at least 2 hours” to indicate that for the most part GPs can’t just diagnosis autism in 5 minutes and that a specialist clinic is needed. However, we wanted to strike the balance of not suggesting a diagnosis of autism takes all day which is likely to be unaffordable. We acknowledge that report writing and family liaison takes additional time that is outside of the diagnostic session. We agree use of the SADOS or DISCO would significantly lengthen the assessment but the use of these instruments is optional.
178.	South London and Maudsley NHS Trust	8	Full	2.5	18	1	‘in order to make sure that the differential diagnosis mentioned above have been excluded’.	Thank you. This has been amended to reflect your comment.
179.	Royal College of Speech and Language Therapists	3.	Full	2.5	18	3	Speech and language therapists should be included in all specialist teams. SLTs are involved in the diagnostic process with adults, for example in Liverpool, Trafford, Nottingham and Kingston-Upon-Thames.	Thank you. We have also stressed the role of speech and language therapists have a greater role in helping children with autism, rather than adults, but that they form an important professional group for adults too.
180.	Royal College of Speech and Language Therapists	4.	Full	2.5	18	4	The correct protected title is “speech and language therapist”.	Thank you. This has been amended to reflect your comment.
181.	Nottinghamshire Healthcare NHS Trust	1 1	Full	2.5	18	4	We would advise use of the full title ‘speech and language therapist’.	Thank you for your comment, this has been amended.
182.	Northumberland, Tyne & Wear NHS Trust		Full	2.5	18	3	It is unclear how their training might equip neurologists to diagnose ASC	Thank you, this has been amended to reflect your comment and the term deleted.

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183.	The Royal College of Psychiatrists, Learning Disability Faculty	2 6	Full	2.5	18	3	It is unclear how their training might equip neurologists to diagnose ASC	Thank you, this has been amended to reflect your comment and the term deleted.
184.	Sheffield Asperger Syndrome Service	1 5	Full	2.6	18	1 0	"Only a few specialist services for the assessment and diagnosis of adults with autism currently exist in the UK" – the services that do exist should be recognized and mentioned in the document. Some well recognized services are not mentioned e.g. the Sheffield Asperger Syndrome Service, an NHS National Tertiary Service, which was originally set up by Professor Digby Tantam in 1995 and which has developed into a team offering specialist diagnostic and psychometric assessment, post-diagnostic support, groups, specialist counseling, psychological interventions, training and consultation.	Thank you for drawing our attention to the Sheffield Service, which we have added.
185.	AUTISM ALLIANCE UK	5	Full	2.6	18	5	We endorse this introduction (lines 7-17) and note the need for specialist assessment and diagnosis. One of our member charities is engaged in a project to set up such a facility	Thank you for your comments.
186.	WaASP		Full	2.6	18	1 0	After 'established.' we request that you insert the sentence 'The majority of NHS trusts have failed in their duty to provide a coherent pathway definition for adults with Asperger's syndrome'	Thank you for your comment; however it is not within the scope of the guideline to make such comments.
187.	Welsh Government		Full	2.6	18	5	AND Welsh Autism Strategy, Adult Assessment and Diagnosis Network	Thank you. This has been amended to reflect your comment.
188.	Hertfordshire Partnership NHS foundation Trust	2	Full	2.6.1	18	2 7	The NHS needs to work closely with Social Care and Education, since ASC does not just affect mental health but has an impact on independent living (housing, employment, social networks, leisure, shopping, travel)….Care pathways should therefore include liaison with these other agencies…. In order to strengthen the case for involving these agencies, it could also be said that the environment of the person with ASC (housing, employment etc, supra) has a recursive impact upon how well they are able to manage their ASC and also upon their mental health.	Thank you for you comment.
189.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.6.1	18	5	AND Welsh Autism Strategy, Adult Assessment and Diagnosis Network	Thank you. This has been amended to reflect your comment.
190.	Welsh Health		Full	2.6.1	18	2	The level of training and knowledge is limited amongst ALL	Thank you. This has been amended to reflect

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	Boards ASD Assessment & Diagnosis (Adults) Network					1	healthcare professionals, not just primary care	your comment.
191.	Association Directors of Adult Social Services	1 1	FULL	2.6.1	18	2 0 - 2 4	Support planning in identifying the approaches to achieve outcomes and promote independence not dependence. The support may require specific support in specific areas, some may require wrap around support encompassing dual needs such as a LD etc. Clarify what "Treatment" for Autism means, including the treatment of symptoms i.e. anxiety.	Thank you, these issues are dealt with a range of recommendations and are fully explained in the relevant sections.
192.	Welsh Government		Full	2.6.1	18	2 1	The level of training and knowledge is limited amongst ALL healthcare professionals, not just primary care	Thank you. This has been amended to reflect your comment.
193.	The Royal College of Psychiatrists, Learning Disability Faculty	5	Full	2.6.1	19	2 4	The cost range of supporting people with autism is much broader than that specified	Thank you. This comment probably refers to section 2.7. The cost range is based on published cost elements and figures (Knapp et al., 2009).
194.	Northumberland, Tyne & Wear NHS Trust		Full	2.6.2	18	2 7	2.6.2 The use of initial capitals implies that 'Social Care and Education' refers to the statutory services. There should be mention also of the Independent/Voluntary sector which provides a range of services not necessarily confined to these areas	Thank you. This has been amended to reflect your comment.
195.	Northumberland, Tyne & Wear NHS Trust		Full	2.6.2	18	2 7	2.6.1 and 2.6.2 We strongly support the contention that care pathways need to start with identification/diagnosis and end with a full package of support, and that wide and careful liaison between NHS outside agencies is crucial	Thank you for your comment.
196.		1 2	Full	4.3.4	18	3 0	It would be useful to make reference here to non-statutory organisations as they often have a key role in the planning and delivery of support services for adults with autism (e. National Autistic Society).	Thank you for your comments. We are unsure which section you are referring to and therefore unable to fully respond to your comment. Section 4.3.4 is a review of the literature in which the NAS was not mentioned.
197.	Nottinghamshire Healthcare NHS Trust	1 0	Full	2.6.2	18	3	We are unclear as to what the evidence is regarding the presence of a neurologist on the core diagnostic team for autism? In our experience neurologists are not typically core to an ASD diagnosis. Also, we have found the presence of a speech and language therapist particularly helpful within the core diagnostic team for adults, particularly where there may be undiagnosed developmental speech and language impairments (which can	Thank you for your comments. We have amended this in line with your comments.

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							either form part of the diagnostic presentation or be a differential diagnostic issue).	
198.	Nottinghamshire Healthcare NHS Trust	6 7	Full		18	3	Again, in view of core diagnosing criteria would question whether SLT should be mentioned as one of the 'qualified clinicians'.	Thank you, speech and language therapists are mentioned in relation more specifically to children.
199.	The Royal College of Psychiatrists, Learning Disability Faculty	2 7	Full	2.6.2	18	2 7	The use of initial capitals implies that 'Social Care and Education' refers to the statutory services. There should be mention also of the Independent/Voluntary sector which provides a range of services not necessarily confined to these areas	Thank you. This has been amended to reflect your comment.
200.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	2.7	18	3 2	We question the use of a study with health costs from USA where they have an entirely different health structure and it doesn't appear this has been adjusted for. Need to have access to UK info here, and if none available to recommend it for future research	Thank you. Chapter 2 is an introductory chapter, which gives background information on the condition, including associated costs. The reference to US costs is for information purposes only, and does not affect guideline recommendations in any way. Besides, we do acknowledge that Knapp and colleagues explained that "the different methodology, availability of data, different support systems and the assumption of a different discount rate in the USA contributed to the higher estimate of lifetime cost in the USA".
201.	WaASP		Full	2.7	18	4 0	We request that you add a final sentence to this paragraph; 'The difficulties experienced by NHS Trusts and administrators in identifying a pathway for adults with Asperger's syndrome has resulted in a great deal of time spent by statutory bodies up and down the country seeking a solution for treating a disorder that falls outside their standard structure. The current expenditure on office and clinicians' hours in the absence of clear direction is wasteful'.	Thank you for your suggestion. Unfortunately, we are unable to add anecdotal evidence in this section. This section is a review of costs associated with support of people with autism, based on published literature.
202.	Welsh Government		Full	2.7	18	3 2	We question the use of a study with health costs from USA where they have an entirely different health structure and it doesn't appear this has been adjusted for. Need to have access to UK info here, and if none available to recommend it for future research	Thank you. Chapter 2 is an introductory chapter, which gives background information on the condition, including associated costs. The reference to US costs is for information purposes only, and does not affect guideline recommendations in any way. Besides, we do acknowledge that Knapp and colleagues explained that "the different methodology, availability of data, different support systems and the assumption of a different discount

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								rate in the USA contributed to the higher estimate of lifetime cost in the USA".
203.	NCCMH expert reviewer	1 0	Full	2.7	19	2	The health economic analyses produced by Knapp and his team (bibliography: Knapp M, Romeo R, Beecham J. Economic consequences of autism in the UK. London: Mental Health Foundation and Autism Speaks; 2007.) are referred to in the introduction to the guideline. That work was completed before results were available regarding the prevalence and severity of ASD in adults in the community (Brugha et al, 2011; bibliography). Several key assumptions underlying the Knapp study are not supported by the subsequent prevalence research in adults. Therefore the results of the earlier work by Knapp et al should be considered with caution until the economic evaluation is updated in the light of current information on the adult general population. Further information is published on January 31, 2012, that takes into account the epidemiology of adults with intellectual disability and ASD (The report is at: www.ic.nhs.uk/pubs/autism11), which is very relevant to the economic modelling. These findings will cast a very different light on the extrapolation from childhood research in the NICE draft to the effect that at least 40% of adults with ASD do not have an intellectual disability (Baird et al 2006, quoted on page 81, line 6) giving for the first time ever precise population estimates for the number of adults who do and who do not have intellectual disability.	Thank you. The report by Knapp et al is the most up-to-date published evidence on the costs of children and adults with autism. According to the new study, the new estimated prevalence is 1.1% instead of 1% that was used in Knapp et al. Nevertheless, Knapp et al reported a sensitivity analysis using a higher prevalence of 1.16%, the results of which have now been included in the guideline text. The change in prevalence affects only the total cost of autism, and not the cost per person with autism. The study by Knapp et al is a cost of illness study and NOT an economic evaluation of interventions for people with autism, and its findings, although very useful in demonstrating the costs associated with support of people with autism, did not directly affect guideline recommendations as they did not assess the cost effectiveness of interventions for autism. The economic model developed for this guideline, which assessed the cost effectiveness of employment support for adults with autism, did not rely on the prevalence of autism and therefore was not affected by the slight increase in the estimated figure.
204.	Calderstones Partnership NHS Foundation Trust	4	Full	2.7	19	2	Should this say '*autisms*' or 'autism'?	Thank you for pointing this typo out, it has been amended.
205.	Specialist Autism Services	4	Full	2.7	20	7	Hoping that National Audit Office report 5 June 2009, Supporting People with Autism through Adulthood has been reviewed.	Thank you. Yes, it has been reviewed and this evidence in now included in the relevant chapter (chapter 6). In any case, the guideline does include recommendations on the establishment of specialist community-based multidisciplinary autism teams.

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206.	Nottinghamshire Healthcare NHS Trust	6 6	Full	3.3	22	2 2	Missed opportunity that there has been no Speech and Language Therapist (SLT) on the Guideline Development Group Members given that social-communication difficulties are part of the core diagnosing criteria.	Thank you for your comments. The membership of the GDG was consulted on during the scoping and deemed to be appropriate.
207.	AUTISM ALLIANCE UK	6	Full	3.3	22	2 4	As noted, "a representative from a service organisation" is not strong representation from specialist service providers, and the guideline suffers from this weakness, especially in Section 6	Thank you for your comment. The guideline states that there was *a representative from a service user organisation* and not a service provider organisation.
208.	AUTISM ALLIANCE UK	7	Full	3.3.3	23	1 3	As noted, "a representative from a service organisation" is not strong representation from specialist service providers, and the guideline suffers from this weakness, especially in Section 6	Thank you for your comment. The guideline states that there was *a representative from a service user organisation* and not a service provider organisation.
209.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	3.5.1	25	1 4- 2 5	No evidence of consultation with the Welsh Learning Disability, Autism and Neuro-developmental Disorders Research Network (LDAN)– funded by the Welsh Government and supported by NISCHR CRC.	Thank you for raising this with us. This has been an oversight and we will revise our methodology in future.
210.	Welsh Government		Full	3.5.1	25	1 4- 2 5	No evidence of consultation with the Welsh Learning Disability, Autism and Neuro-developmental Disorders Research Network (LDAN)– funded by the Welsh Government and supported by NISCHR CRC.	**Thank you for raising this with us. The onus is on organisations to register as stakeholders. This can be done on line and at any stage during the development of a guideline. All stakeholders are automatically included in correspondence relating to the guideline and will be alerted when the consultation draft is available.**
211.	Royal College of Nursing	3	Full	3.5.3	30	3 6	Contributions of experience of people with autism, service delivery and provision and their families were not evident in this document. It could have been better if these views included actual patients and / or carers' views rather than their narratives.	Thank you for your comments. The guideline development group did in fact include a member with autism. Also, stakeholders are welcome to submit their feedback during the consultation phase. We are unable to interview people directly and use this information in the guideline as this is primary research and fall outside the methodology of NICE guidelines.
212.	NCCMH expert reviewer	2	Full	3.5.6	34	1 1	Section 3.5. 6 refers to methods and standards for synthesising the evidence from test accuracy studies. In my opinion, the methods used to review case identification instruments do not incorporate adequately the use of published standards for	Thank you for your comment. As a result of your, and other peoples comments, and our awareness of the limitations of some of the included diagnostic test accuracy studies we

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							evaluating tests such as those developed by the Cochrane Collaboration (Reitsma JB, Rutjes AWS, Whiting P, Vlassov VV, Leeflang MMG, Deeks JJ. Assessing methodological quality. In: Deeks JJ, Bossuyt PM, Gatsonis C, editors. Cochrane Handbook for Systematic Reviews of Diagnostic Test Accuracy Version 1.0.0. The Cochrane Collaboration; 2009. p. 1-27). In my opinion there are substantive errors in the review of test accuracy studies that might not have occurred had a full standard been used. Explanatory details to follow below.	have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline). This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16
213.	Northumberland, Tyne & Wear NHS Trust		Full	4.1	50 - 73		4.1 and onward: That relationships are a central concern to those with autism and their carers, reflects the conceptually useful dichotomy between affective and cognitive empathy. The value of diagnosis to people with autism supports the centrality of work toward awareness and diagnosis in the autism strategy. The primacy that has been given to these issues in the full guide is good.	Thank you for your comments.
214.	Royal College of Nursing	4	Full	4.2	50	24	Assessment review question – there is a need to tailor assessment, diagnostic and intervention to individual needs	Thank you for your comment. We agree that it is important that assessment, diagnosis, and intervention takes into account the individual needs of adults with autism. Please see recommendations 4.3.7.5 and 4.3.7.7 which address this issue.
215.	Royal College of Nursing	5	Full	4.2	50	40	Personal experience is beneficial – for example, the use actual case stories would be more beneficial.	Thank you for your comment. Personal experience of care is reviewed in this section where published in peer reviewed journals which are amenable to systematic search.
216.	Nottinghamshire Healthcare NHS Trust	13	Full	4.3.3	52	26	Although not peer reviewed research, we feel it would be pertinent here to refer to the evidence gained through the Mencap report 'Death by Indifference' (2007) – highlighting experiences of people with ASD and families experiencing professionals as not understanding or being able to read their non verbal communication.	Thank you for your comment. This report is not autism specific and therefore did not meet inclusion criteria for the review.
217.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	4.3.3	56	7-13	It is with these impacts in mind that the action plan for adults with ASD in Wales has included the provision of pre and post-diagnostic counselling in order to address such issues.	Thank you for your comments. In response to yours and others' comments we have now made an additional recommendation regarding post-diagnostic support.
218.	Welsh Government		Full	4.3.4	56	7-	It is with these impacts in mind that the action plan for adults	Thank you for your comments. In response to

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						1 3	with ASD in Wales has included the provision of pre and post-diagnostic counselling in order to address such issues.	yours and others' comments we have now made an additional recommendation regarding post-diagnostic support.
219.	Nottinghamshire Healthcare NHS Trust	1 4	Full	4.3.4	59	1 3	A general observation about the relationships section – this section appears to be focussed heavily on the experiences of people who are verbal. It would be useful to include non-verbal individuals, and could usefully include literature reviews of using interactive approaches such as Greenspan, Zeedyk, and Intensive Interaction references such as Caldwell and Nind and Hewitt would provide more of a balance. www.intensiveinteraction.co.uk Caldwell, P. (2000) *You don't know what it's like*. Finding ways of building relationships with people with severe learning disabilities, autistic spectrum disorder and other impairments. Brighton: Pavilion Nind, M. (1999) Intensive Interaction and autism. A useful approach? *British Journal of Special Education*. 26/2 96-102. Zeedyk, M. Suzanne, Caldwell, Phoebe and Davies, Clifford E.(2009)'How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities?', European Journal of Special Needs Education,24:2,119 —137 To link to this Article: DOI:10.1080/08856250902793545	Thank you for your comment. The experiences of non-verbal adults with autism are represented on the GDG by the carers and in the qualitative literature under experience of carers and families. The increased risk of bias in other techniques designed to elicit the experience of care of non verbal adults with autism prohibits their inclusion in this review.
220.	Association Directors of Adult Social Services	1 2	FULL	4.3.4	62	3 4	Re enforce the need for awareness of being different from each other not to make assumptions of the autistic person will present identical to another with varying level and degree of impact on the individuals personality, wants, co morbidities.	Thank you for your comment. We agree that it is important to be aware that autistic people will not present identically to each other, however this was not a theme which emerged from the qualitative review for experience of care.
221.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	4.3.6	64	5- 1 0	It would be appropriate also to talk here and elsewhere in the document about the necessity to make "reasonable adjustments" under the Equality Act to ensure equality of access to health and social care and support	Thank you for your comments**,** but to make such recommendations is outside the scope of the guideline.
222.	Welsh Health Boards ASD Assessment &		Full	4.3.6	64	1 9- 2	Part of the work of the Welsh network has been to work together with regional leads and stakeholder groups to enable to provision of information at all levels – however, there is a	Thank you for your comment. The precise issue you raise, although important, is outside the scope of the guideline. However,

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	Diagnosis (Adults) Network					5	profusion of information in the public and professional domains from a wide variety of resources and of variable quality. There needs to be some quality standards applied to information provided by statutory bodies.	the guideline recommends what information should be provided to service users and carers, see sections 1.1.4, 1.1.6, 1.1.13, 1.1.14, 1.3.3, 1.3.5, 1.8.2 and 1.9.4 (recommendation numbers have been revised to: 1.1.4, 1.1.6,1.1.17, 1.1.18, 1.3.3, 1.1.7, 1.7.2 & 1.8.4).
223.	Welsh Government		Full	4.3.6	64	5- 1 0	It would be appropriate also to talk here and elsewhere in the document about the necessity to make "reasonable adjustments" under the Equality Act to ensure equality of access to health and social care and support	Thank you for your comments, but to make such recommendations is outside the scope of the guideline.
224.	Welsh Government		Full	4.3.6	64	1 9- 2 5	Part of the work of the Welsh network has been to work together with regional leads and stakeholder groups to enable to provision of information at all levels – however, there is a profusion of information in the public and professional domains from a wide variety of resources and of variable quality. There needs to be some quality standards applied to information provided by statutory bodies.	Thank you for your comment. The precise issue you raise, although important, is outside the scope of the guideline. However, the guideline recommends what information should be provided to service users and carers, see sections 1.1.4, 1.1.6, 1.1.13, 1.1.14, 1.3.3, 1.3.5, 1.8.2 and 1.9.4 (recommendation numbers have been revised to: 1.1.4, 1.1.6,1.1.17, 1.1.18, 1.3.3, 1.1.7, 1.7.2 & 1.8.4).
225.	AUTISM ALLIANCE UK	8	Full	4.3.7	64	3 6	4.3.7. Recommendations. We endorse these recommendations, subject to the detailed comments given below	Thank you for your comments.
226.	Association Directors of Adult Social Services	1 6	FULL	4.3.7	64- 66 65 66	Al l 2 8 3 1 1- 6	The guidance / recommendations need to be prominent (linked to above) Including other specific guidance points in the rest of the document such as 72-73, 116 Work in partnership with universal services, other agencies, housing, police, social care, primary care etc Guidance for consistent communication approaches required including written format advice and support. Needs to be promoted within National awareness campaign of inclusion and adaptation not just via the LA's Providing support not just care and treatment Section 4.3.7.8 is incomplete and therefore can not be commented upon. Removal of the term specialist Autism Team, as this is not an expectation. Should it be specialist autism interventions or	Thank you for your comments. We agree that a number of the issues you raise are important and we do address some, for example links with primary care and social care services. As is the need to provide advice in appropriate formats, National awareness campaigns are outside our scope. The specialist team recommendation was supported by the review of the work of the NAO and the expert view of the GDG. You provide no evidence to support your assertion it should be removed. We are unsure what your final point is referring to.

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							professionals in autism. Further explanation of this section, what type of setting is being suggested? Changing the professional from whom to whom?	
227.	Royal College of Nursing	6	Full	4.3.8	69	2 6	Public awareness and education of people with autism and their integration into society requires robust information sharing and collaborative working by agencies supporting care in this area. There is a need for attitudinal changes in the wider society including those who support and care for people with learning difficulties including autism.	Thank you for your comment. We agree that it is important that there is public awareness of autism, this arose in the service user experience of care review, see section 4.3.4. However, the role of agencies supporting care in this area did not emerge as a theme.
228.	Nottinghamshire Healthcare NHS Trust	2 1	Full	4.3.8	70	8	We would advise use of the full title 'Speech and Language Therapy'	Thank you for your comment. This has been amended in section 4.3.8 of the full guideline.
229.	Nottinghamshire Healthcare NHS Trust	2 2	Full	4.3.8	70	9	Re: SLT & OT uptake was low in some areas (HARE2004). If this statement is to be included it perhaps needs to be qualified with a question (as in other sections of the guidance) highlighting that people (with ASD, carers, professionals) will not necessarily understand how to use a service if it has not been made available to them previously, or information has been given about it.	Thank you for your comment. This has been amended from "though uptake was low in some areas" to "though low numbers of people using these services were reported" in section 4.3.8.
230.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	4.3.9	71	3 6	There really are no services. How are families and individuals to be proactively supported to maintain their mental health (duty of care)?	Thank you for your comment. We agree that it is important that families and service users receive appropriate support, see recommendation 1.1.10.
231.	The Royal College of Psychiatrists, Learning Disability Faculty	6	full	5	74	1	The whole section on case identification and assessment is thorough and gives very sensible and practical advice, especially on simple screening tools for General Practitioners and other individuals who may first have an index of suspicion. The focus on specific issues for women, older adults and BME populations is particularly welcomed.	Thank you for your comments.
232.	South London and Maudsley NHS Trust	1 0	Full	5.1	73	2 8	If they are carers, they have a statutory right to a carer's assessment.	Thank you for your comment. We have highlighted carers' right to an assessment in recommendation 4.3.11.3.
233.	NCCMH Expert Reviewer	4	Full	5.1	74	1 2	See comment 5	Thank you for your comments. This has been amended in sections 2.2, 5.1 and 5.2.1 of the full guideline.
234.	Northumberland,		Full	5.1	74	1	Dysexecutive syndrome and communication difficulties,	Thank you for your comment we have

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	Tyne & Wear NHS Trust					2	although subtle, can have a disproportionate effect on more able adults, affecting their potential for autonomous function and, for this reason, they should be emphasised as should the support required throughout their care pathway	amended the introductory chapter to include this (see section 2.1.5).
235.	Northumberland, Tyne & Wear NHS Trust		Full	5.1	74	1 3	Is it only 20% of adults that have not had a formal diagnosis – the guidelines might cite the source of this figure.	Thank you for your comments. This has been amended in sections 2.2, 5.1 and 5.2.1 of the full guideline.
236.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	5.1	74	1 8	This does not take account of the work of the Welsh Network for Assessment and Diagnosis	Thank you for highlighting this omission. We have amended this section to include information about the Welsh Network for Assessment and Diagnosis.
237.	The Royal College of Psychiatrists, Learning Disability Faculty	3 1	Full	5.1	74	1 2	Dysexecutive syndrome and communication difficulties, although subtle, can have a disproportionate effect on more able adults, affecting their potential for autonomous function and, for this reason, they should be emphasised as should the support required throughout their care pathway	Thank you for your comment we have amended the introductory chapter to include this (see section 2.1.5).
238.	The Royal College of Psychiatrists, Learning Disability Faculty	3 3	Full	5.1	74	1 3	Is it only 20% of adults that have not had a formal diagnosis – the guidelines might cite the source of this figure.	Thank you for your comments. This has been amended in sections 2.2, 5.1 and 5.2.1 of the full guideline.
239.	Welsh Government		Full	5.1	74	1 8	This does not take account of the work of the Welsh Network for Assessment and Diagnosis	Thank you for highlighting this omission. We have amended this section to include information about the Welsh Network for Assessment and Diagnosis.
240.	NCCMH Expert Reviewer	5	Full	5.1	75	6	Both on pages 74 & 75 on lines 12 & 6 respectively, the text explains that a further explanation of the issue of '20% of adults with autism have never received a formal diagnosis' is further clarified in Chapter 2 (text states 'see Chapter 2'). In Chapter 2, I could find no mention of this 20% figure in the text. The obvious place to include it is in section 2.2, Incidence and Prevalence (page 16, FULL). Could you clarify this issue please? It seems to be a very important point which will be of value to clinicians and families.	Thank you for your comments. This has been amended in sections 2.2, 5.1 and 5.2.1 of the full guideline.
241.	AUTISM ALLIANCE UK	1 1	Full	5.2.1	75	1 5	5.2.1 Introduction. This (lines 16-30) is very well expressed	Thank you for your comments.
242.	South London and Maudsley NHS Trust	1 1	Full	5.2.1	75	2 9	I've also seen people who actually had a learning disability diagnosed with autism (ie they didn't have autism).	Thank you for your comments.
243.	Nottinghamshire	2	Full	5.2.1	75	3	It may be useful to refer here to Bishop, D.Whitehouse, A.	Thank you for your comment. This reference

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	Healthcare NHS Trust	5				0	Watt, H. and Line, E. (2008) Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder DOI: 10.1111/j.1469-8749.2008.02057.x Published online 31st March 2008 paper on people diagnosed with Specific Language Impairment who are later diagnosed as ASD in adulthood.	has been added to section 5.2.1 of the full guideline.
244.	Royal College of Nursing	9	full	5.2.5	77	1 4	Diagnosis – early identification and treatment and management of co-existing condition. There is a need for support for families here.	Thank you for raising this important issue. We have addressed this issue by adding a new recommendation regarding post-diagnostic support.
245.	AUTISM ALLIANCE UK	1 2	Full	5.2.7	79	5	5.2.7. Clinical evidence summary. This section is well expressed and we endorse the approach, subject to the detailed comment below	Thank you for your comments.
246.	Nottinghamshire Healthcare NHS Trust	2 6	Full	5.2.7	79	1 8	This may be covered in the Allison et al (in press) 'red flags' paper, but we feel it would be useful here to add in more specific information regarding potential markers for autism in adults. We note the presence of such markers in the NICE guideline for children and young people (Full guideline, tables 1-3, pp63-66) which has been reported locally to be very helpful.	Thank you for your comment, the purpose of the initial recommendations was to highlight key signs or symptoms or previous contact with services which would alert a healthcare professional to the possible presence of autism. The GDG took the view that an extensive list of symptoms as you suggest would not be feasible for use in primary care and similar settings.
247.	Nottinghamshire Healthcare NHS Trust	2 7	Full	5.2.7	80	2 5	The inclusion of this factor may not account for adults with or suspected of having Asperger syndrome, who have not previously been in receipt of any services.	Thank you for your comment. Please see recommendation 5.3.12.1 in the full guideline where it is made clear that previous or current contact with services is only one of a number of factors which might prompt further assessment, and further assessment would not be ruled out on the basis that an individual had previously not been in receipt of any services
248.	AUTISM ALLIANCE UK	1 3	Full	5.2.7	80	1 5	The two bullet points at lines 15 and 16 identifying the two key diagnostic issues for autism are too widely expressed. As expressed, someone who is shy would meet the first criterion. "Resistance to change" in the second criterion (line 16) is again too wide: people can resist change for many reasons, some of them entirely valid. Taking the two together, someone who is "shy and timid" or "shy and unselfconfident" could easily fall within the criteria as expressed here. We suggest "persistent	Thank you; this has been amended to reflect your comment.

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							and substantial difficulties in social engagement" (etc) as being preferable in line 15.	
249.	AUTISM ALLIANCE UK	1 4	Full	5.2.7	80	1 6	We suggest "Strong resistance to change in, for example, diet, routine, environment" as a possible alternative to line 16.	Thank you; this has been amended to reflect your comment.
250.	Northumberland, Tyne & Wear NHS Trust		Full	5.2.7	80	1 6	It is unclear whether 'repetitive or stereotypic behaviours' includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise.	Thank you for your comment, repetitive or stereotypic behaviours does cover restricted and circumscribed interests
251.	The Royal College of Psychiatrists, Learning Disability Faculty	3 4	Full	5.2.7	80	1 6	It is unclear whether 'repetitive or stereotypic behaviours' includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise.	Thank you for your comment, repetitive or stereotypic behaviours does cover restricted and circumscribed interests
252.	AUTISM ALLIANCE UK	1 5	Full	5.3.1	81	9	We suggest adding after "services" [the first word in line 9] the words "in respect of their autism"	Thank you; this has been amended to reflect your comment.
253.	South London and Maudsley NHS Trust	1 2	Full	5.3.1	81	1 1	Or the Autism Assessment Clinic at the Maudsley Hospital in Camberwell, London	Thank you for bringing this to our attention, it has been added.
254.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	5.3.1	81	3	This does not take account of the work of the Welsh Network for Assessment and Diagnosis	Thank you for highlighting this omission; we have amended this section to include information about the Welsh Network for Assessment and Diagnosis.
255.	Welsh Government		Full	5.3.1	81	3	This does not take account of the work of the Welsh Network for Assessment and Diagnosis	Thank you for highlighting this omission; we have amended this section to include information about the Welsh Network for Assessment and Diagnosis.
256.	NCCMH expert reviewer	4	Full	5.3.5	85	2	A staff completed questionnaire tested in mental health service users NYLANDER2001 was not subjected to data extraction; by contacting the authors who are still active clinical researchers in Gothenburg Sweden it may be possible to calculate test statistics (Study ID NYLANDER2001). The same test has also been used in samples of patients on high secure wards in England and appears to be useful in identifying male patients likely to have an ASD (for example, see Study ID FERRITER2001). As this test has the unusual merit of having been tested in samples in which it would be expected to be useful and used in future practice I advise that with little further effort it could be incorporated into the NICE review.	Thank you for your comment. The NYLANDER2001 study was excluded from the review as the sensitivity and specificity data was unreliable, given that not all participants had a clear diagnosis. The FERRITER2001 study was also excluded from the review as sensitivity and specificity data could not be extracted from the paper.
257.	NCCMH expert reviewer	3	Full	5.3.7	89		Table 12 summarises evidence for four studies testing the Autism Quotient (AQ, 50, 21, and 10 item versions). For the shorter versions (21, 10 item AQ) sensitivity, specificity, LR+	Thank you for your comment. Diagnostic accuracy studies were reviewed which compared a recognised diagnostic accuracy

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							are very high and LR- is very low, which would be interpreted as showing that this is a good test. However the test samples are not of adults on whom the test would be used or needed in practice. Two groups of study subjects are described both with statistically extreme certainty regarding the reference diagnosis: patients seen by an autism clinic with a confirmed diagnosis and general population controls including university students. Furthermore a (screening) test is hardly needed and would not be used for either of these groups. Different results would be obtained if the test was evaluated in for example patients that GP's, area social workers, or general psychiatrists consider might merit referral to an autism assessment clinic. But there are no evaluations of this test in such populations (and the need for this should be highlighted). The same problem was first recognised in medicine some decades ago because initially promising screening tests for physical diseases such as cancer, when re-evaluated in settings in which they were expected to be used, failed to work adequately (Ransohoff DF, Feinstein AR. Problems of spectrum and bias in evaluating the efficacy of diagnostic tests. N Engl J Med 1978 Oct 26;299(17):926-30. AND Mulherin SA, Miller WC. Spectrum bias or spectrum effect? Subgroup variation in diagnostic test evaluation. Ann Intern Med 2002 Oct 1;137(7):598-602). This problem is addressed in the Cochrane standards referenced above.	test (the index test) to a gold standard clinical diagnosis according to DSM-IV/ICD-10 criteria. However, we are aware of the limitations of such studies and have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline). This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general population screener, and as such the emphasis was on sensitivity over specificity.
258.	South London and Maudsley NHS Trust	1 3	Full	5.3.8	93	5	I think you mean to identify 'possible' autism – these are screening, not diagnostic instruments.	Thank you for your comment. The word 'possible' has been added prior to all 'autism' references in section 5.3.8 of the full guideline
259.	South London and Maudsley NHS Trust	1 4	Full	5.3.8	93	1 5	Don't know what normal means here – seems strange usage. Redundant I think. Why not say autism 'without intellectual disability'?	Thank you for your comment. The subheading in section 5.3.8 of the full guideline has been amended from 'Identification of *normal/high-functioning autism'* to 'Identification of *possible autism when IQ>70'*
260.	South London and	1	Full	5.3.8	94	1	Surely you mean possible autism. Don't know the instrument,	Thank you for your comment. The word

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	Maudsley NHS Trust	5				9	unless it includes a detailed developmental history, it's probably a screening instrument.	'possible' has been added prior to all 'autism' references in section 5.3.8 of the full guideline. The PDD-MRS is a case identification instrument consistent with its inclusion in this section of the review.
261.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	5.3.9	95	2 4	This section is equally applicable to those whose primary language is Welsh. As this guidance is for England and Wales, there need to be a consideration throughout of the need for assessment, support and information to be given through the medium of the individual's preferred language	Thank you for your comment but this is a matter for local implementation. The issue of accessible information is addressed in the 'person centred care' section of the NICE guideline.
262.	Welsh Government		Full	5.3.9	95	2 4	This section is equally applicable to those whose primary language is Welsh. As this guidance is for England and Wales, there needs to be a consideration throughout of the need for assessment, support and information to be given through the medium of the individual's preferred language	Thank you for your comment but this is a matter for local implementation. The issue of accessible information is addressed in the 'person centred care' section of the NICE guideline.
263.	AUTISM ALLIANCE UK	1 6	Full	5.3.9	96	7	Older adults (lines 8-36). We endorse this introduction	Thank you for your comments.
264.	NCCMH Expert Reviewer	6	Full	5.3.9	97	2 7	The issue of possibly significantly higher prevalence (6%) than for the general population of ASD in gender dysphoria seems to me to be of ethical importance. Is there a need to specifically raise this issue with gender reassignment health services (GRHS)? I suspect that the level of knowledge about ASD (including among the mental health colleagues within these GRHS teams) may be low. I have raised this issue with the special health board in Scotland that has responsibility for GRHSs. I think that NICE could take a helpful lead on this issue. What should clinicians do, for example, about the issue of a patient attending for gender reassignment surgery who is suspected of having a hitherto undiagnosed ASD? What should clinicians do if they suspect that a patient has received gender reassignment surgery without their concurrent presentation of ASD having been noticed by the clinical service before that (irreversible) surgery was undertaken? In short, would improved ASD awareness in GRHSs significantly change / improve clinical practice in this very vulnerable and cost-intensive group of patients?	Thank you for your comment, the GDG could find no evidence relevant to this the issue that would support a recommendation/discussion of the type you refer to with GRHS. This may be an issue for commissioners to take up with local GRHSs. We felt more data on the prevalence of the problem in people with autism (not the usual focus for a NICE recommendation) was needed before we could make a research recommendation.
265.	Welsh Health Boards ASD Assessment & Diagnosis (Adults)		Full	5.3.1 1	97	3 6	Unclear why SCQ and PDD-MRs are not in the list of options and the objectives do not say this has to be self-report	Thank you for your comment. As outlined in section 5.3.2 and in Chapter 3 of the full guideline, in addition to examining sensitivity, specificity and psychometric data for

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	Network							diagnostic test accuracy studies, the GDG also considered the clinical utility of case identification instrument. For instance, would the instrument be feasible and implementable in routine clinical care? The GDG considered the ASQ/SCQ and PDD-MRS data and decided not to recommend these instruments based on concerns regarding their clinical utility. Namely, that the ASQ/SCQ is not freely available and can only be used with permission from the developers, and the PDD-MRS has to be administered by a practitioner with considerable experience. These considerations are outlined together with the review of the diagnostic accuracy data in section 5.3.7 of the full guideline.
266.	Welsh Government		Full	5.3.1 1	97	3 6	Unclear why SCQ and PDD-MRs are not in the list of options and the objectives do not say this has to be self-report	Thank you for your comment. As outlined in section 5.3.2 of the full guideline, in addition to examining sensitivity, specificity and psychometric data for diagnostic test accuracy studies. In order for the GDG to consider recommending a case identification tool for prompting further assessment of autism it was required to have clinical utility such that the case identification instrument would be feasible and implementable in routine clinical care. The GDG considered the ASQ/SCQ and PDD-MRS data and decided not to recommend these instruments based on concerns regarding their clinical utility. Namely, that the ASQ/SCQ is not freely available and can only be used with permission from the developers, and the PDD-MRS has to be administered by a practitioner with considerable experience. These considerations are outlined together with the review of the diagnostic accuracy data in section 5.3.7 of the full guideline.
267.	Sussex Partnership NHS Foundation	2	Full	5.3.1 1	98	1 3	From our clinical experience of using the AQ-50 with a large number of patients, we felt it should be noted in the guidance	Thank you for your comment, we have adjusted the recommendation in light of your

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	Trust						that individuals who lack insight into their social communication difficulties may not be picked up by this screening tool if self-completed.	and others' comments.
268.	Sussex Partnership NHS Foundation Trust	3	Full	5.3.1 1	98	1 3	From our clinical experience of using the AQ-50, we have found a lot of individuals with autism struggle with the wording of the rating 'strongly disagree etc' and found this difficult to understand and sometimes respond with the opposite of their intention. We felt a visual rating scale would be more appropriate to this population.	Thank you for your comment. This may the case but unfortunately we found no evidence of the use of such measures and are therefore unable to recommend.
269.	Royal College of Speech and Language Therapists	5.	Full	5.3.1 1	98	8- 2 4	It is unclear whether the AQ-10 is being recommended for use in primary care as a initial screener? Line 10 suggests its not however line 22 suggests is would be appropriate. Speech and language therapists report that they have false positive results from using the AQ-26 with adults with no learning disability especially when the cases are more complex.	Thank you for your comment, we have adjusted the recommendation in light of your and others' comments. It is intended to be used to inform a primary care practitioner where an index of suspicion already exists, not as a general screening tool.
270.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 0	Full	5.3.1 2	99		It might be better to refer to 'Child Health services' rather than simply 'CAMHS'. Adults would rarely have 'current' contact with CAMHS 'Learning disability services' could be replaced with 'mental health and learning disability services'	Thank you for your comment we have amended this to read 'mental health or learning disability services.'
271.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 2	Full	5.3.1 2	99		Explanation of neurodevelopmental disorder should be given ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment, this has been amended.
272.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 4	Full	5.3.1 2	99		Scores less that 7 on the AQ, it should not debar them from further assessment. If this is not clear it will be used as a gate-keeping tool	Thank you for your comment. Please see recommendation 5.3.12.2 in the full guideline which includes 'a high index of suspicion based on clinical judgement' as a basis for offering a comprehensive assessment for autism
273.	Calderstones Partnership NHS Foundation Trust	5	Full	5.4	100 Ge ner al		In adult learning disability services (for individuals with an IQ below 70), due to the complexities of differential diagnosis (personality disorder, schizophrenia, disrupted attachment etc) and the frequent lack of available/reliable family informants, it is important to use an MDT approach to diagnosis, and also use a combination of diagnostic tools such as the DISCO or ADI-R and the ADOS together. This reduces diagnostic uncertainty,	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of

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							however is obviously more costly for purchasers.	autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
274.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.1	100	3 1	Although implied throughout, it might be helpful to make it clear at this stage that an informant is necessary in order both to give a developmental history and to give an external (and often more objective) account of the individuals behaviour	Thank you for your comment. Please see recommendation 1.2.5 in the NICE guideline where it is made clear that a comprehensive assessment where possible should involve a family member, carer or other informant
275.	Royal College of Nursing	7	Full	5.4.1	100	1	Assessment and effective diagnosis with the appropriate resource is needed if these guidelines are to succeed in addressing the needs of these people and their families especially adults. Also reviews are not mentioned. This should include care provision.	Thank you for your comment, funding matter for implementation. The requirement for review is set out in recommendation 1.6.1 (revised recommendation number: 1.3.5).
276.	The Royal College of Psychiatrists, Learning Disability Faculty	4 4	Full	5.4.1	100	3 1	Although implied throughout, it might be helpful to make it clear at this stage that an informant is necessary in order both to give a developmental history and to give an external (and often more objective) account of the individuals behaviour	Thank you for your comment. Please see recommendation 5.4.8.1 in the full guideline where it is made clear that a comprehensive assessment where possible should involve a family member, carer or other informant
277.	Royal College of Speech and Language Therapists	6.	Full	5.4.4	108	3 3	The activities in modules 1 and 2 of the ADOS G are not age-appropriate for adults with learning disabilities.	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline
278.	Royal College of Speech and Language Therapists	7.	Full	5.4.4	108	3 5	There is specific training for the ADOS and you are assessed to check you have inter-rater reliability.	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline
279.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 7	Full	5.4.3	104 - 122		It is noted that the tools are considered appropriate for use in gathering information for clinical assessment, however due to lack of researched evidence they not been included among the suggested aids to diagnosis. This needs clarification It is not clear in the NICE version why the ADI and DISCO be excluded	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
280.	Tees, Esk & Wear Valleys NHS	1 9	Full	5.4.3	111 -2		The times given to administer the assessment tools appear very brief and not consistent with clinical practice	Thank you for your comment. The times given to administer are taken from the

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	Foundation Trust							evidence.
281.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	104-122	general	Evidence to justify AQ does not seem to be available for scrutiny and so recommendation for widespread use is not appropriate.	Thank you for your comment; however this is not the case. The evidence was fully reviewed in section 5.3.5 and 5.3.7 of the full guideline (Allison *et al.,* 2012).
282.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	104-122		Use of ADOS training needs clinical staff to attend training course.	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline
283.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	104-122		For ADI-R training DVDs are available from WPS the publishers	Thank you for your comment. However, no amendment was considered necessary to the guideline as it is stated that training is required for the ADI-R.
284.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	104-122		Standardised measures does assist clinical practice but diagnosis cannot be made using any single measure but always needs to involve multidisciplinary assessment with info from more than one source and setting leading to clinical diagnosis and appreciation of skills and needs of the individual (and their family and local supports). Current literature is that there is no community based evidence available to recommend use of any one assessment or diagnostic tool.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
285.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	104-122	general	5.4.4 – 5.4.8 The rationale of the review of autism instruments is not entirely clear. The criteria for diagnosis are those set out in (for example) ICD & DSM. It is a clinical judgement whether the individual meets those criteria based on the information that the clinician gathers. This section accepts the ADI-R and DISCO as instruments that help the researcher to identify cases against which other instruments may be tested. However, apparently because they lack the studies to confirm their statistical value, they have not been included among the suggested aids to diagnosis – instead, the guidelines recommend the use of instruments that have been validated against cases identified with (for example) the ADI-R. Even if this interpretation of the guidelines is incorrect, it needs clarification and, because of their standing, explicit statements about the status of the ADI and DISCO.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
286.	The Royal College	45	Full	5.4.4 –	104 -	Ge	**5.4.4 – 5.4.8** The rationale of the review of autism instruments is not entirely clear. The criteria for diagnosis are those set out	Thank you for your comment. We have revised these recommendations to take

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	of Psychiatrists, Learning Disability Faculty			5.4.	122	n er al	in (for example) ICD & DSM. It is a clinical judgement whether the individual meets those criteria based on the information that the clinician gathers. This section accepts the ADI-R and DISCO as instruments that help the researcher to identify cases against which other instruments may be tested. However, apparently because they lack the studies to confirm their statistical value, they have not been included among the suggested aids to diagnosis – instead, the guidelines recommend the use of instruments that have been validated against cases identified with (for example) the ADI-R. Even if this interpretation of the guidelines is incorrect, it needs clarification and, because of their standing, explicit statements about the status of the ADI and DISCO.	account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
287.	Nottinghamshire Healthcare NHS Trust	3 0	Full	5.4.4	105	2 3	There appears to be no further reference to the use of the Sensory Behavior Schedule, nor any research relating to its validity. We wonder if the Brown & Dunn (2002) 'adolescent/adult Sensory Profile' may have more validity to recommend? There is some evidence base for reliability and validity, though not ASD specific e.g. Brown, C. Tollefon, N. et al (2000) The Adult Sensory Profile: measuring Patterns of Sensory Processing American Journal of Occupational Therapy, 55, 75-82. Other assessment tools have also been administered in research examining sensory presentations in ASD e.g. Kern, J et al (2006) Examining sensory quadrants in autism Pfeiffer, B. et al (2005) Sensory modulation and affective disorders in children and adolescents with Asperger disorder American journal of Occupational Therapy, 59, 335-345 Kern, J. et al (2006) The pattern of sensory processing abnormalities in autism. Autism, 10, 480	Thank you for your comment. The inclusion criteria for autism assessment instruments were that diagnostic instruments were developed for the assessment of autism (but not generic assessment instruments developed to diagnose a range of disorders). On this basis the Sensory Behaviour Schedule (SBS) was excluded from further review as it was not autism-specific. This has been added as a footnote in section 5.4.4
288.	Nottinghamshire Healthcare NHS Trust	3 1	Full	5.4.4	105	2 6	We wonder if it may be useful here to make recommendations regarding a broader remit of assessments specific to multidisciplinary colleagues, such as clinical psychology occupational therapy and speech and language therapy. For example, additional assessments that would be used by a Speech and Language Therapist to contribute to diagnosis could usefully include:	Thank you for your comment. In terms of the clinical evidence summary the GDG decision was to include only diagnostic instruments that were developed for the assessment of autism (and not generic assessment instruments developed to diagnose a range of disorders). However, the GDG recognised that a comprehensive assessment should be

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							The TROG (Test for Reception of Grammar Bishop 2003) highlights someone's ability to understand specific grammatical structures: To assess language skills. The Clinical Evaluation of Language Fundamentals (Semel, Wiig, Secord 2006) assesses several areas of language including concepts and following directions, recalling sentences, word classes, word definitions and understanding spoken paragraphs: To assess different aspects of language and pragmatic rating scale. The Awareness of Social Inference Test (Flanagan, McDonald, Rollins 2002) assesses an ability to read emotions from both verbal and non verbal situations and read social inference including simple and paradoxical sarcasm: (used in conjunction with Strange Stories). Might also use colour cards pack 'what are they thinking' here. The Putney Auditory Comprehension Screening Test (Beaumont et al 2002) can be used to assess a persons response to yes/no questions. – Might use informally to assess someone's responses to absurdity of questions and to consider integration of verbal and non verbal communication. The Communication Activities of Daily Living (Holl, Fromm, Frattali 1999) assesses functional communication including reading and using numbers, social interaction, sequential relationships and contextual communication. Some social aspects of assessment, as well as planning and sequencing skills in relation to time. The ERRNI (Expression, Reception, and Recall of Narrative Instrument Bishop 2004) explore a person's ability to understand, follow sequences, explain a story and then recall this after an interval. Consideration of organisation and planning of communication as well as interpretation of social situations in stories. The Communication Checklist - self report (Bishop,	team-based and draw on a range of professions and skills, and in addition to assessing core symptoms of autism should assess behavioural problems, functioning in different settings, and sensory sensitivities, and this is reflected in recommendations 5.4.8.1 and 5.4.8.3 in the full guideline.

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							Whitehouse and Sharp 2009) and The Communication checklist – Adult (other report) (Whitehouse and Bishop 2009) Excellent resources for highlighting differences in language and social/pragmatic difficulties – could be used as a screening resource. Assessing and Developing Communication and Thinking Skills in people with Autism (Silver, 2005). Would use the assessment interview section especially with those who are non verbal.	
289.	NCCMH expert reviewer	7	Full	5.4.4	105	1 4	The Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al., 2002). The decision not to include this highly regarded assessment method is in my opinion unjustified. I recognise the problem that there is insufficient test data on the DISCO in the public domain. But it is the only truly diagnostic assessment method currently available by which I mean that it evaluates the full range of neuro-developmental disorders seen in children and adults, such as specific speech and language impairment, Tourettes, ADHD etc. Whereas well regarded and NICE endorsed methods such as the ADI-R and the ADOS only test for one disorder: autism, and therefore cannot address the issue of clinically systematically identifying co-morbid developmental disorders. Training in the DISCO is also by far the most thorough of its kind and is highly regarded in the NHS. An abbreviated version of the DISCO is being developed for initial use in busy autism clinics. I would recommend adding the DISCO to the short form of the guideline (page 18 of 50, paragraph 1.2.8).	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
290.	NCCMH Expert Reviewer	8	Full	5.4.4	108	3 5	I think the statement 'no specific training is required for clinical use (although experience with autism is required to use it effectively)' could be reconsidered. Those of us who use ADOS regularly know that it is a challenging instrument to master even by a clinician with several years experience of ASD assessment. It is potentially misleading to explain the situation in the way you have. 'Experience with autism' is not the only issue. As well as requiring some experience of autism, clinicians need to be shown, by someone who knows what they are doing, how to use the ADOS materials. As an alternative suggestion in this part of the text, you could	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline

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							advise: 'whilst no specific training is required for clinical use, clinicians will not be able to use ADOS effectively without some form of ADOS orientation or even mentoring.' In explanation, you could reference our study (which was also referenced by the NICE guideline for children and young people with ASD) which explains a model of ADOS orientation for clinicians new to autism assessment: A comparison of a specialist autism spectrum disorder assessment team with local assessment teams. McClure, I; MacKay, T; Mamdani, H; McCaughey, R. Autism, vol. 14 (6) 589-603; 373369; 1362-3613 (2010).	
291.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	108	3 5	ADOS definitely needs training both for clinical and research use etc. The statement 'no specific training is required for clinical use' implies that there is evidence of its effectiveness when used by someone who has not had such training. This statement appears incorrect and should be removed unless convincing evidence can be cited.	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline
292.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	108	2 6- 2 7	The comment that the ADI-R is 'not excessively lengthy' contradicts published critiques so that the term 'excessively needs to be expanded.(also see comment below for Table 15 about the times given for assessments).	Thank you for your comment. The phrase 'and is not excessively lengthy' has been amended in section 5.4.4 of the full guideline
293.	The Royal College of Psychiatrists, Learning Disability Faculty	4 7	Full	5.4.4	108	3 5	The statement 'no specific training is required for clinical use' implies that there is evidence of its effectiveness when used by someone who has not had such training. **This statement appears incorrect and should be removed unless convincing evidence can be cited**.	Thank you for your comment. This has been amended in section 5.4.4 of the full guideline
294.	The Royal College of Psychiatrists, Learning Disability Faculty	4 8	Full	5.4.4	108	2 6- 2 7	The comment that the ADI-R is 'not excessively lengthy' contradicts published critiques so that the term 'excessively needs to be expanded. (also see comment below for Table 15 about the times given for assessments)	Thank you for your comment. The phrase 'and is not excessively lengthy' has been amended in section 5.4.4 of the full guideline
295.	WaASP		Full	5.4.4	108	1 5	We have not previously heard of this diagnostic tool AAA which sounds on the face of it, excellent. Can further information be found?	Thank you for your comment. The Adult Asperger Assessment (AAA) includes the Autism-Spectrum Quotient (AQ) and the Empathy Quotient (EQ). For further information about the AAA, please see section 1.3.1 in appendix 14 of the full guideline for the study characteristics for the

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								included study for the AAA (BARONCOHEN2005) or see full reference: Baron-Cohen, S., Wheelwright, S., Robinson, J., *et al*. (2005) The Adult Asperger Assessment (AAA): a diagnostic method. *Journal of Autism and Developmental Disorders, 35*, 807-819.
296.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	108 - 109	general	For some instruments it is mentioned that clinical experience (as against specific training) is necessary. This stipulation should be made for all the instruments, but clinical experience alone is not sufficient for some tools	Thank you for your comment, This stipulation has subsequently been removed for the ADOS as training is required. As a result, section 5.4.4 should no longer make the clinical experience versus training differentiation and should thus address your point.
297.	The Royal College of Psychiatrists, Learning Disability Faculty	49	Full	5.4.4	108 - 109	General	For some instruments it is mentioned that clinical experience (as against specific training) is necessary. This stipulation should be made for all the instruments.	Thank you for your comment, This stipulation has subsequently been removed for the ADOS as training is required. As a result, section 5.4.4 should no longer make the clinical experience versus training differentiation and should thus address your point.
298.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	109	27	It is unclear why the CARS cannot be used alone to reach a diagnosis of autism.	Thank you for your comment. The CARS cannot be used alone to reach a diagnosis of autism as it has been suggested that scores do not correspond to current DSM-IV/ICD-10. However, the CARS has subsequently been removed from this section as it has only been validated in children (mean age of sample <17 years)
299.	The Royal College of Psychiatrists, Learning Disability Faculty	50	Full	5.4.4	109	27	It is unclear why the CARS cannot be used alone to reach a diagnosis of autism.	Thank you for your comment. The CARS cannot be used alone to reach a diagnosis of autism as it has been suggested that scores do not correspond to current DSM-IV/ICD-10. However, the CARS has subsequently been removed from this section as it has only been validated in children (mean age of sample <17 years)
300.	Sussex Partnership NHS Foundation	5	Full	5.4.4	110 - 15		Tools such as the ADI and DISCO are excellent in children fulfilling the Gold standard for assessment of ICD & DSM criteria. The only question about adulthood validity is the	Thank you for your comment. We have revised these recommendations to take account of your comment and included

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	Trust						reliability of the informant ie accuracy of parental memory. In the absence of any other means of obtaining developmental history for substantive diagnosis, acquiring this data could be a recommendation of the group and quantify its validity	separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
301.	The Royal College of Psychiatrists, Learning Disability Faculty	51	Full	5.4.4	111-12		Table 15 The times given for assessments using various instruments seem remarkably brief, particularly in the case of any but the most straightforward adult with clear-cut autism - e.g. more realistic times for the ADI would be 2-3.5 hours; the ADOS (module 4) is more likely to take an hour; the CARS would be about an hour. Shorter interview times suggest either an unusual level of expertise in the interviewer (that is unlikely to be achieved by people of more average experience) or that the interview has become a checklist of leading questions and that the answers lack the support of corroborative detail.	Thank you for your comment. However, the administration times are based on the test manufacturer's guidelines.
302.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	111-2		Table 15 The times given for assessments using various instruments seem remarkably brief, particularly in the case of any but the most straightforward adult with clear-cut autism - e.g. more realistic times for the ADI would be 2-3.5 hours; the ADOS (module 4) is more likely to take UP TO an hour; the CARS would be about an hour. Shorter interview times suggest either an unusual level of expertise in the interviewer (that is unlikely to be achieved by people of more average experience) or that the interview has become a checklist of leading questions and that the answers lack the support of corroborative detail.	Thank you for your comment. The times given to administer are taken from the evidence.
303.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.4	112		Table 15 For the ADOS-G, the statement 'Not designed to measure change but can be used for response to treatment.' seems internally inconsistent in that, if it can be a measure of response, it must be measuring change. A compromise position is that learning effects must be taken into account.	Thank you for your comment. We agree that this statement is misleading and have removed it from the table in the full guideline.
304.	The Royal College of Psychiatrists, Learning Disability Faculty	51	Full	5.4.4	112		Table 15 For the ADOS-G, the statement 'Not designed to measure change but can be used for response to treatment.' seems internally inconsistent in that, if it can be a measure of response, it must be measuring change.	Thank you for your comment. We agree that this statement is misleading and have removed it from the table in the full guideline.
305.	NCCMH expert reviewer	6	Full	5.4.4	113		Assessment methods, Section 5.4. In regard to diagnostic instrument testing the same limitations as set out above should apply to the results reported in table 16. For example, this	Thank you for your comment. Diagnostic accuracy studies were reviewed which compared a recognised diagnostic accuracy

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							limitation specifically applies in my view to the RAADS-R (table 16) (Ritvo et al., 2008 [RITVO2008]; Rivto et al, 2011 [RIVTO2011].). The specificity and sensitivity results (both = 1.0; RIVTO2011) should have caused some scepticism. According to the methods of the two published evaluations (RAADS and RAADS-R) by the authors the test samples had little uncertainty and were not samples in which the test would be used in practice: the group seen by clinics were only those with a confirmed diagnosis (removing those who were not diagnosed leading in effect to a biased sample). Thus the studies should also have included patients referred to the clinic found not to have autism; this might have provided information on whether the questionnaire is useful to clinics screening received referrals. The RAADS-R is also discussed here in the section on assessment methods: in my opinion it is not an assessment method (what is also concerning is that no training in its use is required – although it is expected that the administrator has training, unspecified, in autism). It's recommended use is also listed in the short form of the guide and should not be (page 18/50, paragraph 1.2.8). The RAADS-R could however prove to be a good test: we are testing it against a reference diagnosis in a random sample of adult users of mental health service users funded by NIHR-CLAHRC: http://www2.le.ac.uk/departments/health-sciences/research/psychiatry/adult/freya-links/Protocol-ASD%20v7.1-11102010x.pdf	test (the index test) to a gold standard clinical diagnosis according to DSM-IV/ICD-10 criteria. However, we are aware of the limitations of such studies and have subsequently added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline). This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. The RAADS-R is intended to be administered by clinicians in conjunction with a clinical interview and is therefore classified as an assessment instrument.
306.	AUTISM ALLIANCE UK	17	Full	5.4.4	116	14	We endorse the view that any assessment process should be undertaken by professionals who are trained and competent and have specific knowledge of autism and its assessment. "Any assessment" should also include any assessment of needs for services: as discussed earlier (our comment 10) "basic" understanding is not enough.	Thank you for your comment. We have made this clear in the recommendation.
307.	Brain-in-Hand Ltd	3	Full	5.4.5	116	12	1.2.5 very strongly agree that "A comprehensive assessment should: • be undertaken by professionals who are trained and competent • be team-based and draw on a range of professions and skills • where possible involve a family member, carer or other informant or use documentary evidence"	Thank you for your comment. We agree a comprehensive assessment is incredibly important.

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							This should help to ensure adequate standards and to minimise under/over diagnosis	
308.	Nottinghamshire Healthcare NHS Trust	3 2	Full	5.4.5	116	3 6	These needs to read 'impairment of…' not just the descriptors.	Thank you for your comment. However, these are components of a comprehensive assessment and do not necessarily infer impairment. Please see recommendation 5.4.8.3 in the full guideline where the elements of a comprehensive assessment are listed along with their quantifiers, e.g. symptoms, problems, functioning, disorders, and sensitivities
309.	Nottinghamshire Healthcare NHS Trust	3 3	Full	5.4.5	116	4 1	It would be useful to add in sensory difficulties here.	Thank you for your comment. The list provided in section 5.4.5 outlines the key components of a comprehensive autism assessment as identified by the GDG and is not intended to be exhaustive. However, please see recommendation 5.4.8.3 in the full guideline where hyper- and hypo-sensory sensitivities are listed as a necessary assessment/enquiry during the comprehensive autism assessment
310.	South London and Maudsley NHS Trust	1 6	Full	5.4.5	116	1	Important: I don't agree with the GDG here. The whole point is to improve access to diagnostic and care/support services for people with ASDs. If you make the diagnostic process logistically complex (and you certainly are) you will make access to diagnosis difficult, by definition. There are large numbers of people out there with clear ASDs in whom any competent psychiatrist could include the diagnosis and exclude differentials by reference to developmental information (however acquired) and current state. It's only with the less obvious cases or partial phenotypes that recourse should be made to special tools, in my view. Schizophrenia is also a non-dichotomous disorder that may present in very subtle ways – are you suggesting that the diagnosis should only be made by specially trained people using a particular tool? This would be totally unworkable in the	Thank you for your comment. We agree that the use of a range of additional measures to structure the assessment and aid diagnosis will not be necessary in all cases. This is what we intended in our initial recommendations – we have revised them in order to remove any misunderstanding.

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							clinical context and with current resources, and would prevent diagnosis and treatment. At the rates of ASD that you correctly describe, the numbers of people with possible ASDs seen by CMHTs is huge. Put this (even implied) bar to diagnosis in at this time (ie 'you have to be an expert and use a special tool') when overall services in the NHS are being cut and resources are increasingly scarce and you will scare clinicians off making the diagnosis, even where it's obvious, with clear consequences for the person concerned. For clarity, I am not saying that in a non-completely obvious case a diagnosis should be made in the absence of a special tool with the psychometric properties you have reviewed; I am saying that as with any other mental disorder, in an obvious case the diagnostic criteria are contained within ICD/DSM and should be used by clinicians. The RCPsych has recently produced a very helpful but non-standardised interview schedule to aid clinicians in the making of a diagnosis in an obvious case. In my opinion your guidance as it currently stands will decrease rates of diagnosis and act counter to your intent.	
311.	Royal College of Nursing	8	Full	5.4.5	116	1	Role of clinicians in assessment – need to look at their skills/training	Thank you for your comment. This will be an implementation issue for each service.
312.	Nottinghamshire Healthcare NHS Trust	3 4	Full	5.4.5	117	3 2	Re: specialist diagnostic assessment must also address individual needs in relation to personal and social functioning and educational, housing and occupational needs. The assessment of these functions and needs may be provided from within a specialist autism team, <u>but where this is not possible it should be the responsibility of the people within the team </u>[our emphasis] to obtain and coordinate these specific assessments by other competent individuals. We would suggest that relates to commissioning and not just service providers.	Thank you for this comment.
313.	Nottinghamshire Healthcare NHS	3 5		5.4.5	117	4 1	It would be useful to clarify here whether the group is separating out that there may be additional 'communication	Thank you for your comment. The heading under which this appears 'Assessment of

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	Trust						problems' different to those integral to autism?	coexisting conditions' in section 5.4.5 and the beginning of the sentence 'significant coexisting…communication problems' distinguishes the communication problems referred to here as distinct from those integral to autism
314.	South London and Maudsley NHS Trust	17	Full	5.4.5	117	26	Dysmorphic, not dimorphic.	Thank you for your comment. This has been amended in section 5.4.5 of the full guideline.
315.	British Dietetic Association	6	Full	5.4.5	118	14	To include nutrition and diet related problems	Thank you for your comment. However, this list is illustrative rather than exhaustive
316.	British Dietetic Association	7	Full	5.4.5	118	17	Consider including reference to the American consensus report Buie T, Campbell D, Fuchs GJ III, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics. 2009; 125(s1):S1–S18 – and inclusion of the table which identifies signs of gastro distress which warrant further investigation by gastroenterologists – eg tip toeing → possible constipation, etc.	Thank you for your comment. This section summarises GDG consensus judgements based on the reviewed evidence and the report mentioned was not included in the review
317.	Nottinghamshire Healthcare NHS Trust	36		5.4.5	118	7	Given that communication issues are listed as co-existing with autism, it may be useful to note here the useful addition of assessment related to speech, language, and communication.	Thank you for your comment. Please see recommendation 1.2.10 (revised number) in the NICE guideline where 'communication difficulties' are listed as a coexisting condition which should be taken into account and assessed for during a comprehensive assessment
318.	Nottinghamshire Healthcare NHS Trust	37		5.4.5	119	4	We also feel it would be important to note communication difficulties as pertinent in relation to risk issues e.g. non-verbal individuals with severe learning disability being misinterpreted when in pain; e.g. individuals with Asperger syndrome misinterpreting social situations with risky consequences.	Thank you, we think this issue is dealt with in the advice for assessment and use of a range of aids to assessment and diagnosis.
319.	Nottinghamshire Healthcare NHS Trust	38	Full	5.4.5	119	31	This assessment feedback could usefully include treatment options regarding speech, language and communication, and not just the current skills.	Thank you for your comment, in response to this and others' comments we have added a recommendation regarding post-diagnostic support.
320.	Northumberland, Tyne & Wear NHS Trust		Full	5.4.5	119	24	An initial discussion should address whether, whatever the findings of the assessment, the individual wished for (or would be helped by) a diagnosis of Autism. In someone who already has acquired the label, it should address whether it still applies.	Thank you for your comment, in response to this and others' comments we have added a recommendation regarding post-diagnostic support.
321.	Welsh Health		Full	5.4.5	119	1	Here and elsewhere in the guidance reference is made to	Thank you for your comment. The

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	Boards ASD Assessment & Diagnosis (Adults) Network						challenging behaviour. The guidance should take into account and reference appropriately the joint report of the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists : Challenging Behaviour – A Unified Approach : good practice guidance for the support of people who present behavioural challenges.	recommendations are based on a review of the evidence and the interpretation of that by the GDG. It is not NICE style to incorporate other reports if they are not based on systematic review of the evidence.
322.	Welsh Government		Full	5.4.5	119	1	Here and elsewhere in the guidance reference is made to challenging behaviour. The guidance should take into account and reference appropriately the joint report of the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists : Challenging Behaviour – A Unified Approach : good practice guidance for the support of people who present behavioural challenges.	Thank you for your comment. The recommendations are based on a review of the evidence and the interpretation of that by the GDG. It is not NICE style to incorporate other reports if they are not based on systematic review of the evidence.
323.	Sussex Partnership NHS Foundation Trust	4	Full	5.4.7	120	1 1	We felt that tools such as the DISCO and ADI, although not found to have sufficient reliability and validity data in adults, could be recommended as tools to guide the gathering of developmental history for diagnosis. This is consistent with the recommendation that the NICE-recommended tools were to augment a clinically-led assessment. We also felt that the associated training for these courses was a helpful tool in developing broader skills in assessment of autism.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
324.	British Psychological Society		Full	5.4.7	121	4	Professional guidance on assessment and intervention for challenging behaviour for people with learning disabilities is available (British Psychological Society, 2004; Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists, 2007). It would be helpful to direct readers to this guidance for more in-depth information in this area.	Thank you for your comment. The recommendations are based on a review of the evidence and the interpretation of that by the GDG. It is not NICE style to incorporate other reports if they are not based on systematic review of the evidence.
325.	British Psychological Society		Full	5.4.7	121	1 1	Information about sensory sensitivities in the proposed NICE guidance is limited. It would be useful to direct readers to literature where this is further discussed (e.g. Royal College of Nursing, 2011).	Thank you for your comment. The recommendations are based on a review of the evidence and the interpretation of that by the GDG. It is not NICE style to incorporate other reports if they are not based on systematic review of the evidence.
326.	AUTISM	1	Full	5.4.8	121	1	Recommendations. We endorse the recommendations subject	Thank you for your comments.

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	ALLIANCE UK	8				3	to the following specific comments, some of which are critical	
327.	Welsh Government		Full	5.4.8	121	1 4	The Welsh Government has commissioned the Network to develop an All Wales Diagnosis and Pre-Post Diagnosis Counselling Service for adults with ASD. This is also relevant to those people who, when assessed, are not diagnosed with ASD.	Thank you, in response to your and other peoples' comments, we have added a new recommendation on providing a post-diagnostic follow-up appointment to discuss the implications of diagnosis (see recommendation 1.2.18 in the NICE guideline)
328.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	5.4.8	121	1 4	'Suspected' – change to "possible"	Thank you for your comment but the GDG preferred the term 'suspected' as it implied a greater deal of certainty than 'possible'.
329.	Association Directors of Adult Social Services	1 3	FULL	5.4.8	121 - 126		Include the development of techniques with the individual to manage specific issues. Including management of risk, introduction of practical interventions and inclusion of routines and rituals positively where appropriate.	Thank you for your comment. We have included the need to manage risks tailored to the individual in recommendation 1.2.13. (revised recommendation number 1.2.15).
330.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 0	Full	5.4.8	122		The common risks could include the risk of breakdown of stable placement (including educational, employment, family) or financially The guidelines will also apply to adult mental health and forensic setting, a wider list of disorders could be included Assessment should explain how symptoms and traits functioning, the emphasis should be on formulation rather than simply diagnostic labelling. This is the emphasis within the TEWV draft pathway that was presented to NICE after being requested, for their consideration in developing the guidelines It is disappointing that there is no reference to the pathway's examined and any good practice already in evidence given such documents were requested and provided	Thank you for your comment. The assessment of risk, including risk of breakdown of family or residential support is covered by recommendation 5.4.8.8 in the full guideline. The list of possible differential diagnoses and coexisting disorders or conditions is not intended to be exhaustive but is an illustrative list of conditions which commonly coexist with autism. We agree that the purpose of assessment should be to assess needs and not just a diagnostic labelling process, and this is reflected in recommendation 5.4.8.3 in the full guideline where the elements of a comprehensive diagnostic assessment are outlined. The review of existing pathways was part of the systematic literature search. However, although providing helpful contextual information, this evidence did not meet eligibility criteria for inclusion in the guideline as clinical evidence.
331.	Tees, Esk & Wear	2	Full	5.4.8	124		It may be more helpful to comment on a risk of altered	Thank you for your comment. It is difficult to

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	Valleys NHS Foundation Trust	2					sensitivity and idiosyncratic responses	amend this as there was no evidence is supplied to support this.
332.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 4	Full	5.4.8	124		Structure - This should include predictability - as defined in NAPC - the lack of ambiguity	Thank you for your comment, This is at a level of detail not appropriate in guideline recommendation.
333.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 5	Full	5.4.8	145		The team should be real rather than virtual The TEWV team was cited as an example of local innovation within the Strategy by creating a team to share goals and actions in a defined pathway The teams should be created as part of current functioning services in MH and LD with a specialist tertiary service to refer to in defined situations. This should not be an automatic referral as expertise is needed in secondary MH	Thank you for your comment. We agree that this should be a 'real team', sharing a common team base and have a common operational policy. The precise structure is for local services to determine but as can be seen in our recommendation on team functioning it is clear that we do not expect that all people with autism will be referred to the specialist team.
334.	The National Autistic Society	8	Full	6.1		1 6 – 1 8	The Autism Act 2009 is an enabling piece of legislation that compelled the Secretary of State to produce a strategy and statutory guidance. Some may be confused, due to the wording, of the extent that the Act includes direct clauses relating to the goals set out in the strategy. We would recommend a slight amendment and suggest that you start the paragraph by talking about the Autism Act 2009 first and then move onto the strategy and statutory guidance. Often, when we are discussing the Act etc, we say: *Following the passing of the Autism Act 2009, the Adult Autism Strategy was published in March 2010. After the 2010 election the new Government said that it was committed to taking the strategy forward and we have been working with the Department of Health on implementation. Subsequently, and in line with the Act, statutory guidance for local authorities and local health bodies was published on 17th December, 2010. The guidance sends a clear message that local authorities and the NHS must improve:* • *training for their staff* • *identification and diagnosis of autism in adults* • *planning of services for people with autism, including the transition from child services to adult services* • *local leadership*	Thank you for your suggestion, we have reviewed the text in light of your comment and made some adjustments.

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335.	The National Autistic Society	9	Full	6.1		18	Should be 'Act' not 'act'	Thank you for pointing this error out, it has been amended.
336.	The National Autistic Society	10	Full	6.1		19	Should be 'statutory guidance' and not 'strategic guidance'.	Thank you for pointing this error out, it has been amended.
337.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	6.1	128	28	Are the MH guidelines adequate for extrapolation to this area, just because there is little ASD adult research?	Thank you for your comment. We believe that the NICE guideline represent the best sources of advice on the treatment of comorbid conditions in the absence of much evidence which directly addresses the issue. Where possible we have provided some advice about the manner in which the treatment of coexisting disorders (and any adaptations to current treatment) should be adjusted but it will be up to individual clinicians to make an informed judgement as to what extent they follow the advice the in the relevant guidelines.
338.	Calderstones Partnership NHS Foundation Trust	6	Full	6.2	131	7, 8.	States *'Error! Reference not found'*.	Thank you for pointing this out, it has been amended.
339.	Northumberland, Tyne & Wear NHS Trust		Full	6.2.2	130		Table 7 Population The GDG decision that extrapolation from an intellectual disabilities population was valid (as against 'might be valid') implies a level of confidence which should be explained more fully. It would seem similar to the issue of using the evidence from populations with mental health problems dealt with in 6.3.1	Thank you for your comment. The term 'valid' here refers to the use of the method. When using evidence extrapolated from other populations the GDG 'downgraded' the quality rating of the evidence and developed recommendations accordingly.
340.	The Royal College of Psychiatrists, Learning Disability Faculty	64	Full	6.2.2	130		**Table 7 Population** The GDG decision that extrapolation from an intellectual disabilities population was valid (as against 'might be valid') implies a level of confidence which should be explained more fully. It would seem similar to the issue of using the evidence from populations with mental health problems dealt with in 6.3.1	Thank you for your comment. The term 'valid' here refers to the use of the method. When using evidence extrapolated from other populations the GDG 'downgraded' the quality rating of the evidence and developed recommendations accordingly.
341.	Northumberland, Tyne & Wear NHS Trust		Full	6.3	131 - 132		Although comments on style are asked for only for the NICE Guidance, the reader needs to refer to the Full document to understand the reasons for the recommendations and, in particular, for omissions. The Full guideline needs therefore to be reasonably accessible and might be edited with this in mind. A particular example is Section 6.3. where the repetition might	Thank you for your comment, the evidence chapter is structured according to a recognised template and by necessity there may be repetitions but we will seek to minimise these in our final edit.

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							be substantially reduced by condensing 6.3.1, 6.3.2 and 6.3.3 and simplifying the English (6.3.3 being particularly difficult to understand)	
342.	The Royal College of Psychiatrists, Learning Disability Faculty	6 5	Full	6.3.1	131 - 132		Although comments on style are asked for only for the NICE Guidance, the reader needs to refer to the Full document to understand the reasons for the recommendations and, in particular, for omissions. The Full guideline needs therefore to be reasonably accessible and might be edited with this in mind. A particular example is Section 6.3. where the repetition might be substantially reduced by condensing 6.3.1, 6.3.2 and 6.3.3 and simplifying the English (6.3.3 being particularly difficult to understand)	Thank you for your comment, the evidence chapter is structured according to a recognised template and by necessity there may be repetitions but we will seek to minimise these in our final edit.
343.	AUTISM ALLIANCE UK	2 5	Full	6.3.2	132	2 2	In our general comments at the start of this response we note the slight evidence base for Section 6, which is noted here	Thank you for your comments.
344.	The National Autistic Society	1 1	Full	6.3.5		5 – 1 8	As this guideline has so excellently picked out, the key to supporting adults with autism is to ensure that they supported early through activities that meet their needs. The NAS has long campaigned to see local authorities and the NHS spend money on 'prevention' rather than on 'crisis management'. Unfortunately, in our experience, this is still frustratingly lacking in many areas. Too often we are seeing adults falling into the criminal justice system or into acute mental health services because of the lack of support. We are also acutely aware of the drastic impact this has on families/carers. As the National Audit Office[9] has shown, supporting adults with autism when they go into crisis is costly and often done out of area – which will be discussed below. Clearly, the GDG have been unable to cost many of the savings according to the very high standard that NICE would normally expect, nonetheless, we believe it would be a missed opportunity for this guideline not to stress the vital importance of prevention. We would suggest, therefore, that in section 6.3.5 recommendations (or at very least free text) could be inserted	Thank you for your comment. Our view is that the economic model developed for this guideline did meet NICE criteria and high standards. Clinical data and costs considered in the model were based on published evidence. On the other hand, a number of input parameters in the NAO model were based on unpublished sources and assumptions. Moreover, the scope of the NAO economic analysis was broader than the perspective recommended by NICE (i.e. NHS and personal social services). Therefore, in the guideline model the GDG considered inclusion of costs according to the NICE recommended perspective, based on the best evidence available. The NAO model assessed the effectiveness of identifying and managing adults with high-functioning autism using a multidisciplinary team vs. standard care (and all related clinical benefits and cost savings related to identification and presence of a MDT). The greatest proportion of savings was

[9] NAO (2009) *Supporting people with autism through adulthood*, The National Audit Office.

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							to stress this and that these recommendations (or text) are included in the shorter NICE version. These recommendations need not be extensive, but should emphasise the need to look very closely at services being commissioned – or potentially being commissioned – and judging them not solely based on their outcomes, but on a benchmark of how much is being spent on adults with autism before the services existed or in similar sized local authorities. It should also stress that the recommendations made in this guideline are there to stop individuals failing into crisis or needing those, expensive, extra levels of support. We would also suggest that it may be useful for quotes to be drawn from Department of Health guidance – such as Prioritising Need in the context of Putting People First – and the strategy/statutory guidance which also highlight the importance of spend to save arguments.	attributable to the high rate of recognition (leading to further support) of this population by the MDT compared with standard care (4% vs. 1%) which was based on a NAO survey and (unpublished?) data from specialist services. The GDG judged that the NAO economic model was characterised by several limitations, as the analysis was based on a number of assumptions. Nevertheless, the economic model has been included in the guideline systematic review of economic literature and is presented in chapter 6.
345.	AUTISM ALLIANCE UK	2 6	Full	6.3.5	133	4	6.3.5 Recommendations. These are fine as far as they go. It is sensible in addition to refer back to (or repeat) the need for awareness, including specialist awareness, of autism and how it may present	Thank you for your comment.
346.	Hartlepool Borough Council (Tees Valley ASD Group, Middlesbrough Council Stockton Borough Council, Redcar & Cleveland Council)	1	Full	6.4.1	133	2 1	Would NICE consider the inclusion within its findings the NHS-Specialised Services National Definitions Set (3rd Edition) in particular Specialised Mental Health Services (all Ages) Definition No 22. Section 7 of the guidance refers to Specialised Services for Aspergers Syndrome and Autism Spectrum Disorders (AS and ASD) and provides detailed description of Specialised service activity	Thank you for your comment. We have considered this but do not think it appropriate to include these definitions in the guideline. They may be helpful to local services when implementing the guideline.
347.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	6.3.5	133	5	There is no principle covering carer needs.	Thank you for your comment. Please see section 4.3.11 of the full guideline which makes recommendations for involving families and carers, including offering support to access the help and support they need.
348.	Northumberland, Tyne & Wear NHS Trust		Full	6.4.2	136		Studies considered: It is regrettable that no studies on entire care pathways for people with autism were identified. This may reflect methodological difficulties and a recent climate of	Thank you for your comment. We agree it is regrettable there are no studies in this area.

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							constant service change.	
349.	NCCMH expert reviewer	8	Full	6.4.4	141	3	I wish to comment on the key adaptation in recommendation 7 (table 20) in regard to the 'professional overseeing the whole period of care'. The cited study SCHALOCK1984 (page 156, table 27) might be viewed as supporting the following advice. For each service area and care pathway there should be a clear and agreed specification of how the oversight role is locally agreed (and managerially supported). Good practice indicates that this role is often successful within a secondary care health team if it is taken on by a team social worker with training and experience in dealing with mental health issues. This coordination role should be agreed by area social service access teams working with the primary care team for service users not in contact with a secondary care team or with a local specialist autism team if one exists. Staff undertaking this role need additional training in supporting adults with ASD. In the short form of the guidance the wording is appropriate and need not be altered (page 36 of 50; 1.9.7, final bullet point).	Thank you for your comment, the Schalock study compares intervention for community living skills across two settings and as such does not relate to recommendation 7 in table 20. We note your comments on care coordination, but think it is a matter for local determination which professionals take on this role.
350.	Royal College of Nursing	1 0	Full	6.4.4	141	2 1	Transition from childhood to adult social care needs to be seamless. Often there are issues on who is responsible for which service or provision, for instance, in housing and some aspects of care, there is no clear cut information of professionals' responsibilities. Also, an adult may get better care by staying within the family unit (if they wish). In practice, this is often not taken into consideration.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
351.	Association Directors of Adult Social Services	1 4	FULL	6.4.4	141 - 143		Feedback supported the development of local strategy groups for pathway development across all health and social care inclusive of employment and universal services. Needs to interface with Transition and skills development for young people preparing for their future as an adult.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
352.	Social Care Institute for Excellence	3	Full	6.4.5	143	T e xt b o	The point about services being built around the pathway, and not vice versa, is a good one, but perhaps could be expressed more clearly.	Thank you for your comment. We have reviewed the recommendation and have decided not to amend it.

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353.	Social Care Institute for Excellence	4	Full	6.4.6	144	28-31	Unclear. As it reads it seems to lack adult mental health or learning disability input. This is clarified to some extent in 6.4.7.2, but the two sections could be re-drafted to make it clearer.	Thank you for this comment we have amended this section in light of yours and others' comments.
354.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	6.4.7	144	26	The experience in Wales of locality stakeholder groups has been mixed – successful in enabling engagement with 3rd sector and social services but poor in engaging health and criminal justice systems. Groups are not proven an efficient means to generate care pathways. Definitely agree involvement of all elements required. In Wales we have experience of trying to implement care pathways in our Local Health Board areas which is but a sub group of a macro ASD pathway – and have an appreciation of the scale of the change programme required. It would be more useful to state that a project plan needs to be generated within designated areas with clear leads established for the individual components. The project plan needs to have within it clear lines of accountability including senior representation in the statutory organisations.	Thank you, we agree with this comment but this is a matter for local implementation, not for the guideline.
355.	Welsh Government		Full	6.4.7	144	26	We have local ASD stakeholder groups whose responsibility is to engage with all statutory organisations and the third sector. Groups are not proven an efficient means to generate care pathways. Definitely agree involvement of all elements required. In Wales we have experience of trying to implement care pathways in our Local Health Board areas which is but a sub group of a macro ASD pathway – and have an appreciation of the scale of the change programme required. It would be more useful to state that a project plan needs to be generated within designated areas with clear leads established for the individual components. The project plan needs to have within it clear lines of accountability including senior representation in the statutory organisations.	Thank you, we agree with this comment but this is a matter for local implementation, not for the guideline.
356.	Association Directors of Adult Social Services	17	Full	6.4.7	144-145		A clear rational and clear outline of the scope for specialist Autism Teams needs to be made, whilst there is a recognition that specialist knowledge is required and in some cases due to	Thank you for your comment. We agree that it would be inappropriate for all care to be provided by specialist services and this is

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							the level of complexity some specialist intervention required, this must be balanced with the risk of exclusion from mainstream services whereby everything is seen as an Autism issue with assumptions and stereotyping re-enforced, losing the individual to the diagnosis without a clear framework established. As it could be perceived that the experts are the only person who can work with someone who has Autism, which not only becomes discriminatory for an individual on the spectrum who require low grade support and who does not want to be in a specialist team but is also not sustainable both in cost and equality. Further review of the processes and eligibility criteria should be reviewed from the positive examples of specialist teams already established to determine the mechanisms to minimise the risks of the above and the longer term sustainability as the growth of the population of individual's with an Autism diagnosis increases, prior to a blanket recommendation being made. Consideration of a range of options to reflect the diagnosis across the full spectrum needs to be made including reasonable adjustments being available with appropriate training to support individuals within existing resources particularly where there are comorbidity needs with access to specialist practitioners in Autism where required.	made clear in our recommendations. The other issues you raise are essentially matters for local implementation and outside of the scope of the guideline.
357.	AUTISM ALLIANCE UK	3 3	Full	6.5.1	149	7	The draft states that "in some few cases there are residential services for people with autism" (emphasis added). We would challenge the word "few". People with autism have different needs, and many will not need residential services. Equally, there will be a sizeable minority for whom residential services are appropriate. Alliance members support more than 500 adults in residential accommodation.	Thank you for highlighting this, it was a error and has been amended.
358.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 7	Full	6.5.4	156 /16 7		The place and provision of specialist provision in mental health services, including specialist autism inpatient and day-patient provision needs to be defined. This is of ongoing concern in the case of MH admission for able adults. This will also be helpful from a commissioning perspective in considering the development of specialist services above what is currently in local existence	Thank you for your comment, we agree but see this as largely a matter for local implementation and determination.
359.	Northumberland, Tyne & Wear NHS Trust		Full	6.5.4	156 - 167	g e n	It would be helpful to have guidance about the place and provision of specialist provision in mental health services, including access to specialist autism services such as second	Thank you, we agree and believe that we set out these options both in the assessment recommendations and those for the structure

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						er al	opinion, further specialist assessments if not available in local team such as OT, SALT etc. inpatient and day-patient provision. (areas which would appear to fall under Section 4.2a of the Final Scope).	and role of the specialist teams. We do not consider it appropriate to provide further detail on these issues which should be a matter for local determination.
360.	The Royal College of Psychiatrists, Learning Disability Faculty	7 1	Full	6.5.4	156 - 167	G e n er al	It would be helpful to have guidance about the place and provision of specialist provision in mental health services, including specialist autism inpatient and day-patient provision. (areas which would appear to fall under Section 4.2a of the Final Scope).	Thank you, we agree and believe that we set out these options both in the assessment recommendations and those for the structure and role of the specialist teams. We do not consider it appropriate to provide further detail on these issues which should be a matter for local determination.
361.	Northumberland, Tyne & Wear NHS Trust		Full	6.5.4 - 6.5.6	156 - 158		Do these recommendations apply to people of normal+ intellectual ability (e.g. people with Asperger syndrome)? If so, it should be made explicit, particularly as the ‘evidence’ is all to do with people of limited intellectual ability.	Thank you for your comment. They do apply to people across the whole range of intellectual abilities. When any recommendation is limited to a specific group this is specified.
362.	Nottinghamshire Healthcare NHS Trust	4 7	Full	6.5.4	156	1	It would be useful in this section to incorporate evidence of other clinical approaches such as Intensive Interaction approaches e.g. Zeedyk & Caldwell; Nind & Hewitt (references made above in point 14).	Thank you for your comment. However, there was no evidence which met the eligibility criteria for review on these other clinical approaches. For instance, Zeedyk and Caldwell describes an intervention but would have been excluded from our comparison of clinical effectiveness as there is no control group meaning that efficacy data cannot be extracted.
363.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	6.5.7	164	1 3	Explain how person-centred planning actually become personalisation – beyond the rhetoric?	Thank you for your comment. We have made a significant number of recommendations that address the issue of the development of a person centred approach including the active involvement of the person with autism (and where appropriate their families and carers). We assume by personalisation that you are referring to the move to develop individual budgets to people with autism which is currant being implemented in health and social care. This is an important issue but is outside the scope of the guideline.
364.	Northumberland, Tyne & Wear NHS Trust		Full	6.5.7 - 6.5.1	158 - 167		It would be helpful to include guidance on the support/management/training/supervision of care staff working with people with autism.	Thank you for your comment, this is an important point but beyond the scope of the guideline. This is for local and national

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				0				implementation.
365.	AUTISM ALLIANCE UK	3 4	Full	6.5.8	166	2 1	Section 6 acknowledges the weak evidence base from settings of care for adults with autism. The decision was taken to extrapolate from (again quite limited) data from settings for adults with intellectual disabilities. This approach is, of course, fraught with danger: people with autism, by definition, are not neurotypical, and data from non-specialist autism settings may have little relevance and may be misleading. The dangers manifest themselves strongly on page 166, in section 6.5.8 at lines 21-23. The evidence, as noted, is exclusively based on populations with intellectual disabilities, rather than on people with autism. The comment is then made that "it should be noted that a significant proportion, if not the majority, of individuals with autism who live in residential accommodation will have intellectual disabilities". The logic here has self-evidently gone seriously wrong: • many people with autism in residential accommodation do not have intellectual difficulties • even if, as stated, the majority of people with autism in residential accommodation have intellectual difficulties, the converse does not apply: i.e. it is not the case that the majority of people with intellectual difficulties in residential accommodation have autism, and it is therefore misleading to extrapolate from a larger population to the much more specific autism population • the primary purpose of the Guideline is, we suggest, to concentrate on autism and on what works for people with autism. In this section, the decision has been taken to use a flawed proxy for autism (intellectual disability) as a basis for recommendation. This is logically and in practical terms a serious error. The approach should be based on outcomes for people with autism, some but not all of whom will have intellectual difficulties, rather than on outcomes for people with intellectual difficulties, some of whom will have autism • more specifically, the evidence summary, explicitly and	Thank you for your comment. The GDG considered very carefully whether or not to extrapolate from a learning disabilities population when considering recommendations for residential care. Given the significant proportion of people with autism and learning disabilities in residential care the GDG considered this an appropriate extrapolation in line with the agreed methods. In developing the recommendations for this section the GGD had in mind the needs of people with autism with all ranges of intellectual ability.

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							startlingly, does not include evidence from ANY specialist autism service. This makes any recommendations of limited – and perhaps negative – value.	
366.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	6.5.8	166	17	The conclusions in this paragraph are welcome and not dissimilar to the situation for people with intellectual disability alone. This should be consistent with information coming from the DoH review post "Winterbourne" and the emerging findings of the CQC programme of unannounced inspections with regard to concerns about standards of care and safeguarding in institutional settings.	Thank you for your comment. This section is a clinical summary of the evidence reviewed and therefore it would not be appropriate to include information from policy documents in this section.
367.	Welsh Government		Full	6.5.8	166	17	The conclusions in this paragraph are welcome and not dissimilar to the situation for people with intellectual disability alone. This should be consistent with information coming from the DoH review post "Winterbourne" and the emerging findings of the CQC programme of unannounced inspections with regard to concerns about standards of care and safeguarding in institutional settings.	Thank you for your comment. This section is a clinical summary of the evidence reviewed and therefore it would not be appropriate to include information from policy documents in this section.
368.	Nottinghamshire Healthcare NHS Trust	48	Full	6.5.9	166	35	Re: the GDG also concluded that certain environments were more conducive to the effective provision of care to adults with autism. We feel it is important to add that staff attitudes and values, and their knowledge of ASD can also have a significant impact to effective provision.	Thank you for this comment, the recommendations have been amended in line with your suggestions.
369.	Nottinghamshire Healthcare NHS Trust	49	Full	6.5.9	166	39	Again, we would reiterate the importance, particularly within residential care settings, to include staff values and beliefs.	Thank you for this comment, the recommendations have been amended in line with your suggestions.
370.	Hertfordshire Partnership NHS foundation Trust	5	Full	6.5.9	166	31	Small group living situations should be preferred over larger settings This observation is not evidence or research based but comes from clinical experience. Because their particular profile of skills and difficulties is very different from the profile of a person with an intellectual disability, a small group living situation may pose particular challenges for someone with autism. The first of these challenges is environmental: a "small group living situation" is likely to be interpreted by care providers as a small house: this may not afford the person with ASC the sort of space envisaged later on in the Guideline (point 6.5.10.3 on page 169). The second is interpersonal: for some, more able people with ASC, living in close proximity with a small group of	Thank you for your comment. The GDG considered very carefully whether or not to extrapolate from a learning disabilities population when considering recommendations for residential care. Given the significant proportion of people with autism and learning disabilities in residential care the GDG considered this an appropriate extrapolation in line with the agreed methods. In developing the recommendations for this section the GDG had in mind the needs of people with autism with all ranges of intellectual ability. The recommendation

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							people may be particularly challenging. The third has to do with staffing: meeting the particular needs of people with ASC can be intense and demanding. In a small setting, there will be correspondingly fewer staff on duty at any one time and, therefore, fewer opportunities for shared thinking, mutual support, and supervision. For some more able people, what might work best would be an individual flat, with staff support on-site as needed and a shared space for the residents to interact as and when they chose – but, if there is currently no research that addresses this idea, it is perhaps beyond the scope of the Guidelines.	does not specify that all care should be provided in small group homes, but also now makes reference to individual accommodation. We should also emphasise that privacy and space can be provided in small residential settings and are not simply a function of larger settings.
371.	Association Directors of Adult Social Services	2 4	FULL	6.5.1 0	167	1	Section 6.5.10 is a very low baseline of recommendations for residential care provision. It is not clear from the recommendations that a residential environment as described goes far enough in enabling and developing the skills of the person with autism. Useful for clarity for prescribers what experiments not to take in the management of Autism.	Thank you for your comment, we have revised the recommendations in light of your and others' comments.
372.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	7	168	1	It is important to emphasise that Psychosocial interventions can be delivered by a range of services and not solely specialist health services	Thank you for your comment, we agree and do not limit their provision to specialist health services in the guideline.
373.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7	Sec tion 7		Good to see clinical judgement of GDG group despite limited evidence with respect to recommendations re. the use of psychosocial/behaviour intervention programmes for adults with key principles including functional behavioural analysis, client and family preferences, behavioural principles etc.	Thank you for your comments.
374.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7	Sec tion 7		Good to see list of recommendations on how CBT (and other psychological interventions) might be adapted in order to increase their effectiveness in autism such as a more concrete, structured approach with greater use of written and visual information than might typically be the case in CBT, a focus on behavioural rather than the cognitive aspects of CBT and use of shorter sessions or regular breaks, group-based approaches and avoidance of metaphors or hypothetical situations, and the importance of increased involvement of a family member or key worker as co-therapist to support the generalisation of benefits.	Thank you for your comments.
375.	Cochrane Collaboration		Full	7	Sec tion		GDG were of the view that interventions to develop structured leisure activities should be recommended for adults with autism	Thank you for your comment, we agree the evidence is limited but we used what was

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	Developmental, Psychosocial and Learning Problems Group				7		of all intellectual abilities. Good to see clear recommendations for structured leisure activities for adults with ASD given how neglected an area of clinical service and research this is. However, only two RCTs including in total 46 persons with ASC (65 controls), one with moderate level and one with low level of evidence, indicate that the recommendations are based on very limited research, suggesting that future interventions should be closely linked to scientific design and evaluations.	available to inform GDG decision making as this is an important area and might have been neglected if we did not make recommendations.
376.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7	Section 7		Pleasing to see that based on the positive evidence from adults and the GDG expert knowledge, the GDG judged that social skills group interventions may help to address significant issues for adults with autism, including social isolation, which may in turn impact on other outcomes such as employment. While more research is needed it is important that these interventions are included for adults and integrated within employment support programs. However, all the RCTs were all on low or very low level suggesting that the recommendations are based on limited research. Hence, future social skills group interventions should be closely linked to scientific design and evaluations.	Thank you for your comment, we agree and have tried to address these issues in our research recommendations.
377.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7	Section 7		Supported employment is likely to be a cost-effective intervention for adults with autism, as it can increase the rate of employment in this population group, improving a person’s well-being, and it can also potentially reduce the economic burden to health and social services and the wider society. Appropriate recommendations emanate from the literature search and secondary analysis of research and extrapolation of economic impact data. However, and as shown in the report, there are multiple outcomes (four are mentioned) that need to be contrasted against each other in future research, since they are, in fact, mostly independent variables. Recommendations need to take that into account.	Thank you, we agree with this comment. However, the final suggestion would entail an inappropriate level of detail for recommendations.
378.	Nottinghamshire Healthcare NHS Trust	52	Full	7	168	1	There is currently no review of potential treatments for sensory sensitivities in autism, which could be a useful addition to this section. It would be useful, If not undertaken already, to liaise with the ‘Sensory Integration Network UK and Ireland’ in order to provide clinical opinion and advice regarding the current evidence base. The evidence base for treatment of sensory aspects of ASD is	Thank you for your comment. We agree that sensory sensitivities are an important feature of autism. However, there were no available data on interventions aimed at sensory sensitivities for adults with autism which met eligibility criteria for review. The references you list would also not meet the eligibility criteria for the review, as Edelson et al (1999)

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							scarce; it is primarily case studies and anecdotal, however, the following may be useful to consider: Edelson, S. Goldberg, M. et al (1999) Behavioural and physiological effects of deep pressure on children with autism: A pilot study evaluating the efficacy of Grandin's hug machine. American Journal of Occupational Therapy, 53(2), Mar-Apr 1999, 145-152. Pfeiffer, B. & Kinnealey, M. (2003) Treatment of sensory defensiveness in adults Occupational Therapy International, 10(3), 175-84.	examines children with autism, and the adult participants in Pfeiffer and Kinnealey (2003) are not autistic. The expert opinion within the GDG was that there was not reason to believe that interventions aimed at sensory sensitivities would be either significantly beneficial or significantly harmful, and given the lack of any evidence for clinical efficacy, there were therefore insufficient grounds for a recommendation.
379.	Nottinghamshire Healthcare NHS Trust	53	Full	7.1	168	10	Importantly, Sensory Integration is listed here, but there are no reviews of any evidence. – Has group approached the Sensory Integration network been approached regarding the evidence base? We are aware that Winnie Dunn has done work in this area which could be usefully considered.	Thank you for your comment. We agree that sensory sensitivities are an important feature of autism. However, there were no available data on interventions aimed at sensory sensitivities for adults with autism which met eligibility criteria for review.
380.	European Association for Behaviour Analysis	2	Full	7.1	168	23	The correct term for the field is 'applied behaviour analysis' (not behavioural). No one, other than critics of applied behaviour analysis, uses the term 'operant conditioning therapy'.	Thank you for your comment. The term 'applied behavioural analysis' was adopted as it is commonly used interchangeably with 'applied behaviour analysis'. The term 'operant conditioning therapy' was adopted as the GDG judged it to be the correct explanatory term.
381.	European Association for Behaviour Analysis	3	Full	7.1	168	25	Behavioural interventions for autism based on applied behaviour analysis address skills across all domains and curriculum areas (language, social skills, play, leisure, problem solving etc.).	Thank you for your comment. This sentence has been modified to read '…have been used to target core symptoms and to modify challenging or aggressive behaviour or teach adaptive behaviours, such as activities of daily living'
382.	European Association for Behaviour Analysis	4	Full	7.1	168	26	There is no reason to start this sentence with the word 'alternatively'. Any good behavioural intervention will teach social skills and would not describe this as being through a 'social learning framework'.	Thank you for your comment. The word 'alternatively' has been removed.
383.	European Association for Behaviour Analysis	5	Full	7.1	168	41	This paragraph presupposes that quality of life was not at the forefront of behavioural interventions… Please note that one of the defining features of applied behaviour analysis is that it is concerned with behaviour change (in a very broad and general sense) that is of social significance to all stakeholders.	Thank you. The explicit focus of leisure programmes is on improving quality of life.

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384.	Welsh Government		Full	7.1	168	1	It is important to emphasise that Psychosocial interventions can be delivered by a range of services and not solely specialist health services	Thank you, we agree with this statement. In development of NICE guidelines we do not refer to specific healthcare professionals or settings unless there is good reason to do so.
385.	British Psychological Society		Full	7.1	169	9	The BPS welcomes the recognition that many adults with autism (especially those with a learning disability) will also display behaviours that challenge services and that specific guidelines are required to address their needs. However, we do have some concerns that the way in which challenging behaviour is conceptualised within the guidelines appears to locate the problem primarily with the individual who has autism. The term 'challenging behaviour' is socially constructed and is a product of an interaction between the individual and their environment. It is therefore essential that assessment and intervention address the person, the environment and the interaction between the two (Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists, 2007). The BPS recommends that this is emphasised more explicitly within the guidelines as an over-arching principle and framework to understand the 'challenging behaviour' of an adult who has autism.	Thank you for your comment. The specific text you are referring to makes no reference to challenging behaviour. We have included a definition of challenging behaviour in our glossary.
386.	European Association for Behaviour Analysis	6	Full	7.2	175	4	Where are all the studies related to Functional Communication Training?	Thank you for your comment. There were no studies which examined functional communication training interventions in adults with autism which met the eligibility criteria for inclusion in this review.
387.	Queen's University Belfast,	2	Full	7.2	175 - 178		The definition of behavioural therapies is extremely limited, eg does not include anything on the Verbal Behaviour approach or full Functional Analysis. (there is a mix up between Functional Analysis with Functional Assessment see 5.4.8.16), The review also focuses on a very limited set of behaviours. Social learning is included as a separate heading which is very confusing (eg video modelling is a behavioural intervention, See Nikopolou & Keenan's book)	Thank you for your comment. We accept that there is no agreement on the definition of terms between different clinical and academic groups. However, the GDG decided to use the term 'functional analysis' as it is in wide use in the NHS. In order to be clear about the nature of any psychological intervention the GDG specify the nature and content of those interventions in the recommendations in order to avoid any confusion in the use of different terms to describe these interventions. The inclusion of different interventions is

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								based on the availability of good quality evidence as to intervention effectiveness. Thus, any exclusion, such as the Verbal Behaviour approach is because there was no evidence which met eligibility criteria for the efficacy of this intervention. The GDG recognised that therapies are not discrete or mutually exclusive, for instance, most communication therapies involve behavioural strategies and most social programmes involve some form of communication skills and behavioural methods. However, the GDG took the view that it was appropriate to classify interventions by the main target/ focus of the intervention, rather than the methodology, as this aids implementation of the recommendations by healthcare professionals. Explanation of the rationale for our classification of psychosocial interventions has been added to section 7.1 of the full guideline to make this clear.
388.	Queen's University Belfast,	3	Full	7.2	175 - 178		The approach is very traditional and RCT and stats based. It does not include other validated methodologies such as single-system designs (time-series) etc.	Thank you for your comment. NICE guidelines consider evidence according to an established hierarchy of study types and well-conducted randomised controlled trials (RCTs) are at the top of this hierarchy. This is because RCTs provide the greatest degree of certainty that can be attributed to the conclusions drawn from the study.
389.	Queen's University Belfast,	4	Full	7.2	175 - 178		There are a number of systematic reviews and meta analysis on behaviour interventions now available that are not included (granted that the focus is mostly on children not adults), yet the authors include meta analysis under antipsychotic drugs,	Thank you for your comment. The behavioural intervention studies identified by the literature search did not report data which was in a suitable format to be entered into meta-analysis. The review on antipsychotics, on the other hand did identify and include RCT data for adults with autism and adults

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								with learning disabilities which could be meta-analysed and this is the reason for the different approaches. Any data for behavioural interventions in children with autism is outside the scope for this guideline but will be covered by the 'Management and treatment of autism in children and young people' guideline which is currently under development.
390.	Queen's University Belfast,	5	Full	7.2	175 - 178		the review on communication does not even include anything on PECS, and the review on behaviour management does not include FA and Self-injurious or otherwise challenging behaviour (see Iwata et al and many others). In fact, behaviour management seems to be equated with life skills training (in itself of course a very important areas), but under behaviour management I would have expected a proper review of work re Challenging behaviours.	Thank you for your comment. PECS was included as a search term. However, no studies which met the inclusion criteria were identified. This was mainly because these interventions were tested with children with autism, and where this is true these trials will be reviewed in the 'Management and treatment of autism in children and young people' guideline which is currently under development. PECS has however been added to the list of psychosocial interventions in section 7.1 of the full guideline as the GDG recognized that it is a widely used intervention. With regards to the outcomes for behaviour management interventions, these were data-driven, so self-injurious behaviour or otherwise challenging behaviour are omitted because no evidence was identified which met eligibility criteria to be included in the review.
391.	Queen's University Belfast,	7	Full	7.2	175 - 178		there are a number of cost-benefit analysis in the literature that are not mentioned. while most of them start with early intervention, they usually include life-time cost analyses (eg. Knapp et al).	The economic literature review included studies that assessed the cost effectiveness of interventions aimed at adults with autism, as this type of evidence would help formulating recommendations. Although early interventions for children do have life-time cost implications, they are not relevant in the context of this guideline (the guideline is not

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								making recommendations for interventions for children). The study by Knapp et al is NOT a cost-benefit analysis, but a cost of illness study. This means that the study estimated the total costs incurred by children and adults with autism, but did not assess the cost effectiveness of any interventions for this population, and therefore it is not relevant for inclusion in this chapter or for making recommendations. The findings of this study have been reported in the introductory chapter 2 (section 2.7), as background information.
392.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7.2	175 - 178	5. 4. 8. 1 6	The definition of behavioural therapies is extremely limited, e.g. does not include anything on the Verbal Behaviour approach, or full Functional Analysis.	Thank you for your comment. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. Therefore, any exclusion, such as the Verbal Behaviour approach is because there was no evidence which met eligibility criteria for the efficacy of this intervention.
393.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7.2	175 - 178		The approach does not include methodologies such as single-system designs (time-series).	Thank you for your comment. NICE guidelines consider evidence according to an established hierarchy of study types and well-conducted randomised controlled trials (RCTs) are at the top of this hierarchy. This is because RCTs provide the greatest degree of certainty that can be attributed to the conclusions drawn from the study.
394.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7.2	175 - 178		The review on communication does not include anything on PECS, and the review on behaviour management does not include FA and self-injurious or otherwise challenging behaviour.	Thank you for your comment. PECS was included as a search term. However, no studies which met the inclusion criteria were identified. This was mainly because these interventions were tested with children with autism, and where this is true these trials will be reviewed in the 'Management and treatment of autism in children and young people' guideline which is currently under development. PECS has however been

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								added to the list of psychosocial interventions in section 7.1 of the full guideline as the GDG recognized that it is a widely used intervention. With regards to the outcomes for behaviour management interventions, these were data-driven, so self-injurious behaviour or otherwise challenging behaviour are omitted because no evidence was identified which met eligibility criteria to be included in the review.
395.	Royal College of Speech and Language Therapists	8.	Full	7.2.3	179	N/A	There is no mention of using AAC (e.g. PECS), social stories, Intensive Interaction / Sunrise Programme or other commonly used speech and language therapy interventions to support the communication or understanding of individuals with autism.	Thank you for your comment. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. However, as the GDG recognised that there was a lack of evidence for some widely used interventions, PECS, social stories and intensive interaction have been added to the list of psychosocial interventions in section 7.1 of the full guideline.
396.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	7.2.6	178	21	It is not clear whether the evidence considered was only with regard to improving the communication abilities of the individual themselves. Communication interventions are often about improving the way in which others understand and communicate with the individual. We would support research recommendations in this area particularly for people with intellectual disabilities.	Thank you for your comment, we have included a recommendation about augmented communication and stress throughout the document the importance of knowledge and understanding of autism. This of course will include the challenges of communicating with autistic people for staff working with them.
397.	Welsh Government		Full	7.2.6	178	21	It is not clear whether the evidence considered was only with regard to improving the communication abilities of the individual themselves. Communication interventions are often about improving the way in which others understand and communicate with the individual. We would support research recommendations in this area particularly for people with intellectual disabilities.	Thank you for your comment, we have included a recommendation about augmented communication and stress throughout the document the importance of knowledge and understanding of autism. This of course will include the challenges of communicating with autistic people for staff working with them.
398.		7	Full	7.3	179	1	Why a whole section on the generally discredited intervention	Thank you for your comment, the GDG

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	European Association for Behaviour Analysis						'Facilitated Communication'? Why not have a whole section on 'behavioural interventions based on applied behaviour analysis' – rather than separate sections on behavioural interventions for communication, behaviour management, social skills, leisure etc.	considered it important to make a recommendation about facilitated communication because of the concerns about potential abuse in this area. The guideline was structured in this way to facilitate understanding and implementation of the guideline by people working in the NHS.
399.	Nottinghamshire Healthcare NHS Trust	54	Full	7.3	179	1	This section appears to focus mostly on behavioural approaches and facilitated communication. It would be useful to incorporate approaches such as use of visual communication to support understanding and structure, visual info as a means of communication, information giving approaches such as Social Stories and Comic Strip Conversations, and interactive approaches such as Intensive Interaction. Whilst we appreciate that there may not be RCT evidence to support these, there are useful of case studies. If not done so already, it may be useful to liaise with the Royal College of Speech and Language Therapists?	Thank you for your comment, the GDG considered it important to make a recommendation about facilitated communication because of the concerns about potential abuse in this area. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. However, as the GDG recognised that there was a lack of evidence for some widely used interventions, social stories and intensive interaction have been added to the list of psychosocial interventions in section 7.1 of the full guideline. NICE guidelines consider evidence according to an established hierarchy of study types and well-conducted randomised controlled trials (RCTs) are at the top of this hierarchy. This is because RCTs provide the greatest degree of certainty that can be attributed to the conclusions drawn from the study. Case studies have been excluded from the review due to the high risk of bias for such studies.
400.	Queen's University Belfast,	6	Full	7.3	179 - 180	1- 13	the inclusion of such a long section on Facilitated Communication is really worrying, this is totally discredited in the literature and is very outdated now (at least the recommendations are in line with the literature with regard to FC, although there is no mention any of the studies discrediting it)	Thank you for your comment, the GDG considered it important to make a recommendation about facilitated communication because of the concerns about potential abuse in this area. We have expanded section 7.3.6 to take

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								account of your comments.
401.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7.3	179 - 180	1-13	Why is Fac Comm included at such length – no evidence for such.	Thank you for your comment, the GDG considered it important to make a recommendation about facilitated communication because of the concerns about potential abuse in this area.
402.	Specialist Autism Services	1	Full	7.3.3	180	17	What of other further communication therapies, such as Social Communication Strategies, PECS, MAKATON, Hanem Approach, Semantic Pragmatic Interventions, Attention Support, Derbyshire Language Scheme, Auditory Processing Interventions, SULP	Thank you for your comment. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. However, as the GDG recognised that there was a lack of evidence for some widely used interventions, alternative and augmentative communication interventions, have been added to the list of psychosocial interventions in section 7.1 of the full guideline.
403.	Northumberland, Tyne & Wear NHS Trust		Full	7.3.8.1	181		Augmented communication is limited to a research recommendation. However, in the form of, for example, picture exchange and object exchange as well as visual information in TEACCH, has a wide usage currently and needs more exploration and guidance.	Thank you for your comment. We have made a research recommendation for this as we were unable to find any good quality evidence to recommend this. We have added alternative and augmentative communication interventions to the list of psychosocial interventions in section 7.1 of the full guideline as the GDG recognised that these are widely used interventions.
404.	Nottinghamshire Healthcare NHS Trust	55	Full	7.3.8.1	181	16	In terms of this research recommendation it would be important to ensure that we do not confuse the term 'augmented' communication – which is part of a wider remit of Alternative and Augmentative Communication, with 'Facilitated Communication'. People with autism may use high or low technology devices to augment their communication skills e.g. a symbol board / talking mats / a voice output device – but it would damaging to associate this with facilitated communication.	Thank you for your comment. We have included facilitated communication in the glossary which should distinguish this intervention from alternative and augmentative communication interventions.
405.	Nottinghamshire Healthcare NHS Trust	56	Full	7.3.8.1	181	22	We are unsure that the term 'probable' is really necessary here and may be misleading.	Thank you for your comment, the GDG did not make the change you suggested as it was felt that communication difficulties could

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								also be due to learning disabilities, not just autism.
406.	The Royal College of Psychiatrists, Learning Disability Faculty	7 2	Full	7.3.8 .1	181		**7.3.8.1** Augmented communication is limited to a research recommendation. However, in the form of, for example, picture exchange and object exchange as well as visual information in TEACCH, has a wide usage currently and needs more exploration and guidance.	Thank you for your comment. We have made a research recommendation for this as we were unable to find any good quality evidence to recommend this. We have added alternative and augmentative communication interventions to the list of psychosocial interventions in section 7.1 of the full guideline as the GDG recognised that these are widely used interventions.
407.	Nottinghamshire Healthcare NHS Trust	5 7	Full	7.4	182	1	General comment – we are concerned that by focusing on behaviour management, guidance is limited thinking about changes to the person, rather than changes to the environment, or changes in skill and knowledge in the staff team.	Thank you for this comment, we have made a number of recommendations regarding the manner in which care is delivered, the settings in which interventions are provided and any necessary adaptations to environments to facilitate the care of people with autism.
408.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	7.4	182	1	The lack of research evidence for behavioural approaches needs to be addressed. The recommendations have face validity. However, more vigilance and attention needs to be in place to ensure individual positive outcomes as it could be deemed that “off licence” approaches are being used.	Thank you for comment there is no licensing for any behavioural intervention. In developing our recommendations we follow the methods set by NICE. We agree that further research in this area is needed and have made a number of research recommendations.
409.	Welsh Government		Full	7.4	182	1	The lack of research evidence for behavioural approaches needs to be addressed. The recommendations have face validity. However, more vigilance and attention needs to be in place to ensure individual positive outcomes as it could be deemed that “off licence” approaches are being used.	Thank you for comment there is no licensing for any behavioural intervention. In developing our recommendations we follow the methods set by NICE. We agree that further research in this area is needed and have made a number of research recommendations.
410.	Nottinghamshire Healthcare NHS Trust	5 8	Full	7.4.2	182	3 4	Again the guidance could useful refer to RCP/BPS guidance on challenging behaviour (CR144).	Thank you for your comment. It is not NICE style to include as evidence reports if they are not based on systematic review of the evidence.
411.	Welsh Health Boards ASD Assessment &		Full	7.4.6	187	1	The recognition and management of mild and moderate anxiety / depression if of particular relevance to the ne Wels Mental Health Measure and the assessment and management of such	Thank you for this comment.

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	Diagnosis (Adults) Network						issues in primary care	
412.	Welsh Government		Full	7.4.6	187	1	The recognition and management of mild and moderate anxiety / depression is of particular relevance to the Welsh Mental Health Measure and the assessment and management of such issues in primary care	Thank you for this comment.
413.	British Psychological Society		Full	7.4.8	187	g e n er al	The BPS welcomes the emphasis on functional analysis and behavioural interventions as initial treatment for challenging behaviour. It would be helpful to reference government guidance on challenging behaviour for people with a learning disability (Department of Health, 2007, p.7) that states that "Challenging behaviour is socially constructed; it is the product of individual and environmental factors interacting together". This emphasises that interventions need to focus not only on the individual, but also their context.	Thank you for your comment. We have included a definition of challenging behaviour in our glossary.
414.	Northumberland, Tyne & Wear NHS Trust		Full	7.5.1	188 - 198		The section on cognitive therapies is dominated by the management of anger. However, at least as frequent is anxiety. Its management includes work to teach the person to recognise and label the emotion (emotional literacy – which may be best supervised by a SALT), techniques for its management (including relaxation training) and strategies for its avoidance as well as its management. In short, all the material of anger management and should be given equal emphasis.	Thank you for your comment, however you provide no evidence to support your suggestions and therefore it is not appropriate for us to make an amendment to the guideline.
415.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 8	Full	7.5.1	188 - 198		There should be consideration of wider therapeutic input including anxiety management - which clinically is the most common presentation. There should also be expressed direction to consider provision of emotional literacy etc	Thank you for your comment, however you provide no evidence to support your suggestions and therefore it is not appropriate for us to make an amendment to the guideline.
416.	The Royal College of Psychiatrists, Learning Disability Faculty	7 4	Full	7.5.1	188 - 198		The section on cognitive therapies is dominated by the management of anger. However, at least as frequent is anxiety. Its management includes work to teach the person to recognise and label the emotion (emotional literacy – which may be best supervised by a SALT), techniques for its management (including relaxation training) and strategies for its avoidance as well as its management. In short, all the material of anger management and should be given equal emphasis.	Thank you for your comment, however you provide no evidence to support your suggestions and therefore it is not appropriate for us to make an amendment to the guideline.
417.	Institute of	3	Full	7.5.3	192	1 2	I am the first author (Russell, A.J.) of the single study identified in this area and need to declare this in relation to my	Thank you for your comment. This has been amended.

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	Psychiatry, Kings College London						comments. Line 12on p192 states that the methods for distinguishing OCD from repetitive behaviours are not elaborated on. In fact the paper states that the methods are described in an earlier study and the reference is provided (Russell et al, (2005) British Journal of Psychiatry 186 p525.	
418.	Institute of Psychiatry, Kings College London	4	Full	7.5.4	195	3 2	Although I appreciate that the evidence as provided by the Russell et al (2009) is not of a high standard due to the methodological limitations outlined and also as evidenced by the overall effect calculated, I am concerned that the statement 'the study failed to find evidence for significant treatment effects with participants receiving CBT showing no significant difference in severity of OCD symptoms to participants receiving treatment as usual' is somewhat misleading. In fact the original paper (Russell et al., 2009) did find a statistically significant effect of CBT with a standardised treatment effect size of 1.01 and there was a significantly greater proportion of treatment responders in the CBT group. The paper states *'a mixed model ANOVA with 1 between-groups factor (CBT vs TAU) and 1 within-groups factor (time) revealed a significant group by time interaction on the YBOCS total severity score (F=4.341, p=.049). …..Repeated measures t-tests showed significant pre-to-post treatment decreases o the YBOCS total severity and obsessions severity ratings for the CBT but not the TAU group. In terms of a clinically meaningful change, 58% of the people in the CBT group had a >25% reduction on the YBOCS compared with 16% of people in the TAU group. We conclude that (1) OCD symptoms in ASD do not show any change over time in the absence of treatment (2) a considerable proportion of individuals with ASD and OCD show significant improvement with standard psychological treatment adapted for this population'*. My comment is that although the evidence is of low GRADE and the overall effect size from the forest plot not significant, the statement 'the study failed to find evidence for significant treatment effects with the participants receiving CBT showing no significant difference in severity of OCD symptoms……' is at worst incorrect and at best misleading.	Thank you for your comment. When analysing evidence for inclusion in the guideline we adopt a common method to facilitate comparison between studies. In the particular case you refer to we use mean post test scores, and when the data is analysed in this way, the group difference is not statistically significant.
419.	Institute of Psychiatry, Kings	5	Full	7.5.4	195	3 4	My comment refers to the statement made in reference to the study described in Russell et al 2009 which states that 'the study also failed to detail any specific modifications to the	Thank you for this comment. It would have been helpful to include additional data as in the unpublished paper which we requested

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	College London						standard CBT treatment and this may reflect the fact that no such adaptations took place'. The paper Russell et al (2009) clearly states that 'a considerable proportion of individuals with ASD and OCD show significant improvement with standard psychological treatment adapted for this population and (3) CBT for OCD can be conducted in the usual fashion but with some adaptations'. The original manuscript reviewed did detail the adaptations as we conducted a post-hoc review of the treatment notes but unfortunately there was insufficient word limit in the journal to include this material. It is available in an unpublished Phd thesis (Russell 2010, University of London) and also forms the basis of a treatment manual for a Randomized Controlled Trial that we refer to in the 2009 paper, which is now complete and is in submission for review with a scientific journal. It was in fact part-funded by the NIHR. Subject to the journal's and other author's agreement, the manuscript and findings of the RCT comparing adapted CBT for OCD with Anxiety Management in 46 people with ASD and co-morbid OCD could be made available if required.	and you sent us. However, as this paper is currently being considered for publication, you asked that we do not include the data in the guideline.
420.	ADRC	1 5	Full	7.5.7	197	1	Many of the recommendations outlined for interventions such as anger management, etc. may be considered to be somewhat vague and require more detail.	Thank you for your comment. We have included details for the delivery of anger management interventions in the recommendations.
421.	Specialist Autism Services	7	Full	7.6.6	201	3 0	Re-iteration for the value of "soft targets" rather than rigid outcomes.	Thank you.
422.	Association Directors of Adult Social Services	1 8	Full	7.6.6	201 - 202	3 0- 3 7 / 7- 1 5	Whilst withstanding the need for specialist provision to meet the overarching needs of people on the Autistic Spectrum the Key Recommendation is the recognition of the person, interest and routines in order to establish a person centred experience which will support a positive experience. Rather than assuming what is right for one person on the Autistic spectrum is right for another. It may not need to be a programme as a group rather supporting an individual to build experiences and activities into their lives which they choose and would enjoy. The programme / approach is dependent of the level of need whilst the activity the same for anyone with or without a diagnosis. Such as Trainspotting or Photography, attending a club of the hobby may be more satisfying dependent on the individual and the management of their own anxieties and social interactions.	Thank you for your comment, the recommendations for leisure programmes state that personal preference should be taken into account.

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							A more social account may be more appropriate with the use of the Think Local Act Personal focus on personalisation and outcomes.	
423.	European Association for Behaviour Analysis	8	Full	7.7.1	203	1	It seems as if 'social learning interventions' are simply interventions that target social skills… This seems out of place. Why not have 'communication-based interventions'? Why have 'behavioural therapies aimed at communication' and not 'behavioural therapies aimed at social skills'. Better to just combine these into 'behavioural interventions based on applied behaviour analysis'.	Thank you for your comment. The GDG recognised that therapies are not discrete or mutually exclusive, for instance, most communication therapies involve behavioural strategies and most social programmes involve some form of communication skills and behavioural methods. However, the GDG took the view that it was appropriate to classify interventions by the main target/ focus of the intervention, rather than the methodology, as this aids implementation of the recommendations by healthcare professionals. Explanation of the rationale for our classification of psychosocial interventions has been added to section 7.1 of the full guideline to make this clear.
424.	Sussex Partnership NHS Foundation Trust	6	Full	7.7.3	207	3	We wondered why there was no mention of the approach of Social Stories as a social learning tool?	Thank you for your comment. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. However, social stories have been added to the list of psychosocial interventions in section 7.1 of the full guideline as the GDG recognised that social stories are a widely used intervention.
425.	Association Directors of Adult Social Services	1 9	FULL	7.7.7	211		Recommendation to support young people as part of their preparing for adulthood. Consider as part of transition planning where not already undertaken. Minimising the risk of entrenched routines in adulthood that re-enforce feelings of worthlessness and isolation. Improving aspirations and confidence. Working with Education and Children's services to proactively support young people in identifying techniques that can be carried with them into adulthood.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
426.	Brain-in-Hand Ltd	5	Full	7.7.7	211	5	Group-based social learning programmes to improve social interaction should typically include....." More emphasis is needed on programmes for those who	Thank you we do make a specific recommendation that social learning interventions should be delivered individually

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							cannot work well in groups – especially in the summary	when appropriate.
427.	Association Directors of Adult Social Services	20	FULL	7.8	7.8 chapter		A detailed analysis touching upon comparisons that may not apply like for like, too many variables to compare particularly with reference to Day Services vs Supported employment. And accommodation options. There should be reference to Eligibility and FAC Criteria and specific clarity of the group of people demonstrating a saving. The recommendations do not reflect the how to achieve the savings identified in the text and would therefore question its direct relevance for the guidance but recognise the scope for more detailed work, this is not however specific to Autism and is reflective of the Valuing Employment Now employment focus for people with a learning disability. Linking into the Autism Strategy and the outcomes personalised agenda we would have expected recommendations on utilising the mainstream support work programmes and access to work resources in order to make reasonable adjustments to support individuals on the Autistic Spectrum into Employment and retaining employment. In addition to training employers to communicate with the individual to ascertain how their autism effects them and what he/she believes would support them in their employment, for example lighting and noise tolerance	Thank you, we are unclear on the point you are making here.
428.	NCCMH expert reviewer	9	Full	7.8.1	212	4	7.8.1 lines 4-5. It is likely that unemployment rates are high in adults with ASD but the cited NAS survey estimates are somewhat misleading as only adults with a diagnosis were surveyed by the NAS. The adult psychiatric morbidity survey covering all working age adults found that there was no statistically significant association between ASD and unemployment in cases compared to non cases living in the community (Brugha et al., 2011 (see Bibliography)).	Thank you for your comment. However, your suggested change has not been made as it is made clear in the text that the quoted employment rate refers to individuals with a diagnosis of autism
429.	Northumberland, Tyne & Wear NHS Trust		Full	7.8.1	212	4	The studies are those of adults who have who have attained a diagnosis. However. The adult psychiatric morbidity survey found that there was no association between ASD and unemployment in cases living in the community (Brugha et al.2011)	Thank you for your comment. However, your suggested change has not been made as it is made clear in the text that the quoted employment rate refers to individuals with a diagnosis of autism
430.	The Royal College of Psychiatrists,	76	FULL	7.8.1	212	4	The studies are those of adults who have who have attained a diagnosis. However. The adult psychiatric morbidity survey found that there was no association between ASD and	Thank you for your comment. However, your suggested change has not been made as it is made clear in the text that the quoted

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	Learning Disability Faculty						unemployment in cases living in the community (Brugha et al.2011)	employment rate refers to individuals with a diagnosis of autism
431.	Royal College of Nursing	1 1	Full	7.8.1	213	9	Also dignity and respect is part of the awareness and acceptance of who they are.	Thank you for your comments, this sentiment is covered by 'self-worth'.
432.	Specialist Autism Services	6	Full	7.8.2	214	1 1	There would need to be, particularly for this client group, clarification and demarcation around the specific role of someone assigned for employment support and if that may overlap to home or social support.	Thank you for your comment, the recommendation we have developed for employment and other psychosocial interventions are not intended to be interpreted in isolation. It will be for the judgement of healthcare professionals working with the individual with autism to identify which range of interventions best meet the individuals needs.
433.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	7.8.8	234	1 3	The appointment by the Welsh Government of an Autism Employment Ambassador in 2010 was a first in the UK	Thank you for your comment, however this information would not be appropriate to include in the recommendations.
434.	Welsh Government		Full	7.8.8	234	1 3	The appointment by the Welsh Government of an Autism Employment Ambassador in 2010 was a first in the UK	Thank you for your comment, however this information would not be appropriate to include in the recommendations.
435.	Nottinghamshire Healthcare NHS Trust	6 1	Full	7.8.8	234	1 3	This is a laudable recommendation, but guidance needs to consider who is expected to deliver this, presumably recommendation is not within the NHS, but additional statutory and non-statutory organisations (for which there will be considerable resource and funding implications).	Thank you for your comment. NICE provides costing and implementation tools for services to prepare for guideline implementation that are separate from the guideline. It is not within the remit of the guideline to determine how recommendations will be financed locally.
436.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		Full	7.9.4	240	3	Mothers - change to primary caregiver? Is research only on mothers?	Thank you for your comment. However, the suggested change has not been made as all the included evidence on support for families and carers was targeted at mothers.
437.	WaASP		Full	7.9.6	240	2 0	We have difficulty in understanding the sentence beginning 'While,…'	Thank you for your comment. However, we do not agree that this sentence is unclear.
438.	Association Directors of Adult Social Services	2 2	FULL	7.9.7	241		Need to include eligibility and facs criteria for LA's and link into the existing assessment process. Such as	Thank you for this comment, eligibility and FACS criteria are outside the scope of this guideline. The issues you raise with regard to family

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							Provision of information of local support available in information on National Autism Specific information and organisations. Consideration of the family's needs and impact of autism including the needs and traits of the family unit should be taken into consideration when undertaking the assessment of the individual's needs and that of the Parent or Carer depending on the age of the person being assessed. Where specific approaches are being applied ensure that the family are able to support the individual through the consistent application within the home setting. Including understanding the use of rituals and routines etc	interventions are covered in chapter 4.
439.	Northumberland, Tyne & Wear NHS Trust		Full	8	242	g e n er al	8 Biomedical Interventions A distinction is made between the core symptoms of Autism and those of comorbid conditions. In practice, emotional arousal or distress will amplify the core symptoms so that treating the former will improve the latter; the result is that a treatment will often show an improvement in core symptomatology that is not sustained or independent of the treatment of the comorbidity – this is not quite the same as saying that the treatment did not improve the core symptoms. It is a reflection of the difficulty in measuring the outcome of any programme. (There are parallels here with the debate as to the efficacy of stimulants in ADHD).	Thank you for your comment, we accept that in clinical practice distinguishing between the impact of different interventions on the core and coexisting conditions can be difficult - careful clinical judgement is required in assessing the benefits of any intervention. However in making our recommendation we felt it important to point out the limitations for interventions for core symptoms as the evidence base in this area does not support the use of any particular intervention.
440.	Nottinghamshire Healthcare NHS Trust	6 2	Full	8	242	1	Catatonia in autism not mentioned within the guideline, which we feel would be important to include. It would be useful to reference work by Wing and Shah (e.g. BJPsych, 2000) in this area. The relationship of catatonia and neuroleptic malignant syndrome may point to the neurosensitivity to neuroleptics. Although ECT is not proven, and lorazepam may be helpful, there is some case evidence about this and the treatment reported by Fink and Taylor 2003 ; Fink Taylor & Ghazziudin, 2006 may be useful to review	Thank you for this recommendation we have amended the introduction to refer to catatonia. WE could find no good quality evidence to link catatonia and neuroleptic malignant syndrome in autism.
441.	Tees, Esk & Wear Valleys NHS Foundation Trust	3 0	Full	8	242		There needs to be clarification that treatment of the core symptoms is separate from treating the manifested symptoms of e.g. anxiety which is often responsive to psychotropic medication	Thank you for this comment we have made several recommendations about the treatment of coexisting condition.
442.	The Royal College of Psychiatrists, Learning Disability	7 7	Full	8	242 +	G e n	**8** Biomedical Interventions A distinction is made between the core symptoms of Autism and those of comorbid conditions. In practice, emotional	Thank you for your comment, we accept that in clinical practice distinguishing between the impact of different interventions on the core

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	Faculty					er al	arousal or distress will amplify the core symptoms so that treating the former will improve the latter; the result is that a treatment will often show an improvement in core symptomatology that is not sustained or independent of the treatment of the comorbidity – this is not quite the same as saying that the treatment did not improve the core symptoms. It is a reflection of the difficulty in measuring the outcome of any programme. (There are parallels here with the debate as to the efficacy of stimulants in ADHD).	and coexisting conditions can be difficult - careful clinical judgement is required in assessing the benefits of any intervention. However in making our recommendation we felt it important to point out the limitations for interventions for core symptoms as the evidence base in this area does not support the use of any particular intervention.
443.	European Association for Behaviour Analysis	9	Full	8.1	242	1	Why is more of this review devoted to unproven biomedical interventions (pages 242-325) relative to psychosocial interventions (pages 168-235), especially when most are not recommended?	Thank you for your comment. The inclusion of different interventions is based on the availability of good quality evidence as to intervention effectiveness. The systematic search revealed that there was more evidence for biomedical relative to psychosocial interventions. The guideline advises on both effective and ineffective interventions. Thus, inclusion in the review is distinct from that intervention being recommended, as is clear by the recommendations not to use biomedical interventions to treat core symptoms in autism.
444.	Sussex Partnership NHS Foundation Trust	9	Full	8.2.3	254 and following	1 and following	Scales for evaluation of tic disorders and Tourette-related compulsive behaviours may be usefully included in screening assessments, Similarly it is not clear why the Y-BOCS scale is preferred over other obsessionality scales e.g. Leyton in this population	Thank you for this comment, the suggestion you make is best left for individual clinicians to determine. To recommend the assessments you suggest would make the guideline unwieldy and would not facilitate implementation.
445.	Sussex Partnership NHS Foundation Trust	10	Full	8.2.3	254 and following	1 and followi	Given the presentation of adults may often occur in the absence of informants or developmental history and/or in middle age or late, mention could be usefully made of the need to exclude other disorders e.g. Huntington Disease, Wilson Disease, frontotemporal degeneration that may share social cognitive and other symptomatic features.	Thank you for your comment. We agree complex differential diagnosis is an issue for adults with autism that may be complicated by the lack of an informant. We make reference in our recommendations to seeking a second opinion and advice from specialist clinicians.

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446.	Sussex Partnership NHS Foundation Trust	8	Full	8.2.3	General & 254 - 264		We felt the guidance did not make sufficient reference to the issues of differential diagnosis and/or co-morbidities with ADHD & Tic Disorder / Tourette Syndrome and the importance of also assessing for these conditions alongside autism. Both are common, and may be associated with qualitative differences in social cognition and intrinsic obsessive-compulsive behaviours, though evidence-based treatment strategies may be different	Thank you for your comments, we are aware of the extent of comorbidity between autism and conditions such as ADHD and have made recommendations about this.
447.	Association Directors of Adult Social Services	23	FULL	8.2	265		Caution is given to the findings of the study comparing individuals with a LD in the studies with no direct reference to Autism to inclusion of Autism in the findings. No direct deferential can be given to treatment of Autism against the management and treatment of behaviour of an individual with a LD who may or may not have an Autistic Condition. We would also expect as guidance across Health and social care that addition consideration of an individual's capacity should be included within this section through the recognition of the Mental Capacity Act and other appropriate legislation. Clarity should also be given when describing Challenging behaviour with this specific group of people and being explicit about their level of need and any co morbidity. Need to be clear about what is being treated; symptoms or condition and their ability to consent including appropriately explaining of the contra indications or through the support of the nearest relative or IMPCA	Thank you for your comments, we exercised caution when extrapolating from the learning disabilities evidence base and our reasoning behind this is set out in the methods section (see Chapter 3). We have revised the recommendation to make specific reference to the Mental Capacity Act (see recommendation 1.1.15 in the NICE guideline)
448.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	8.2.6	266	1	Supported but recommendations for monitoring have cost implications and there is not health economics evidence cited. Within Wales there are initiatives within the Welsh Community of Practice for Challenging Behaviour and published literature on Positive Behavioural Support that is relevant	Thank you. Monitoring for side effects including weight gain is a good practice point. As stated, the GDG drew on the NICE guideline on the treatment and management of schizophrenia (2009) when formulating advice on the monitoring and management of side effects. No economic evidence was identified for the monitoring of side effects from antipsychotics in adults with autism. However, it is anticipated that the cost of regular monitoring is going to be offset by savings from further and more serious complications (e.g. monitoring weight gain is

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								likely to be cost-effective if it reduces the related risk of metabolic syndrome that leads to diabetes and cardiovascular disease that come with substantial health and cost implications).
449.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		Full	8.2.6	266	3	Need to be more specific about who constitutes a suitably qualified and experienced professional	Thank you, we cannot find the direct reference to this in the text but in regard to clinicians. We set out the requirements for interventions in the recommendations; it is for local services to determine whether staff are capable to deliver these interventions.
450.	Nottinghamshire Healthcare NHS Trust	6 3	Full	8.2.6	266	1 4	We feel it is important to include the potential for neuroleptic malignant syndrome in relation to sensitivity to antipsychotics, and to reference this in the NICE Guideline version of the document, as this is not widely recognised outside of intellectual disability services.	Thank you for your comment, we are aware of this issue and make a specific recommendation about the sensitivity to side effects see 1.3.4.
451.	Welsh Government		Full	8.2.7	266	1	Supported but recommendations for monitoring have cost implications and there is no health economics evidence cited. Within Wales there are initiatives within the Welsh Community of Practice for Challenging Behaviour and published literature on Positive Behavioural Support that is relevant	Monitoring for side effects including weight gain is a good practice point. As stated, the GDG drew on the NICE guideline on the treatment and management of schizophrenia (2009) when formulating advice on the monitoring and management of side effects. No economic evidence was identified for the monitoring of side effects from antipsychotics in adults with autism. However, it is anticipated that the cost of regular monitoring is going to be offset by savings from further and more serious complications (e.g. monitoring weight gain is likely to be cost-effective if it reduces the related risk of metabolic syndrome that leads to diabetes and cardiovascular disease that come with substantial health and cost implications).
452.	Welsh Government		Full	8.3.1	267	2 4	Again reference should be made to the RCPsych CR144 which contains guidelines on the use of medication for challenging behaviour – also the DATABID guidelines produce by University of Birmingham.	Thank you for your comment. It is not NICE style to include, as evidence, reports if they are not based on systematic review of the evidence.
453.	Northumberland, Tyne & Wear NHS Trust		Full	8.6	285	G e n	The prime lesson to be learned from the Secretin trials was the power of the placebo (in this case saline) which was also effective in those probands with severe intellectual disability	Thank you for this comment.

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						er al	Sandler, A. (2005) Placebo effects in developmental disabilities: Implications for research and practice. Mental Retardation and Developmental Disabilities Research Reviews, 11, 164-170.	
454.	The Royal College of Psychiatrists, Learning Disability Faculty	7 8	Full	8.6	285	G e n er al	**8.6** The prime lesson to be learned from the Secretin trials was the power of the placebo (in this case saline) which was also effective in those probands with severe intellectual disability **Sandler, A. (2005)** Placebo effects in developmental disabilities: Implications for research and practice. *Mental Retardation and Developmental Disabilities Research Reviews*, **11**, 164-170.	Thank you for this comment.
455.	Northumberland, Tyne & Wear NHS Trust		Full	8.9	295		The use of extrapolated data from children regarding stimulants for co-morbid conditions (i.e. ADHD) is well served by the balanced qualifications of the utility of the data. The statement that core autism symptoms are unlikely to be worsened is useful in this context.	Thank you for your comment.
456.	Northumberland, Tyne & Wear NHS Trust		Full	8.9.1	298	2 5	The recommendation for the use made for the use of atomoxetene on the basis that 13% dropped out of a study of 16 children (ages 5-14 years) of normal IQ (Posey 2006) in comparison to an 18% drop out from a study of 72 children of a mixed ability range (RUPP 2005). The difference in attrition rate is not statistically significant and the extrapolation to adults dubious, particularly as it is acknowledged that paediatric prescribing differs substantially. Nor is there any comment about the conjoint use of neuroleptics with methylphenidate although the practice is frequent and Posey (2006) mentions its potential.	Thank you for your comment, we have removed this recommendation.
457.	Northumberland, Tyne & Wear NHS Trust		Full	8.9.1	298	2 4	The reference should be (Murray 2010)	Thank you for your comment. This has been amended in the full guideline.
458.	The Royal College of Psychiatrists, Learning Disability Faculty	7 9	Full	8.9.6	298	2 5	The recommendation for the use made for the use of atomoxetene on the basis that 13% dropped out of a study of 16 children (ages 5-14 years) of normal IQ (Posey 2006) in comparison to an 18% drop out from a study of 72 children of a mixed ability range (RUPP 2005). The difference in attrition rate is not statistically significant and the extrapolation to adults dubious, particularly as it is acknowledged that paediatric prescribing differs substantially. Nor is there any comment about the conjoint use of	Thank you for your comment, we have removed this recommendation.

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							neuroleptics with methylphenidate although the practice is frequent and Posey (2006) mentions its potential.	
459.	The Royal College of Psychiatrists, Learning Disability Faculty	8 1	Full	8.9.6	298	2 4	The reference should be (Murray 2010)	Thank you for your comment. This has been amended in the full guideline.
460.	Nottinghamshire Healthcare NHS Trust	6 4	Full	8.10. 1	300	1 1	We feel it is important to draw attention here to the difficulties in diagnosing mental health problems such, as anxiety, for some adults on the autism spectrum due to issues such as: presence of intellectual disability, difficulty with language/ communication to express inner states, mismatch of facial expression to inner states, longstanding sleep wake cycle disruption which may impact on presentation.	Thank you or your comment, we agree and believe our recommendations address the issues of coexisting conditions.
461.	Nottinghamshire Healthcare NHS Trust	6 5	Full	8.11. 1	302	3	Again we feel it is important to acknowledge the potential difficulties in diagnosing depression in relation to: presence of intellectual disability, difficulty with language/ communication to express inner states, mismatch of facial expression to inner states, longstanding sleep wake cycle disruption which may impact on presentation.	Thank you for your comment, we appreciate the impact of communication difficulties on conducting an assessment however, it is not possible in the guideline to consider every eventuality.
462.	Sussex Partnership NHS Foundation Trust	1 2	Full	8.11	302	1 a n d fo llo wi n g	SSRIs are not recommended for repetitive behaviours however we note that the cited studies looked underpowered. SSRIs are beneficial for OCD and for OCBs in other neurodevelopmental conditions (e.g. Tourette Syndrome). Perhaps application to severe repetitive behaviours could be considered potentially useful.	Thank you, the GDG considered this but decided not to adopt your suggestion as the evidence is not available.
463.	British Dietetic Association	1 6	Full	8.12. 1	310	1, 8	Consider changing the term restrictive diets to the more correct term exclusion diets or modified diets	Thank you for your comment. 'Restrictive diets' have been amended to 'exclusion diets'.
464.	British Dietetic Association	1 7	Full	8.12. 1	310	7	Please note that all gluten and casein free diets are actually gluten and milk free diets – calling it a gluten and casein free diet is a misnomer that may mislead nutrition professionals that whey and lactose (other components of milk) are included – which they aren't	Thank you for your comment. However, this change has not been made as the gluten and casein free diet is a widely used term and all the reviewed research uses this term to describe the intervention.
465.	British Dietetic Association	1 8	Full	8.12. 1	310	2 8	Consider changing the term restrictive diets to the more correct term modified diet	Thank you for your comment. 'Restrictive diets' have been amended to 'exclusion diets'.
466.		1	Full	8.12.	310	3	Ketogenic diet is accepted to induce 50% reduction in seizures	Thank you for your comment.

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	British Dietetic Association	9		1		9	in refractory epilepsy in children, and the 2012 update of the NICE guideline recommends consideration of its use.	
467.	British Dietetic Association	20	Full	8.12.1	311	3	It could be noted that ketogenic diets are often gluten and casein free	Thank you for your comment. However, this change has not been made as the GDG considered the description of ketogenic diets to be adequately detailed.
468.	British Dietetic Association	21	Full	8.12.1	311	4	It could also be noted that a number of other dietary modifications that have been proposed to help with autism, including exclusion of multiple foods on top of gluten and milk, and the gut and psychology diet (TM) and the specific carbohydrate diet (TM), probiotics, have no published evidence.	Thank you for your comment. However, it is not possible to list all interventions which have been proposed for autism but which lack any evidence for their efficacy.
469.	British Dietetic Association	22	Full	8.12.1	311	4	To also include a review of the use of omega 3 supplements in autism – see Cochrane review - Cochrane Database Syst Rev. 2011 Nov 9;11:CD007992. Omega-3 fatty acids supplementation for autism spectrum disorders (ASD).	Thank you for your comment. This systematic review was considered, however, the two included studies failed to meet our inclusion criteria, one on the basis of sample size and the other on the basis that the intervention was aimed at a coexisting condition (hyperactivity) rather than the core symptoms of autism
470.	British Dietetic Association	23	Full	8.12.1	312	13	To include an acknowledgement that registered dietitians are best placed assess for dietary adequacy, advise on necessary dietary interventions and to initiate, support and monitor dietary modifications. Exclusion and ketogenic diets can lead to dietary deficiencies when not support by appropriate dietetic support and monitoring.	Thank you for your comment. We have included as a general intervention recommendation that potential adverse effects should be regularly reviewed for any intervention (see recommendation 1.3.5 in the NICE guideline). However, it is a matter for local implementation who performs this review.
471.	British Dietetic Association	24	Full	8.12.2	312	28	Recently published RCTs that should also be considered are: Whiteley P, et al The ScanBrit randomised, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders Nutr Neurosci. 2010 Apr;13(2):87-100; and Adams JB, Audhya T, McDonough-Means S Effect of a vitamin/mineral supplement on children and adults with autism BMC Pediatrics 2011, 11:111 (the first of these seems very well designed with very promising results – the drawback is that actually the intervention group received the dietary modification plus vitamin and mineral supplementation – not just the GFCF diet; the second again has very promising results but some of the laboratory tests	Thank you for your comment. However, neither of these studies meets inclusion criteria as data which could be entered into a meta-analysis could not be extracted. However, these studies have been added to the excluded study characteristics tables in Appendix 14.

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						used are not routinely used in the NHS, and the levels of a number of micronutrients in the formula used are above recommended nutrient intakes, and it also contains a low level of lithium)	
472.	British Dietetic Association	25	Full	8.12.3	315	1, 31	Consider changing the term restrictive diets to the more correct term exclusion diets or modified diets	Thank you for your comment. 'Restrictive diets' have been amended to 'exclusion diets'.
473.	British Dietetic Association	26	Full	8.12.3	316	16	It should be noted that the dose of B6 is high – pharmaceutical level rather than recommended nutrient intake level. And that high doses of B6 can be harmful	Thank you for your comment. We do not recommend the use of vitamins, minerals or dietary supplements for treating the core symptoms of autism.
474.	British Dietetic Association	27	Full	8.12.6	320	13	Re: Safety It is accepted that the safety of dietary manipulation is best gauged by dietitians on an individual basis. Gluten free and casein free diets are perfectly safe when properly implemented and monitored by a dietitian. And followed safely by many children and adults for different conditions. Ketogenic diets have a higher risk of weight loss and nutritional insufficiency but again this is absolutely minimised by dietetic management. Dietitians are best placed to trial dietary modifications on an individual basis, as per the British Dietetic Association Professional Consensus Statement. Multivitamin and mineral supplements at or below the recommended nutrient intakes are safe. The Department of Health provides clear guidance on the safe upper intakes of different vitamins and minerals.	Thank you for your comment. We have included as a general intervention recommendation that potential adverse effects should be regularly reviewed for any intervention (see recommendation 1.3.5 in the NICE guideline). However, it is a matter for local implementation who performs this review.
475.	Northumberland, Tyne & Wear NHS Trust		Full	8.12.6	321		The removal of dental amalgam is sometimes sought as part of the programme of detoxification; this might be a suitable point at which to point up the lack of evidence for its effectiveness and therefore the ethical issues of carrying out such a procedure (let alone suggesting it to someone of limited mental capacity).	Thank you for your comment. The systematic search did not find any evidence for dental amalgam removal in adults with autism and the GDG did not feel that this practice was widespread enough to warrant a recommendation.
476.	The Royal College of Psychiatrists, Learning Disability Faculty	82	Full	8.13	321	General	The removal of dental amalgam is sometimes sought as part of the programme of detoxification; this might be a suitable point at which to point up the lack of evidence for its effectiveness and therefore the ethical issues of carrying out such a procedure (let alone suggesting it to someone of limited mental capacity).	Thank you for your comment. The systematic search did not find any evidence for dental amalgam removal in adults with autism and the GDG did not feel that this practice was widespread enough to warrant a recommendation.
477.	European Association for	10	Full	9	327	1	So many key references missing related to behavioural intervention for autism. There are more references about	Thank you for your comment. NICE guidelines consider evidence according to an

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	Behaviour Analysis						facilitated communication in the reference section! The heavy reliance on RCTS is a big problem because it is unlikely that there will ever be sufficient numbers of RCTs to satisfy an unequivocal recommendation for any particular intervention. This is for two reasons, and these are both general reasons why RCTs are not satisfactory determinants of the scientific validation of autism interventions. First, all interventions for individuals with autism ought to be individualized according to the wide heterogeneity of assessed and expressed deficits. This is particularly true of behavioural interventions (and it ought to be true of all interventions). RCTs are designed to compare groups having one discrete intervention/treatment with another group (or groups) having something else (comparison), or nothing (control). This is perfect for testing a new drug where everyone gets the same drug and dose, but not practical or possible where each intervention is necessarily individualised: different therapists, different levels of experience and competence, different levels of intensity of the intervention, different levels of family involvement, different developmental deficits, different levels of support from residential facilities etc. Second, it would be almost impossible to control for individuals rigidly and inflexibly adhering to the very precise independent variables described above and also not using/trying other sorts of interventions (e.g. diets, vitamin supplements, occasional access to any other of the thousands of treatments and interventions now available). Such confounds would not enable an accurate evaluation. Yes, ideally RCTs are a gold standard, but this is not an all or nothing scientific analysis, and studies that are not RCTs, but have experimental and comparison/control groups provide a level of evidence, as do the 100s if not 1000s of single-case study designs, and it has been argued by many, successfully, that these types of studies should be included in any sort of evaluation of the evidence, albeit not weighted as heavily as the gold-standard RCT. See, for example, the national Autism Center's National Standards Project (2009).	established hierarchy of study types and well-conducted randomised controlled trials (RCTs) are at the top of this hierarchy. This is because RCTs provide the greatest degree of certainty that can be attributed to the conclusions drawn from the study.
478.	Northumberland, Tyne & Wear NHS Trust		Full	9	362	4 4	The reference should be (Murray 2010)	Thank you for your comment. This has been amended.
479.	The Royal College	8	Full	9	362	4	The reference should be (Murray 2010)	Thank you for your comment. This has been

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	of Psychiatrists, Learning Disability Faculty	3				4		amended.
480.	Tees, Esk & Wear Valleys NHS Foundation Trust0	1	Full Guid ance		gen eral		The guidance is greatly welcomed and is needed to guide practice nationally beyond diagnosis	Thank you for taking the time to comment.
481.	NCCMH expert reviewer	1 4	Appe ndice s		19		APPENDIX 6: RESEARCHERS CONTACTED TO REQUEST INFORMATION ABOUT UNPUBLISHED OR SOON-TO-BE PUBLISHED STUDIES. I was asked by NICE and supplied to NICE a pre publication paper evaluating a 20 item version of the AQ in the general population. I find that it has not been used in the review. It was also publically available on line in July 2011 and is now in print (Brugha et al 2012, Validating two survey method for identifying cases of autism spectrum disorder among adults in the community. Psychological Medicine, 42, 647-656.). Test results for the AQ-20 have also been presented at international conferences (these were not in the published article). We found a combination of sensitivity and specificity for an optimal 10+ cut off on AQ-20 (to predict ADOS 10+): sensitivity = 73.7 and specificity = 62.0. Sum = 135.7 (1.36). McNamee argues for minimum of 1.6+. I can supply tables for this analysis so that LR+ and LR- can also be analysed. As this is a general population sample it is unlikely that a test such as this would be used in such a population. Importantly, it demonstrates clearly that sensitivity and specificity are different in a different sample settings - particularly where, as in this example, prevalence of autism is estimated to be low. This is why tests like the AQ need to be evaluated in settings in which they will be used such as primary care, adult mental health clinics etc before being recommended.	Thank you for this comment. We have now added the Brugha et al. (2012) study to our case identification and assessment review (see Chapter 5 of the full guideline).
482.	NCCMH expert reviewer	1 3	Appe ndice s		4		Appendix 16, page 4. Study ID ALLISON2001. My comment is on the coding of the question: 'Was the spectrum of participants representative of the patients who will receive the test in practice?' Yes is recorded by the NICE researcher but it is the incorrect answer. Two groups of study subjects are described in ALLISON2001: patients seen by an autism clinic with a confirmed diagnosis and general population controls including university students. A screening test is not needed and would not be used for either group, as already pointed out	Thank you for your comment. A new set of methodological checklists, based on the QUADAS-2 tool, have been added to Appendix 16 and this amendment should address your concern.

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							above. The same coding error has been made for BARONCOHEN2001, KURITA2005, WAKABAYASHI2005. Perhaps the reviewer has not understood the sampling methods used and the meaning of the above question. I have not checked the sampling for all the other studies; the same error may have occurred also; this should be completely re-checked. There is also a problem with the analysis of these studies mentioned above in my comments (page 99, line 11 etc).	
483.	Royal College of Nursing	1	General		General		The Royal College of Nursing welcomes proposals to develop this guideline. It is timely and will benefit users and healthcare professionals alike.	Thank you for taking the time to comment.
484.	Worcestershire Health and Care NHS Trust	13	NICE		16		Repetitive of advice earlier comments.	Thank you for your comment. The recommendations list at the front of the guideline are the key priorities for implementation, and therefore do repeat later recommendations.
485.	Sheffield Asperger Syndrome Service	16	NICE		7	6	The Family Partnership Model would be helpful to mention. There are many instances where 'working in partnership' is recommended but without referencing any specific model or approach. Hilton Davis is a key author in this area. Reference example: Davis, H. & Meltzer, L. (2007) Working in Partnership with Parents: the Parent Advisor Model. The Psychological Corporation Limited: London, UK.	Thank you for your comment. We could find no evidence to support recommendation for the family partnership model. In the absence of specific evidence we set out recommendations about the principles for delivering care.
486.	Autism Rights Group Highland	4	NICE		7	6	Add: when the autistic person has agreed the involvement.	Thank you we have amended this recommendation.
487.	Autism West Midlands		NICE		general		Remaining comments are on the shorter NICE version	Thank you for your comments.
488.	Royal College of Speech and Language Therapists	9.	NICE		General		This document seems to be conflicting when on the one hand it talks about skilling up **all professionals** who work with people on the spectrum (1.1.1) and then talks about the need for a specialist team (1.1.10)	Thank you, you are right that the recommendation points to the general 'skilling up' of professionals and for specialist teams. We do not think this is contradictory.
489.	Northumberland, Tyne & Wear NHS Trust		NICE		general		Certain respondents from within the NTW "registered stakeholder" contributed in part to the RCPsych response to the draft guideline. Their contribution to NTW's response formed part of a collaborative debate within NTW, and so differences in certain comments here may reflect discussion our internal discussions	Thank you for your comments.
490.	Northumberland, Tyne & Wear NHS		NICE		general		perhaps research recommendations could have been brought together in a separate section.	Thank you for your comment, the research recommendations are listed in section 4 of

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	Trust							this guideline.
491.	Northumberland, Tyne & Wear NHS Trust		NICE		general		There are no recommendation as to the use of • music therapy or art-based therapies • sensory integration or sensory diets – the method of sensory assessment • the various holistic therapies - massage, aromatherapy, acupuncture. • Intensive interaction However, such is there level of use in current practice that there should be a note as to the extent of the evidence supporting their use. In some cases it might be linked to a discussion of the placebo effect (Sandler 2005) Sandler, A. (2005) Placebo effects in developmental disabilities: Implications for research and practice. Mental Retardation and Developmental Disabilities Research Reviews, 11, 164-170.	Thank you for your comments, the expert opinion within the GDG was that there was not reason to believe that arts-based interventions, holistic therapies or sensory integration interventions would be either significantly beneficial or significantly harmful, and given the lack of any evidence for clinical efficacy, there were therefore insufficient grounds for a recommendation.. Although we did make some recommendations regarding diet (see recommendation 1.4.16 in the NICE guideline).
492.	Northumberland, Tyne & Wear NHS Trust		NICE		general		Generally –positive as it goes beyond diagnosis to consider provision and care	Thank you for your comments.
493.	Northumberland, Tyne & Wear NHS Trust		NICE		general		Introduction: the shape of the guidance may be misunderstood by a readers without reference to the full document or who are not intimately familiar with the nature of NICE. Please emphasise that 1. the lack of evidence for effectiveness is not evidence that they are ineffective 2. in certain areas, where evidence has not been available, the guidelines have drawn on the evidence from a related which may be open to question (as discussed in the full document)	Thank you for your comment. We are unable to add these comments to the NICE guideline as we are unable to amend the NICE 'standard text'.
494.	Northumberland, Tyne & Wear NHS Trust		NICE		general		Welcome the emphasis on psycho-social interventions and the careful trialling of bio-medical intervention in the context of broader psycho-social work to address challenging behaviour.	Thank you for your comments.
495.	Pyramid Educational Consultants	1	NICE		General		We would like more emphasis on continuity of skills through the transition into adulthood.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
496.	Pyramid	1	NICE		Ge		Communication and social could be blurred in readers' minds,	Thank you, we feel there is a clear separation

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	Educational Consultants	5			ner al		we would like a clear separation of the two throughout the document.	between the two.
497.	Pyramid Educational Consultants	16	NICE		General		We would also like to see that staff members working with adults receive correct training to implement measures, whether communicative, social or behavioural.	Thank you for your comment. We have set out the requirements for interventions in the recommendations. However, it is for local services to ensure that staff are capable of delivering these interventions.
498.	Pyramid Educational Consultants	17	NICE		General		There is very little mention of education even though in our experience adults with autism, particularly those who are low-functioning can considerably improve their skills and hence their outcomes. We can understand why it may not be politic to talk of education in adults, but like the rest of the adult population, skills can continue to improve, sometimes dramatically. We would like to see this highlighted through the document.	Thank you, however education is outside the scope of this guideline.
499.	Pyramid Educational Consultants	18	NICE		General		We would like the recommendations to highlight the importance of giving adults with autism the skills to run their own lives, including those in residential accommodation much more than they presently do.	Thank you, many of the recommendations about life skills are about increasing life skills and autonomy.
500.	Worcestershire Health and Care NHS Trust	27	NICE		General	All Sections	The draft guidance is very welcome but feels very much biased towards people with Autism and not those with Asperger Syndrome whom our service has been designed for. In just 6 months we have had over 140 referrals for diagnosis and support of already diagnosed people. The most common issues are finding work, housing, alcohol misuse, forensic work. The guidance focuses too much on challenging behaviour which traditionally occurs in learning disabilities. With adults with capacity, average or above intelligence the behaviours are more affected by lack of insight making interventions difficult. The guidance is setting up trusts and local authorities to provide 'gold standard' services without the resources to provide them. From a clinician's point of view having a fully staffed MDT would be fantastic but it difficult to see this ever happening. It also may be setting up people with AS/Autism to expect these teams to appear which is unlikely to be the case. Providing an adult diagnostic service has shown that there are a lot of individuals who need support. However a large number also require considerable time to adjust to the diagnosis as it is not always the answer they expected and can in some cases	Thank you, it is clear from the introduction to the guideline the term 'autism' including those people currently diagnosed with Asperger's syndrome.

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							make things worse in the short term. Until this period has been negotiated intervention on other issues is often impossible to start. There is a lot of emphasis on time scales and care plans that in clinical experience constantly change and revised without ever discharging people from the service.	
501.	The Royal College of Psychiatrists, Learning Disability Faculty	84	NICE		General		There are no recommendation as to the use of • music therapy or art-based therapies • sensory integration or sensory diets – the method of sensory assessment • the various holistic therapies - massage, aromatherapy, acupuncture. • Intensive interaction However, such is there level of use in current practice that there should be a note as to the extent of the evidence supporting their use. In some cases it might be linked to a discussion of the placebo effect (Sandler 2005) Sandler, A. (2005) Placebo effects in developmental disabilities: Implications for research and practice. Mental Retardation and Developmental Disabilities Research Reviews, 11, 164-170.	Thank you for your comments, the GDG did not consider it appropriate to make recommendations in these areas as there is no evidence that they would a) be beneficial, or b) do any harm. Although we did make some recommendations regarding diet (see recommendation 1.4.16 in the NICE guideline).
502.	Autism Rights Group Highland	22	NICE		General		Training should be designed / led by autistic Adults in conjunction with autistic peoples Organisations.	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local and national implementation.
503.	Autism Rights Group Highland	23	NICE		General		Consider differential presentation by women and the 'masking' of autistic differences through years of living and adapting to the NT environment.	Thank you for your comment, issues relating specifically to women are addressed in recommendation 1.9.3. (revised recommendation numbers 1.8.3)
504.	Autism Rights Group Highland	24	NICE		General		Involve autistic peoples orgs in all planning of service development and delivery.	Thank you for your comment. Revised recommendation number 1.1.12 states that people with autism, and their families should have meaningful representation in the autism strategy group, which will plan service development and delivery.
505.	Autism Rights Group Highland	25	NICE		General		How will this be rolled out to include the many adults who either don't have a diagnosis yet or who are currently cared for within the general mental health services or who don't need a continuous care plan, but may need something specific at some stage?	Thank you, this is a matter for local implementation.
506.	Autism Rights	2	NICE		Ge		How binding will these guidelines be for local	Thank you for your comment, NICE

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	Group Highland	6			neral		authorities and who will monitor their proper implementation?	guidelines are not binding but do set standards for the NHS.
507.	Autism Rights Group Highland	27	NICE		General		This is a very good document and shows how much progress has been made in understanding autism since Autistic people were first given a voice, although we still have far to go.	Thank you for your comments.
508.	NCCMH Expert Reviewer	9	NICE		General	General	There appears to be no reference to the sort of "clustering" allocations now conducted in several NHS Trusts in order for patients to be classified according to care clusters that then attract funding from commissioners (PBR – payment by results). There is currently a gap in all these trusts where clustering occurs, in that neurodevelopmental disorders are placed into a "no funding" or 0 cluster, which means that NHS Trusts receive no money for services they might try and provide for people with autism. This needs to be addressed in order to address: a) the commissioner's funding arrangements in mental health, and will not be addressed until there is some clear guidance at national level eg via a NICE guideline suggesting clustering allocations be made for autistic spectrum disorders including those on the high functioning end. b) the public provision of services for people with autism, or we will end up with a two tier service, in which private providers do something for those with the money to pay, and public service providers like the NHS are hamstrung by this ongoing funding debacle/arrangements. I am sure the NICE committee are aware of the commissioning arrangements for autism in LD, but for higher functioning autism than LD, these are rarely in place.	Thank you for your comments, this is an important issue but it is outside the scope of the guideline.
509.	Optical Confederation, and the LOC Support Unit	1	NICE		general		The Optical Confederation works closely with charities, such as SeeAbility, who provide specialist services for people with learning disabilities, autism, acquired brain injury, cerebral palsy, and epilepsy. The vast majority of the people supported by SeeAbility also suffer from a visual impairment. Despite being more prevalent among people with learning disabilities, such as autism, visual impairment is all too often undetected in such people, adding to their sense of isolation and frustration. It is crucial therefore that support staff working with people with sight loss and autism, are able to use effective and	Thank you for your comments, we agree this is an important area and have included the need for the physical needs of people with autism to be met in recommendations 1.1.3, 1.2.7 and 1.2.9 (revised recommendation numbers1.1.3, 1.2.7 and 1.2.10).

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							individualised strategies. SeeAbility also regularly hosts training and awareness courses to enable support staff to have a better understanding about autism and sight loss to equip them with the necessary knowledge and tools to support individuals. We recognise that people with an Autism Spectrum Disorder (ASD) face challenges with: • Communication • Invasion of personal space • Disruption of routine • Introduction of strangers • Introduction of equipment All of these challenges will cause difficulties with normal communication and exam routines[10]. However, with time, patience and training, they can all be overcome. At present, there is no provision for any of these examinations in the General Ophthalmic Services contract. LOCSU is currently developing a pathway for a specialist sight test (or enhanced service) for people with autism. The pathway is designed to provide information, support and improve access to eye care services, thus ensuring that people with autism have good vision (with refractive correction supplied, as appropriate) and that any sight-threatening problems are detected and treated at an early stage. People with autism often require longer appointment times and several visits to the optical practice to become familiar with the environment. They may also need additional time with the optometrist, so that the results of the eye examination can be explained. Once the LOCSU pathway for People with Learning Disabilities (such as autism) is launched, we would be willing and delighted to work with NICE, the Department of Health and the NHS Commissioning Board to commend its early adoption to Clinical Commissioning Groups. People with ASD, or any other disability for that matter, have an equal right to regular and comprehensive eye care as any other group (Disability Discrimination Act and the Equality Act 2010). As recommended by the National Autistic Society, a person with autism should plan an informal trip to their optical practice	

[10] D.R. Simmons et al. / Vision Research 49 (2009) 2705–2706

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							before the actual day of the examination. The involvement of the health professional at these times is extremely useful, in order that the person with an ASD can get to the optician, become accustomed to the room and any equipment, e.g. special chair, eye glasses. All of these components have been incorporated into the design of the aforementioned LOCSU pathway. More information is available here: http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx	
510.	Optical Confederation, and the LOC Support Unit	2	NICE		general		Studies have shown that the estimated prevalence of visual impairment or significant refractive error in people with learning disabilities is 52.43% in children, 62.3% in the 20-49 age group and 70.1% in the over 50s - significantly higher than for the population as a whole.[11] Most of this impairment is due to refractive error and can be corrected with spectacles; however people with learning disabilities are less likely to have sight tests and are also less likely to receive visual aids.[12]	Thank you for your comment. We have included a recommendation regarding sight tests in recommendation 1.2.7.
511.	Autism West Midlands	7	NICE Version	1	General; 3; 8; 15-17; 23; 25		Problematic terminology Our Autism Consultation Work Group (ACWG) found some language used in the NICE Version difficult to understand and attempted literal interpretation of subject-specific terminology such as facilitated communication (ibid: 25) which led to confusion about the meaning of the guideline. Therefore, we recommend that either the NICE Version has a glossary of terms or that terminology is clearly explained in the body of the text. The following terms were highlighted as particularly difficult: • facilitated communication (ibid) • modelling (ibid: 23) • intervention (ibid: 3) • care pathway (ibid: 9)	Thank you for your comment. We have added a glossary to the NICE guideline. In which we have included some of your suggestions. We have amended recommendations to make the other terms clearer.

[11] The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in England Eric Emerson & Janet Robertson – 2011 http://www.improvinghealthandlives.org.uk/gsf.php5?f=10954

[12] McCulloch, D. L., Sludden, P. A., McKeown, K., et al (1996) Vision care requirements among intellectually disabled adults. Journal of Intellectual Disability Research, 40, 140–150 http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2788.1996.715715.x/abstract

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							• psychosocial (ibid: 8) • explanation of the difference between initial assessment and comprehensive assessment (ibid: 15-17) • explanation of group-based social learning programmes (ibid: 23.)	
512.	Craegmoor	8	NICE version and the Full version		General comment		I think this is an excellent document and pleased to see the brief version that is very readable and packed with good information to support staff understanding of those with ASD in their care. I have also looked through the full version and it is great to have that to refer to from the brief version. However the majority of folk will read the brief version. I have not had time to read the full version in enough detail to comment fully on it but there have been sections I have referred to for greater clarification and this has been helpful. This has been a considerable undertaking for all involved but very worthwhile and I believe it will make a real contribution to better services for people with ASD and improved training for the staff who work with them. Thank you to all involved.	Thank you very much for your comments, they are appreciated.
513.	British Psychological Society		NICE version		5	2	The BPS welcomes the prominence given to "person-centred care" and the Mental Capacity Act in the opening section of the guidance.	Thank you for your comments.
514.	Brighton and Hove City Council	9	NICE version		General		The guidance would benefit from reference to social care FACS criteria and the availability of individualised budgets.	Thank you, this is outside the scope of the guideline.
515.	Somerset County Council	16	NICE version		General		How can Autism support development be promoted whilst so many cuts are being introduced? How will clients whose provisions are cut be provided for? Who will monitor service provisions and where will accountability lie?	Thank you, guidelines set standards for care funding considerations are for local and national implementation.
516.	The National Autistic Society	23	NICE version		General	General	In the adult autism strategy, the Government committed to: "…delivering guidance to indicate the kinds of adjustments that might usefully be made, from physical adjustments to premises to improving the ways those delivering services communicate with adults with autism." (p.20-21) The shorter 'NICE' version of this guideline does offer numerous suggestions, but does not provide this specific guidance that is essential to making reasonable adjustments	Thank you for your comment. We agree that adaptations to the environment are important. However we do not agree that we have not made reference to the issues you highlight. We already make reference to visual aids and supports, clear communication and structured routines In addition we have amended our recommendations on the physical

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							when supporting adults with autism. To name just a few, and this list is by means complete, there is no mention that professionals may want to consider using: • Visual supports • Clear and literal communication • Structured and reliable routines • Safe places/quiet rooms which individuals can go to if they are feeling anxious It is not for NICE to, without prompt, fulfil a Government commitment, but there is without doubt some benefit for ensuring that consideration is given as to how this guideline – and in particular the shorter version – could go some way to suggesting some adjustments that professionals may wish to take.[13]	environments to include safe rooms (see revised recommendations 1.8.12-1.8.14 in the NICE guideline).
517.	The Royal College of Psychiatrists, Learning Disability Faculty	15	NICE		Intro		The shape of the guidance is prone to be misunderstood by a reader who does not refer back to the full document and who is not intimately familiar with the nature of NICE. The introduction needs to emphasise the basis of the guidance 1) That NICE usually makes recommendations only where there is a high standard of supportive evidence. However, the lack of evidence for the effectiveness of an instrument/treatment etc. is simply that; it is not evidence that they are ineffective That in certain areas, where evidence has not been available, the guidelines have drawn on the evidence from a related population (with intellectual disability or children) supported by the expert knowledge and judgement of the GDG, to make recommendations. It is open to question as to whether there is adequate evidence that the relevant characteristics of the two populations (with ID/children and with Autism) are sufficiently close to justify this extrapolation. The document draws attention in its footnotes on the occasions when Guidelines have been derived on the basis of this process.	Thank you for your comment, the intention of the NICE guideline is only to provide a summary of recommendations in the full guideline. You are correct that reference to the full guideline is necessary to see the evidence base for these recommendations. With regards to extrapolation, the GDG gave careful consideration as to whether to extrapolate from children or individuals with learning disabilities, and only did so in cases consistent with the extrapolation principles as detailed in Chapter 3. In addition, the quality of all evidence from extrapolated populations was downgraded (within GRADE) to reflect the indirectness of the data.
518.	The Royal College of Psychiatrists,	17	Nice	introducti		3	There is sufficient doubt has arisen as to whether autism is a 'lifelong' condition for this word (which has a number of	Thank you, we disagree. The clear view of the GDG and most international experts is

[13] The NAS would fully expect that the suggestions made to adapting CBT (1.5.3) could be used as a starting point for this.

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	Learning Disability Faculty			on			implications not dealt with by these guidelines) to be omitted.	that autism is a lifelong condition. Furthermore you provide no evidence in support of this assertion.
519.	The Royal College of Psychiatrists, Learning Disability Faculty	1 8	NICE	intro ducti on		3	The emphasis is on autism as a disorder in an individual as well as on families/carers needs. There should also be noted the interaction between the two groups, the complex relationships that can ensue with a substantial impact on the intensity of the autistic symptomatology and the mental well-being of all parties.	Thank you for this comment. We have taken account of the interaction with family in the experience of care chapter of the full guideline.
520.	Autism West Midlands	8	NICE versi on		3-6		Detail about 'for whom this guideline is intended' as specified in NICE FULL Version (NICE, 2011a: 9, lines 23-34) should be included in the introduction to the NICE version (NICE, 2011b). Adults with autism in our ACWG said that they wanted it to be made clear who the NICE Version applied to without having to consult the NICE FULL Version.	Thank you for your comment. We have added the section from the full guideline to the NICE guideline as you have suggested.
521.	The Royal College of Psychiatrists, Learning Disability Faculty	1 9	Nice	intro ducti on		3	Bullying should be mentioned	Thank you for your comment, it would not be appropriate to include such references in the introduction but we have dealt with bullying in our anti-victimisation recommendations.
522.	Northumberland, Tyne & Wear NHS Trust		NICE	Intro ducti on	3		There is sufficient doubt has arisen as to whether autism is a 'lifelong' condition for this word (which has a number of implications not dealt with by these guidelines) to be omitted. We consider lifelong vulnerability but celebrate with families progress if and when symptoms and behaviours subside!	Thank you, we disagree. The clear view of the GDG and most international experts is that it is a lifelong condition. Furthermore you provide no evidence in support of this assertion.
523.	Northumberland, Tyne & Wear NHS Trust		NICE	Intro ducti on	3		The emphasis is on autism as a disorder in an individual as well as on families/carers needs. There should also be noted the interaction between the two groups, the complex relationships that can ensue with a substantial impact on the intensity of the autistic symptomatology and the mental well-being of all parties.	Thank you for this comment. We have taken account of the interaction with family in the experience of care chapter of the full guideline.
524.	Northumberland, Tyne & Wear NHS Trust		NICE	Intro ducti on	3		Bullying should be mentioned	Thank you for your comment, it would not be appropriate to include such references in the introduction but we have dealt with bullying in our anti-victimisation recommendations.
525.	Tees, Esk & Wear Valleys NHS Foundation Trust	4	NICE	Intro ducti on	3		The emphasis is on autism as a disorder in an individual as well as on families/carers needs. There should be some discussion of the complex relationships between the individual and family/ carers given the impact this has on the expression of the disorder. It is not simply the individual but the relationship with others that has an effect on presentation	Thank you for this comment. We have taken account of the interaction with family in the experience of care chapter of the full guideline.

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526.	WaASP		NICE guideline	introduction	3	1	Please amend to read 'Autism and Asperger's Syndrome are a lifelong…' The only use of the term 'Asperger's' in this document is in footnote 1 on page 3; in the 'full' AUTISM document (on which we are commenting separately) it is used 273 times – because the term needs to be used to differentiate Kanner AU from Asperger's.	Thank you, we have considered this but decided not to change it as autism is used to include the full spectrum.
527.	Autism Rights Group Highland	1	NICE	Introduction	4	2 & 4	The way that families are referred to here implies that all autistic adults have families that they wish to be involved (or families at all), the wording should be changed to remove this implication.	Thank you, the section you refer to is a general introduction. We are aware that not all individuals with autism would wish their families to be involved and we have made this clear in a number of recommendations.
528.	Prison Reform Trust	1	NICE	Person centred care	5	1	Person-centred care should include appropriate arrangements for individuals in contact with criminal justice services, and especially for those sentenced to prison and remanded into custody. Good communication will be necessary between the healthcare professionals working with an individual with autism and criminal justice staff, for example, during initial contact with the police, including with criminal justice liaison and diversion and Appropriate Adult services; in court, to help ensure effective participation and to inform pre-sentence reports; and, following sentence, with probation and prison services.	Thank you for your comments. Unfortunately we are unable to amend the section on 'person centred care' as this is NICE standard text. We are unable to make direct recommendations regarding prisons as this guideline has not reviewed the evidence for prison populations as they are outside the scope, although the recommendations may be relevant to those working within prison/forensic services.
529.	Craegmoor	1	NICE	NICE intro	5	3	People with autism tend to go for the familiar or the most predictable so when the document refers to "informed decisions" this needs to be remembered and where possible concrete outcomes of different decisions need to be made as visually clear as possible – could this be added?	Thank you for this comment, we have in a number of recommendations provided advice on the way in which assessments are structured and advice and information is offered.
530.	Worcestershire Health and Care NHS Trust	1	NICE	Introduction	5	3 and general	With limited resources there is often very little choice beyond "do you wish to have input from them team". Being able to offer a wide range of options is only possible with support from all areas of health and social care. While there is some enthusiasm from professionals there remains a feeling that "we can't offer them (people with AS) anything. This is better from Clinical Psychology teams but not the wider system. There are no suggestions about how this message will be put to the other interested health and social care professionals.	Thank you for this comment – we agree the implications of this guideline will need to be carefully considered by service managers and commissioners**.** We hope that this guideline, along with the Autism Act and Autism Strategy will ensure this is no longer the case for people with autism.
531.	Worcestershire Health and Care NHS Trust	2	NICE	Introduction	5	Para 2	When working with adults who have essentially a social communication disorder communication no matter how well the information is given or made is misinterpreted by individuals. Even in written from people with AS often will have one view that is not intended by professionals leading to conflict. The	Thank you for your comment. We feel however that it misrepresents the recommendations. The guideline provides considerable advice on how information is communicated. We have also included a

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							guidance provides no advice on how to do this nor does it suggest beyond 'evidence based' information without given any examples of evidence based examples.	further recommendation on post-diagnostic support.
532.	Worcestershire Health and Care NHS Trust	3	NICE	Introduction	5	Para 2	We agree that there should be a range of options for accessible information to be available, there is no provision given for the cost of providing this or suggestions about good practice in the area.	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local and national implementation.
533.	Worcestershire Health and Care NHS Trust	4	NICE	Introduction	5	Para 4	Transition. There is often a huge disparity of provision between child and adult services with greater resources in child settings. Moving from this to a very small part time team can set the person up for failure.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
534.	Worcestershire Health and Care NHS Trust	5	NICE	Introduction	5	Para 4	There is no suggestion how adult and child services can work across what can be very fixed boundaries and in all cases the child's ongoing care will be with adult services who have fewer resources to provide care and support. The trust has a procedure for the transition but it can still be difficult to make this run smoothly.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
535.	Autism Rights Group Highland	2	NICE	Introduction	5	2	Remove "peoples'" and put individuals; this makes the meaning more direct.	Thank you for your comment but 'people' is consistent with the terminology used elsewhere in the guideline.
536.	The Royal College of Psychiatrists, Learning Disability Faculty	8	NICE /Full	1.1.9 /6.4. 7.3	144	38	We wholeheartedly support the development of specialist community-based multidisciplinary autism teams. The inclusion of specialist care and treatment and its coordination is essential, and was unfortunately missing from the Autism Strategy. The focus on robust, local, clinical care pathways is also extremely important.	Thank you for your comments.
537.	Craegmoor	2	NICE	NICE intro	5	19	Regarding the consent by the person with autism for the involvement of families and carers with regard to treatment. Families need to be listened to with great care as often they do know their son or daughter very well but this may not be reflected in what the individual says – it is not just about supporting the family it is about listening to their contribution to the knowledge that is required when making decisions regarding treatments.	Thank you for this comment. We hope that this has been reflected in some of our recommendations and also in our summary of families' experience of care.

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538.	Autism Rights Group Highland	3	NICE	Introduction	5	19	"If the person with autism agrees, families and carers should have the opportunity to be involved in decisions about treatment and care". This should be moved to be at the very beginning of this section and reiterated throughout, it is an essential for the professional to remember and action.	Thank you, we have significantly revised the structure of the guideline in line with your and others' comments. However it is not NICE practice to repeat recommendations throughout the guideline.
539.	WaASP		NICE guideline	introduction	5	3	We applaud your emphasis on taking individuals' needs into account. The need of a person with Aspergers is typically different from that of a person with Kanner Autism with LD. We understand the clinical association of Kanner's with Asperger's but your guideline is to do with the MANAGEMENT of adults and their treatment. Management requires classification for structural rather than diagnostic purposes and we request your specific recommendation that service for AS be distinct from LDAU. It is important in this context to acknowledge that AU patients with LD are likely to require much more extensive and costly support than (non-LD) Aspergers patients. If the services for the two are lumped together within a single budget there is a strong likelihood that AS patients will continue their long history of deprivation of appropriate services.	Thank you for this comment, throughout the guideline the GDG carefully considered the application of the recommendations to the whole autism spectrum and where there was evidence to refer to specific groups we have done so.
540.	Tees, Esk & Wear Valleys NHS Foundation Trust	2	NICE Introduction		general		There is a problem that unless the reader has read the full guidance there will be poor understanding of the way it has been developed That NICE usually makes recommendations only if there is a high standard of supportive evidence. The lack of evidence does not imply the instruments are poor - simply that there is no supporting evidence but the way it is laid out means the reader may consider the instruments to be considered inappropriate Where evidence has not been available, the guidelines have drawn on the evidence from a related population (with intellectual disability or children) supported by the expert knowledge and judgement of the GDG, to make recommendations. There is concern that these are not comparable groups .	Thank you for your comment, the intention of the NICE guideline is only to provide a summary of recommendations in the full guideline. You are correct that reference to the full guideline is necessary to see the evidence base for these recommendations. With regards to extrapolation, the GDG gave careful consideration as to whether to extrapolate from children or individuals with learning disabilities, and only did so in cases consistent with the extrapolation principles as detailed in Chapter 3. In addition, the quality of all evidence from extrapolated populations was downgraded (within GRADE) to reflect the indirectness of the data.
541.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7		"Neurodevelopmental disorder" might be helpful to give examples eg ADHD, Tourette	Thank you for your comment. We have added examples of neurodevelopmental disorders as you have suggested.

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542.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7		In outlining possible providers and stakeholders, or points of historical contact that may be of diagnostic significance in identification, please be inclusive: list both 'Learning disability services' and 'mental health services'. E.g. an able autistic adult may have had contact with general mental health services, given comorbidity	Thank you, we have revised this recommendation in light of your comments.
543.	British Dietetic Association	1	NICE	Person-centred care	7	12	to include a registered dietitian	Thank you for your comment, the GDG do not consider dietians to be core members of a specialist team.
544.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7 & 15		Key priorities & 1.2.2 Includes the development of restricted, circumscribed interests (such as the development of focal expertise).	Thank you for your comment, but the GDG decided not to include your suggestion as felt it was at a level of detail not appropriate to the recommendation.
545.	Autism West Midlands	17	NICE Version	1.1.10	13		Inclusion of sensory assessments in the specialist community-based multidisciplinary autism team's work programme We welcome the recognition given to the importance of hyper- and hypo-sensory sensitivities in the guidelines (see for example ibid: 17). We recommend that an additional bullet point should be included in section 1.1.10 (ibid: 13) so that the multidisciplinary team have a key role in providing specialist assessment of sensory needs and support in developing strategies to support these needs.	Thank you for your comment, we agree that this is a potentially important area and expect that it is included in the first bullet point of 1.1.10 (revised recommendation number 1.1.14).
546.	Prison Reform Trust	2	NICE	KPIs	7	6	General principles of care: 'All staff working with adults with autism should work in partnership with adults with autism and their families or carers', suggest adding: *and other services the individual with autism is in contact with, for example, criminal justice services.*	Thank you, this is about the therapeutic relationship and would apply across all settings. It seems therefore wrong to single out the criminal justice system.
547.	Prison Reform Trust	3	NICE	KPIs	7	15	Identification and assessment: add to 'one or more of the following': *at risk of anti-social and offending behaviour.*	Thank you, however we do not think anti-social behaviour has sufficient specificity to autism to be included.
548.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7 & 15		Key priorities & 1.2.2 The use of 'and stereotypic..' rather than 'or stereotypic..' will exclude atypical autism, particularly as it is unclear whether it includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise. It would be better to make difficulties in social engagement the key alerting symptom and to include stereotypic behaviours	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.

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							and resistance to change in the list of additional features	
549.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7 & 15		Key priorities & 1.2.2 Given the role of the school heath service it might be better to refer to 'Child Health services' rather than simply 'CAMHS'. It is unclear why an adult might have 'current' contact with CAMHS 'Learning disability services' might be replaced with 'mental health services' to include the other specialities that might be engaged, for example, with an able adult.	Thank you for your comment. We have amended this in line with your comment.
550.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care	7 & 15		Key priorities & 1.2.2 It would be helpful to give examples of what is meant by a neurodevelopmental disorder ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment. We have added examples of neurodevelopmental disorders as you have suggested.
551.	Tees, Esk & Wear Valleys NHS Foundation Trust	9	NICE	Person-centred care	7,15		The use of 'and stereotypic..' rather than 'or stereotypic..' will exclude atypical autism, particularly as it is unclear whether it includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise. It is considered that to make difficulties in social engagement a key alerting symptom and to include stereotypic behaviours and resistance to change in the list of additional features	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
552.	Tees, Esk & Wear Valleys NHS Foundation Trust	13	NICE	Person-centred care	7,15		Explanation of neurodevelopmental disorder should be given ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment. We have added examples of neurodevelopmental disorders as you have suggested.
553.	Northumberland, Tyne & Wear NHS Trust		NICE	Person-centred care & 1	8 & 16		Key priorities & 1.2.3 The AQ should not be given this selective, strong recommendation as a wider population study throws its effectiveness into doubt. Brugha, T. S., McManus, S., Smith, J., et al (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. Psychological Medicine, 42, 647-656.	Thank you for your comment. The GDG considered the diagnostic test accuracy evidence summaries together with the methodological quality reviews (which have been added to Chapter 5). However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general

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								population screener, and as such the emphasis was on sensitivity over specificity.
554.	Tees, Esk & Wear Valleys NHS Foundation Trust	1 1	NICE 7, 15	Pers on-centr ed care	7,1 5		It might be better to refer to 'Child Health services' rather than simply 'CAMHS'. Adults would rarely have 'current' contact with CAMHS 'Learning disability services' could be replaced with 'mental health and learning disability services'	Thank you for your comment. This recommendation has been amended to 'previous or current contact with mental health or learning disability services'.
555.	The Royal College of Psychiatrists, Learning Disability Faculty	3 7	NICE	Key priori ties & 1.2.2	7 &1 5		**Key priorities & 1.2.2** The use of 'and stereotypic..' rather than 'or stereotypic..' will exclude atypical autism, particularly as it is unclear whether it includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise. It would be better to make difficulties in social engagement the key alerting symptom and to include stereotypic behaviours and resistance to change in the list of additional features	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
556.	WaASP		NICE guide line	KPIs	7	1 5	We question the inclusion of a child health representative. Would not a LD representative be appropriate?	Thank you for your comment. This recommendation has been amended
557.	The Royal College of Psychiatrists, Learning Disability Faculty	3 5	NICE	Key priori ties & 1.2.2	7& 15		Key priorities & 1.2.2 Includes the development of restricted, circumscribed interests (such as the development of focal expertise).	Thank you for your comment. 'Repetitive and stereotypic' includes restricted and circumscribed interests.
558.	The Royal College of Psychiatrists, Learning Disability Faculty	3 9	NICE	Key priori ties & 1.2.2	7& 15		Key priorities & 1.2.2 Given the role of the school heath service it might be better to refer to 'Child Health services' rather than simply 'CAMHS'. It is unclear why an adult might have 'current' contact with CAMHS 'Learning disability services' might be replaced with 'mental health services' to include the other specialities that might be engaged, for example, with an able adult.	Thank you for your comment. This recommendation has been amended to 'previous or current contact with mental health or learning disability services'.
559.	The Royal College of Psychiatrists, Learning Disability Faculty	4 1	NICE	Key priori ties & 1.2.2	7& 15		**Key priorities & 1.2.2** It would be helpful to give examples of what is meant by a neurodevelopmental disorder ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment. This recommendation has been amended
560.	Autism West Midlands	9	NICE Versi on	KPIs	7; 12		Distinguishing the local autism multi-agency strategy group and the specialist community-based multidisciplinary team Members of the ACWG were confused about the difference	Thank you for your comment. We believe that the distinction between these groups and this is apparent in the different roles and

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							between the local autism multi-agency strategy group and the specialist community-based multidisciplinary team. We therefore recommend that the final NICE Version explicitly states that they are two separate groups.	responsibilities for these groups.
561.	Autism West Midlands	10	NICE Version	KPIs	7;10-15		The ACWG found the language and discussion on the General principles of care accessible to read and understand.	Thank you for your comments.
562.	Autism West Midlands	11	NICE Version	KPIs	7;10-15		General principles of care: guaranteeing application in practice Although the General principles of care are commendable in content, we are concerned that they may not be applied consistently in practice without mechanisms for implementation. We recommend that more detail is given about the substance of a 'basic understanding' and an 'extensive understanding' of autism in the areas included in 1.1.2 and 1.1.3 (NICE, 2011b: 10). Detail also needs to be included about how the acquisition and deployment of such knowledge will be monitored. Although the NICE FULL Version says that the 'Care Quality Commission will monitor the extent to which Primary Care Trusts, trusts responsible for mental health and social care, and Health Authorities have implemented these guidelines' (NICE, 2011b: 8, lines 34-36) we request that NICE includes a timescale of when the relevant professionals will be expected to have achieved the requisite level of understanding of autism. We specifically endorse the concerns expressed by the Autism Alliance over the capability of the Care Quality Commission to monitor the implementation of the guideline.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
563.	Prison Reform Trust	4	NICE	KPIs	8	12	Challenging behaviours: add to list, at risk of anti-social and offending behaviour.	Thank you, however we do not think anti-social behaviour has sufficient specificity to autism to be included.
564.	The Royal College of Psychiatrists, Learning Disability Faculty	43	NICE	Key priorities & 1.2.3	8 &16		Key priorities & 1.2.3 The AQ should not be given this selective, strong recommendation as a wider population study throws its effectiveness into doubt. Brugha, T. S., McManus, S., Smith, J., et al (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. Psychological Medicine, 42, 647-656.	Thank you for your comment. The GDG considered the diagnostic test accuracy evidence summaries together with the methodological quality reviews (which have been added to Chapter 5). However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of

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								individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general population screener, and as such the emphasis was on sensitivity over specificity.
565.	British Dietetic Association	2	NICE	KPIs	8	1 7	to include dietary input by a registered dietitian to aid good mental and physical health and improve any co-existing physical problems	Thank you for your comment. This recommendation has been amended.
566.	Pyramid Educational Consultants	2	NICE	KPIs	8	8	Psychosocial interventions: no mention is made of intervening to improve communication or intervening to improve independence skills at this point, either of which can significantly improve quality of life.	Thank you for your comment. However, a number of interventions aimed at communication and increasing independence skills are reviewed in the full guideline and psychosocial interventions focused on life skills are recommended (see recommendations 1.4.5-1.4.13 in the NICE guideline).
567.	Pyramid Educational Consultants	3	NICE	KPIs	8	1 6	We are glad to see importance placed on a functional assessment of behaviour.	Thank you for your comments.
568.	Worcestershire Health and Care NHS Trust	6	NICE	KPIs	8	P ar a 1	In clinical experience the Full AQ and AQ-10 identify a high number of false positives. Any results of these should be reviewed by appropriate clinicians before an in-depth/full assessment is offered. A number of people require the questions to be further explained and qualified that could identify false positives. We also note Simon Baron-Cohen was part of the consultation group and though eminent in the field is author/co-authored of the AQ.	**Thank you for your comment. However, as a case identification tool we favoured sensitivity over specificity, and the recommendation highlights the need to use clinical judgement together with the AQ-10. We were aware of Prof. Baron-Cohen's role in the development of the AQ-10. At each meeting Guideline Development Group members are required to declare all pecuniary and non-pecuniary interests relevant to the guideline. Prof. Baron-Cohen declared his involvement in the AQ10 paper. Consequently, in line with our procedure, he withdrew from GDG discussions on the evaluation of the AQ-10 and the development of the recommendation for its use**

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569.	Worcestershire Health and Care NHS Trust	8	NICE	KPIs	9	Full	We welcome the setting up of local strategy groups but these would need to have some power in order to deliver the objectives across existing boundaries.	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.
570.	Prison Reform Trust	5	NICE	KPIs	9	1	Organisation and delivery of care: the development of national criminal justice liaison and diversion services by 2014 means there is a better chance that people who come into contact with criminal justice services will have their support needs recognised and met, including people on the autism spectrum. It would be helpful, therefore, to include 'criminal justice, including liaison and diversion and Appropriate Adult services' in the 3rd bullet point, to read: 'making sure the relevant professionals (health and social care, housing, employment, criminal justice, including liaison and diversion and Appropriate Adult services and the third sector) are aware…'	Thank you for your comment. However, we have not made the suggested change as we feel that your suggestion anticipates legislation that's not yet in place and is too detailed.
571.	Autism Rights Group Highland	5	NICE	1.1.1	10	9	"and their families or Carers" add: if agreed by autistic person.	Thank you for your comment. This has been amended.
572.	Prison Reform Trust	6	NICE	1.1.1	10	5	1.1.1 The 'general principles of care' should include staff working within criminal justice services and within the prison service, in particular.	Thank You for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.
573.	British Psychological Society		NICE / Full	1.1.1 /4.3. 7.2	65	6	Some people with autism are very reluctant to meet new people, which can mean that development of trusting relationships can be slower than with many other populations. We think this should be recognised by adding to this sentence: …take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care. The high degree of anxiety some people with autism feel when meeting new people means that this may take longer than would normally be expected with other groups of people.	Thank you for your comment. We are aware of the potential problems related to anxiety and have included this in recommendation 1.3.2 in the NICE guideline.
574.	Pyramid Educational Consultants	4	NICE	1.1.2	10	12	Why isn't there mention of staff having an understanding of methods to improve the detrimental impact of autism.	Thank you, we believe our recommendations on assessment have a central focus on the impact of autism on people's lives.
575.	Hampshire Autistic Society	2	NICE / Full	1.1.2 /4.3. 7.1	64	44	Add *sensory* to physical environment impact.	Thank you for your comment. The GDG considered your comment but as the important issue of sensory sensitivity had been addressed in a number of other recommendations they decided not to amend the guideline in the specific instances you mentioned. The GDG thought this would be potentiality confusing rather than service to highlight this important issue.

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576.	Nottinghamshire Healthcare NHS Trust	1 6	NICE /Full	1.1.2 /4.3. 7.1	64	3 9	General comment – it would be useful to give some guidance relating to what the training should look like and who should deliver it. Frequency of receiving/delivering training is also important, particularly in areas of care where there may be high staff turnover. There are important training quality issues to consider. Are there any reviews of training packages and their efficacy? It would be useful to make reference to the DoH 'Implementing Fulfilling and Rewarding Lives' document (2011).	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local and national implementation.
577.	The National Autistic Society	3	NICE /Full	1.1.2 /4.3. 7.1		3 9	We believe that the GDG should consider removing the word 'basic' from this recommendation. We also believe that it is essential that as part of this training that staff working with adults with autism require knowledge of how to make reasonable adjustments. By making these changes, the guideline would both remove the prospect of the recommendation being misconstrued and also bring it in-line with the adult autism strategy and statutory guidance. Recommendation 2.10 of the adult autism strategy states: *"This training should focus less on the theory of autism and more on giving staff an insight into how autism can affect people, drawing directly on the experiences and input of adults with autism and their families. This will better enable staff to understand the potential behaviours of adults with autism in different settings, so they can respond appropriately and make reasonable adjustments to better accommodate adults with autism."* (p.27) Also, the statutory guidance states that: *"The most effective training will help staff put what they are learning in context, by reflecting the situations they work in – for example, in terms of the kinds of reasonable adjustments that can be made to their working environment."* (p.13) We believe that there is a danger that if people read the word 'basic' they may deem it appropriate only to ensure staff receive a bare minimum of knowledge around the triad. Although, clearly, having an understanding of the triad and on the impact the individuals autism has on their lives is important,	Thank you for your comment. The word 'basic' has been removed from the recommendation. However, staff training is outside of the scope of this guideline and is a matter for local and national implementation.

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							it is also vital that we ensure that staff not only understand, but can adapt their behaviour accordingly. As well as the above, the word 'basic' is also superfluous due to the list detailing what this training should be - Line 41, 42 & 44. This added detail, with the addition of the need for training to cover reasonable adjustments, as above, means that a description of the training as either 'basic', 'intermediate' or 'specialist' is not necessary.	
578.	Social Care Institute for Excellence	1	NICE / Full	1.1.3 / 4.3.7 .6	64	37 onwards	The section on the whole is very good. I think there should be a more explicit recommendation that staff should get to know the individual with autism, their personal histories, particular interests, etc., to reflect the heterogeneity of the condition. This is covered to an extent in recommendation to develop a "trusting, supportive, empathic and non-judgemental" relationship, and in the call for relationship for continuity wherever possible, but it could be made more explicit. See http://www.scie.org.uk/publications/guides/guide43/index.asp	Thank you, we agree and important issue but we felt this is dealt with in the person focused care section and at a number of points in the assessment recommendations and in considering choice of interventions, and therefore the GDG did not think an additional recommendation was required.
579.	Nottinghamshire Healthcare NHS Trust	18	NICE / Full	1.1.3 /4.3. 7.6	65	31	Re: All health and social care professionals providing care and treatment to adults with autism specifically for the autism or related conditions should have an extensive understanding of the nature, development and course of autism and: We would suggest adding into the bullet list: "Its impact on the communication and social needs of the individual and their communication partner".	Thank you for your comment, we considered your specific suggestion to be too detailed to be included in this recommendation – we feel that this use is covered in bullet point two of the current recommendation.
580.	Nottinghamshire Healthcare NHS Trust	19	NICE / Full	1.1.3 /4.3. 7.6	65	40	We feel this is a particularly important point to make, particularly as social care colleagues can have particularly difficulty understanding the social care needs of adults who are highly intellectually able, but experience difficulties with everyday function. Also, it is useful to additionally note that appearances can be deceptive in terms of perceived and actual abilities.	Thank you for your comment which we found particularly helpful.
581.	Hampshire Autistic Society	5	NICE / Full	1.1.3 /4.3. 7.6	65	35	Add leisure.	Thank you for your comment. However, we have not made this change as the GDG felt that it was too detailed, and was already covered by the categories listed.
582.	Somerset Partnership NHS	2	NICE	1.1.3	10	28	Professionals should have access to multi professional advice/guidance rather than necessarily always having extensive knowledge about co-existing disorders	Thank you, we agree with this comment and it is recognised in our recommendations for the role of the specialist multidisciplinary team.

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583.	Northumberland, Tyne & Wear NHS Trust		NICE	1.1.3	11		1.1.3 'the potential discrepancy…'. This paragraph might put greater emphasis on the hidden nature of disability by stating that 'Dysexecutive syndrome and communication difficulties, although subtle, can have a disproportionate effect on more able adults, affecting their potential for autonomous function'	Thank you for your comment. However, this level of detail is not appropriate for the NICE guideline
584.	The Royal College of Psychiatrists, Learning Disability Faculty	32	NICE	1.1.3	11		'the potential discrepancy…'. This paragraph might put greater emphasis on the hidden nature of disability by stating that 'Dysexecutive syndrome and communication difficulties, although subtle, can have a disproportionate effect on more able adults, affecting their potential for autonomous function'	Thank you for your comment. However, this level of detail is not appropriate for the NICE guideline
585.	AUTISM ALLIANCE UK	9	NICE / Full	1.1.4 / 4.3.7 .3	65	17	"offer access to a trained advocate". Access to advocates is – we agree – often of crucial importance. It is not entirely clear what access should be given and for what purposes, and this could perhaps be expanded with more detail	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
586.			NICE / Full	1.1.4 /4.3. 7.3	65	13	Re: ensure that comprehensive information about the nature of, and treatments and services for, their problems is available in an appropriate language or format (including various visual, verbal and aural, easy read, colour and font formats) Again we are concerned that this is simplified and would lead inadequate judgements being made. A more complete assessment of the individual's speech, language and communication difficulties would give recommendations about how to differentiate information for that person. (Noens, I and Berckelaer-Onnes, I.V. (2004) Making sense in a fragmentary world. Communication in people with autism and learning disability. Autism, 8/2, 197-218.	Thank you for this comment but we have not taken it up as we believe we already provide sufficient advice on the adjustment to be made to the assessment process and the delivery of interventions in recommendations, for example, on staff knowledge and the assessment process itself.
587.	Hampshire Autistic Society	3	NICE / Full	1.1.4 /4.3. 7.3	65	13	Add to this bullet point "and the support to understand such the reasons why difference formats are used with the individual".	Thank you for your comment. However, this level of detail is not appropriate for the NICE guideline
588.	Hampshire Autistic Society	4	NICE / Full	1.1.4 /4.3. 7.3	65	17	Offer access to an "autism" trained advocate.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
589.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.1.4 /4.3. 7.3	65	17	This stipulates a 'trained advocate' – it would be helpful to expand on the extent of the training and the economic impact of this.	Thank you for your comment. The cost of a trained advocate is an implementation issue. NICE produces implementation tools, including a cost impact report of the most 'resource use intensive' recommendations, following guideline publication.
590.	The Royal College of Psychiatrists,	29	NICE /Full	1.1.4 /4.3.	65	17	This stipulates a 'trained advocate' – it would be helpful to expand on the extent of the training and the economic impact	Thank you for your comment.The cost of a trained advocate is an implementation issue.

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	Learning Disability Faculty			7.3			of this.	NICE produces implementation tools, including a cost impact report of the most 'resource use intensive' recommendations, following guideline publication.
591.	Northumberland, Tyne & Wear NHS Trust		NICE	1.1.4	11		1.1.4 It would be helpful to define what is meant by 'trained' Some problems with terminology also found in the national strategy • What is meant by "basic understanding". • What is meant by "all staff".	Thank you for your comment. However, the appropriate level of training is outside the scope of this guideline and will be determined by the NHS. We made amendments to remove 'basic' and further specified what we mean by staff in specific recommendations.
592.	Somerset Partnership NHS	3	NICE	1.1.4	11	7	Suggest: 'enable the person to become more autonomous'	Thank you for your comment. However, we have not made the suggested change as the GDG felt that our wording was more person centred
593.	Somerset Partnership NHS	4	NICE	1.1.4	11	2 4	Sensory processing needs should be included	Thank you for your comment. However, this change has not been made as it was considered to be too great a level of detail.
594.	Somerset Partnership NHS	5	NICE	1.1.4	11	2 7	'**adjusting the physical and social environment accordingly'**	Thank you for your comment. This has been addressed in the revision of other recommendations (see new recommendation 1.1.8).
595.	Tees, Esk & Wear Valleys NHS Foundation Trust	8	NICE	1.1.4	11		The specific nature of training should be defined The disproportionate effect of dysexecutive syndrome and communication difficulties, should be emphasised	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local and national implementation.
596.	The Royal College of Psychiatrists, Learning Disability Faculty	3 0	NICE	1.1.4	11		It would be helpful to define what is meant by 'trained'	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local and national implementation.
597.	British Psychological Society		NICE versi on	1.1.4	11	1 4	*Section 1.1.4:* The BPS welcomes the emphasis given to the role of advocacy. However, it is not appropriate for health and social care professionals to provide access to a trained advocate to each person to whom they provide care and treatment: advocacy is a scarce resource that is not required by everyone. Many people who might be routinely offered advocacy in line with this guideline will accept it even if they do not require it. The BPS would prefer this point to say: • *consider whether a person needs access to a trained*	Thank you, we have amended the recommendation.

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							advocate.	
598.	Autism West Midlands	1 2	NICE Versi on	1.1.4	11		Quality of advocacy We welcome the recommendation that adults with autism should be offered 'access to a trained advocate' (ibid: 11, section 1.1.4) but there needs to be more information in the guideline about what level of training is expected, in order to make sure that advocates are of good quality and have a good understanding of autism.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
599.	Somerset County Council	1	NICE versi on	1.1.4	11 1.1. 4	1 4	Current resources do not allow for access to a trained advocate.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
600.	Prison Reform Trust	7	NICE	1.1.4	11	1 4	1.1.4 Final bullet point: access to a trained advocate will be especially important for individuals within the criminal justice system. For example to respond to any safeguarding concerns and to ensure that the rights of the individual are upheld.	Thank you, we agree advocacy is important for people with autism.
601.	ADRC	9	NICE /Full	1.1.4 /4.3. 7.3	65	1 7	ADRC welcomes the recommendation to offer access to a trained advocate.	Thank you for your comments.
602.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.1.4 /4.3. 7.3	65	1 7	Access to a trained advocate. Who will provide their training and supervision? If not funded by local trusts, will carer be expected to take on this role? Will internal staff provide this or will this be given over to the voluntary sector? How will independent advocacy be achieved?	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
603.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.1.5 /6.3. 5.1	133	1 6	This should include attentional difficulties	Thank you for your comment, but the GDG did not take up your suggestion which seems more concerned with the impact of certain cognitive issue in autism, and not with staff behaviour which this recommendation focuses on.
604.	The Royal College of Psychiatrists, Learning Disability Faculty	6 6	NICE /Full	1.1.5 /6.3. 5.1	133	1 6	This should include attentional difficulties	Thank you for your comment, but the GDG did not take up your suggestion which seems more concerned with the impact of certain cognitive issue in autism, and not with staff behaviour which this recommendation focuses on.

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605.	Autism West Midlands	13	NICE Version	1.1.5	11		Publicising professionals' contact details Adults with autism, their parents and carers often have trouble finding the right person to contact when they need to access a service. Section 1.1.5 would benefit from including a bullet point recommending publication of the roles of key professionals, where they are based and how to contact them in a number of forms (NICE, 2011b: 11).	Thank you for your comment. This level of detail would not be appropriate to include in a recommendation, however the recommendation does state that healthcare professionals should clearly communicate their role and function.
606.	Somerset Partnership NHS	6	NICE	1.1.6	12	5	Local and national resources for carers should be added	Thank you for your comment. Information resources for families and carers are covered in recommendation 1.1.13 (revised recommendation number 1.1.17).
607.	Worcestershire Health and Care NHS Trust	9	NICE	1.1.6	12	3	Often clients have difficulties accessing transport to attend services and this is impossible to provide for services.	Thank you for this comment; it is outside the scope of this guideline.
608.	Worcestershire Health and Care NHS Trust	10	NICE	1.1.6	12-13	Structures	We welcome the suggestions of multi-disciplinary team (MDT) of such scope. The concern is that in the current and future economic climate that funding for such a team will be prohibitive. There is also no distinction between clients with Autism and those with AS who often have very different needs. The concern would be that priorities would divert resources to individuals with Autism to manage challenging behaviours, housing needs rather than those with AS.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
609.	Worcestershire Health and Care NHS Trust	11	NICE	1.1.6	12-13	Structures	Later the guidance suggests that the teams remit would be wide and specialist diagnostic and assessment services, specialist care and treatment services coordination of specialist care and treatment. While in the service advice and training to other health and social care professionals on the diagnosis, assessment, care and treatment of adults with autism support in accessing and maintaining housing, educational and employment services support to families and carers support, treatment and care for adults with autism living in specialist residential accommodation training, support and consultation for staff who care for adults with autism in residential and community settings. To cover a potential 5000+ clients this MDT would need to have multi posts of each professional to cope with demand and risks other areas of provision e.g. mental health service excluding clients who may not wish to use a specialist service,	Thank you for your comment. However, this is outside the scope of this guideline and the precise structure and size of multidisciplinary teams is for local determination.

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							as the MDT will be the 'one stop shop' for all referrals. Also the issue of funding is still	
610.	AUTISM ALLIANCE UK	27	NICE / Full	1.1.7 -10/ 6.4.7 .1-4	144	26	It is essential that the local multi-agency strategy group includes specialist care providers with expert knowledge of care of people with autism. Without that involvement, the strategy group will lack practical knowledge of care following diagnosis, and the strategy will be weakened by this lack of practical knowledge and experience	Thank you we agree.
611.	Association Directors of Adult Social Services	30	NICE	1.1.7 1.1.8	12		Welcome having a coordinating function through an Autism Strategy Meeting (Is this the Partnership Board identified in the Autism Strategy) However clarification on focusing only on LD is concerning as is does not address the support to those who do not have a LD and reinforces a perception that Autism is a LD when this is not the case. In addition referencing to points 16 & 17 the identification of a specialist team needs further discussion. Further clarification of the outcomes that are to be achieved should be explored balancing the risk of isolating the wider spectrum of needs, rather than identifying the need of a specialist team is as opposed to the access to the specialist functions where required. Consideration of the current economical climate needs to guide the recommendations to realistic outcomes that can be met in the longer term with a view to sustainability.	Thank you for your comment. However, it is our intention and we feel it is clear in the recommendations that this guideline is for autistic individuals across the full range of intellectual ability.
612.	Autism Rights Group Highland	6	NICE	1.1.7	12	13	Should also include here Autistic peoples organisations (ie organisations run and controlled by autistic people).	Thank you for your comment. However, it is not appropriate to recommend any particular group.
613.	NCCMH Expert Reviewer	1	NICE	1.1.7	12		"child health and mental health services" Refers to CAMHS not AMH – I presume this is to focus on diagnostic services at the early identification and intervention stage	Thank you for your comment. This recommendation was adopted from the guideline on autism in children and the following recommendation provided the details of adult services. However in light of a number of stakeholder comments, these recommendations have now been combined to make it specific to the adult context.
614.	Sheffield Asperger Syndrome Service	7	NICE	1.1.7	7,12		In page 7 and 12, the multidisciplinary team description puts emphasis on Children Services rather than adult services. The recommendation is taken from the Children NICE guidance without modification.	Thank you for your comment. As you observe, this recommendation was adopted from the guideline on autism in children; the recommendation that followed it was

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								supposed to provide the details for adult services. Clearly this has been misunderstood by readers so in light of your and a number of stakeholder comments, this recommendation has been extensively revised to make it specific to the adult context.
615.	WaASP		NICE guide line	1.1.7	12	2 3	The question is begged, which profession should lead the team? In that AU and AS are both clinical conditions it must be a clinician. We recommend that it be a psychologist. The 'Fulfilling & Rewarding Lives' documents make great play of local services making up local solutions. In that the prevalence (%) of AS is fairly uniform across the country we are pleased to see that your draft does not kowtow to this. We ask that you go further and recommend a psychologist-led team in each statutory service.	Thank you for your comment. The standard term that we use is healthcare professional unless there are very good reasons to specific – for example, prescribing of controlled drugs, some particular role within the NHS (e.g. the coordinating role and gate keeping role of GPs), or some other statutory duty which rests with a particular professional group (e.g. social work roles). We are not concerned with professional roles per se, but with interventions and care being delivered by healthcare professionals with the relevant competencies and experience.
616.	Hampshire Autistic Society	1 6	NICE / Full	1.1.7 /6.4. 7.1	144	2 8	A local autism multi-agency strategy and "delivery group" (or commissioning group – there has to be a group that is responsible for translating strategy into tangible change) should be set up....	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.
617.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.1.7 /6.4. 7.1	144	2 8	Should include commissioner and clinical representation from learning disability services	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.
618.	Welsh Government		NICE /Full	1.1.7 /6.4. 7.1	144	2 8	Should include commissioner and clinical representation from learning disability services	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.
619.	AUTISM ALLIANCE UK	2 8	NICE / Full	1.1.8 /6.4. 6.2	144	3 6	It is essential that the specialist community-based multidisciplinary autism team includes specialist care providers with expert knowledge of care of people with autism. Without that involvement, the multi-disciplinary autism team will lack practical knowledge of care following diagnosis, and the strategy will be weakened by this lack of practical knowledge and experience	Thank you for your comment. However, this is outside the scope of this guideline and is a matter for local implementation.

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620.	British Psychological Society		NICE / Full	1.1.8 /6.4. 7.1	144	2 8	Recommendation 6.4.7.1: The BPS welcomes the requirement to set up a local autism multi-agency strategy group, but would like to see a recommendation that there is representation from learning disability services as well as the other services as a core member of the group, given the number of people with learning disabilities who have a diagnosis of autism and come into contact with the learning disability services. (cont'd/…) The BPS notes that the Learning Disability Services are later referred to specifically (p144, line 34) as recommended representatives on the group, but we feel that they should be core members for the reason detailed above.	Thank you for your comment. This has been amended in the recommendation.
621.	Prison Reform Trust	8	NICE	1.1.8	12	1 7	1.1.8 It is pleasing to note that a representative from the criminal justice system should be included in local autism multi-agency strategy groups. Representation from local criminal justice liaison and diversion services would be especially pertinent given their role in helping criminal justice staff to identify the particular support needs of individuals during their initial contact with the police.	Thank you for your comment. We agree this input is important.
622.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 6	NICE	1.1.8	12		The team should be real rather than virtual The TEWV team was cited as an example of local innovation within the Strategy by creating a team to share goals and actions in a defined pathway The teams should be created as part of current functioning services in MH and LD with a specialist tertiary service to refer to in defined situations. This should not be an automatic referral as expertise is needed in secondary MH	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
623.	Autism West Midlands	1 4	NICE Versi on	1.1.8 & 1.1.9	12-13		The relationship between the local autism multi-agency strategy group and the specialist community-based multidisciplinary team There was insufficient detail in the NICE Version about how and to what extent the local autism multi-agency strategy group and the specialist community-based multidisciplinary team would interrelate. We recommend that some discussion is made of the interaction between these two groups to ensure effective dialogue between them and to ensure that there is feedback from the experiences 'on the ground' of the specialist community-based multidisciplinary team into the local autism	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.

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							multi-agency strategy group.	
624.	Brighton and Hove City Council	3	NICE version	1.1.9	12	20	Amend 1.1.9 to 'Each area should provide access (for those meeting eligibility criteria) to specialist community-based multidisciplinary professionals such as: clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists Also access to support workers (focused on providing employment, housing, further education, advocacy, social inclusion and personal and community safety skills)	Thank you for your comment. However, this is outside the scope of this guideline.
625.	Autism West Midlands	15	NICE Version	1.1.9	12		Inclusion of specialist care providers in the local autism multi-agency strategy group It is essential that the local multi-agency strategy group includes specialist care providers with expert knowledge of care of people with autism. Without that involvement, the strategy group will lack practical knowledge of care following diagnosis, and the strategy will be weakened by this lack of practical knowledge and experience	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation.
626.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.1.9 /6.4.7.3	144	38	It is not clear that there is sufficient evidence to support the development of Autism specific MDT's. This model may create further service interface gaps through which people could fall, and at the very least may increase access time. The need for core services to improve engagement with people with ASD is seen to be a better model, especially where co-morbid conditions are evident. Local services/teams may also effectively signpost to 3rd sector/ Local Authority services. This is of particular pertinence to rural areas with small populations. It would be better that each commissioning body ensures that people with autism in their area need access to the list in 6.4.7.4 and that they have measures in place to monitor their efficacy. As 6.4.8.1 concludes there is little evidence to guide the establishment and development of the teams. We strongly support the need to encourage observational reporting on new services. In Wales we have focussed our efforts on embedding new services in existing L.D./MH services to make them sustainable.	Thank you for your comment. The GDG considered carefully whether to recommend these teams. The decision to recommend was influenced by the fact that a significant number of people with autism are currently denied access to services and the GDG thought that this would not improve without the creation of specialist teams. However, the GDG accept that there is limited evidence, and as a result drew on the expert judgement of the GDG.
627.	British Dietetic Association	15	NICE /Full	1.1.9 /6.4.	144	40	To include registered dietitian (with experience of working with adults with ASD)	Thank you for your comment. However, the GDG felt that a dietician did not constitute a

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				7.3				core member of the autism team.
628.	ADRC	10	NICE /Full	1.1.9 /6.4. 7.3	144	38	ADRC welcomes the recommendation for a specialist community-based multidisciplinary autism team in each area.	Thank you for your comment.
629.	Welsh Government		NICE /Full	1.1.9 /6.4. 7.3	144	38	It is not clear that there is sufficient evidence to support the development of Autism specific MDT's. This model may create further service interface gaps through which people could fall, and at the very least may increase access time. The need for core services to improve engagement with people with ASD is seen to be a better model, especially where co-morbid conditions are evident. Local services/teams may also effectively signpost to 3rd sector/ Local Authority services. This is of particular pertinence to rural areas with small populations. It would be better that each commissioning body ensures that people with autism in their area need access to the list in 6.4.7.4 and that they have measures in place to monitor their efficacy. As 6.4.8.1 concludes there is little evidence to guide the establishment and development of the teams. We strongly support the need to encourage observational reporting on new services. In Wales we have focussed our efforts on embedding new services in existing L.D./MH services to make them sustainable.	Thank you for your comment but the GDG were strongly influenced in their decision by two factors a) the failure of integrated models to develop effective services for people with autism in the England (20% of adults with autism effectively are not offered even a diagnosis) and b) the strong argument for a team to provide advice and support to non-specialist services. Integration with other neurodevelopment disorders (e.g. adults with ADHD), who are also poorly served by existing services, in local service may be possible. We do however agree that it should be carefully monitored and have made a new research recommendation to address this issue.
630.	London Borough of Tower Hamlets	1	NICE /Full	1.1.9 /6.4. 7.3	144	38	We wholeheartedly support the development of specialist community-based multidisciplinary autism teams. The inclusion of specialist care and treatment and its coordination is essential, and was unfortunately missing from the Autism Strategy. Consideration should be given as to whether the guidance should clarify the geographic cover of these teams and also how they would relate to specialist multidisciplinary LD teams for individuals with autism who also have a diagnosed LD. Also, how would the work of these teams be coordinated and which team would take the lead? In addition how would the team for autism interface with MH provision? When the individual shows behaviour that challenges it is clear that an integrated approach (bio-psychosocial) is most helpful and this strengthens the need for well resourced multidisciplinary working whatever the level of ability of the	Thank you for this comment – you raise some important issue but these are for local implementation and outside the scope of the guideline.

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							person with autism.	
631.	Somerset County Council	2	NICE version	1.1.9	12 1.1.9	20	If Autism is to become a separate Team, how will it be funded? Will there be additional funding?	Thank you for this comment – this is an important issue but is for local implementation and outside the scope of the guideline.
632.	Somerset County Council	3	NICE version	1.1.9	13 1.1.9	1	Specialist support workers would focus on employment or further education: support workers would have a more generic role excluding further education and employment	Thank you for this comment – this is an important issue but is for local implementation to determine.
633.	Northumberland, Tyne & Wear NHS Trust		NICE	1.1.9	12		1.1.9 The multidisciplinary team should be a real (rather than a 'virtual') team whose members should be able to meet and work together on common tasks.	Thank you for this comment we agree but is for local implementation and outside the scope of the guideline.
634.	Northumberland, Tyne & Wear NHS Trust		NICE	1.1.9	12		1.1.9 It would be helpful to emphasise that the presence of autism does not absolve adult mental health from its responsibility to provide an effective service for all	Thank you for this comment – we agree and we have adjusted the recommendations to make this clearer.
635.	Somerset Partnership NHS	8	NICE	1.1.9	12	24	OTs will need to have had sensory integration training	Thank you for this comment – this is an important issue but is for local implementation to determine
636.	The Royal College of Psychiatrists, Learning Disability Faculty	68	NICE	1.1.9	12		**1.1.9** The multidisciplinary team should be a real (rather than a 'virtual') team whose members should be able to meet and work together on common tasks.	Thank you for this comment we agree but is for local implementation and outside the scope of the guideline.
637.	The Royal College of Psychiatrists, Learning Disability Faculty	70	Nice	1.1.9	12		**1.1.9** It would be helpful to emphasise that the presence of autism does not absolve adult mental health from its responsibility to provide an effective service for all	Thank you for this comment – we agree and we have adjusted the recommendations to make this clearer.
638.	NCCMH Expert Reviewer,	2	NICE	1.1.9	12		no reference to what kind of psychologists or psychiatrists – deliberate in a positive way?	Thank you for your comment.The standard term that we use is healthcare professional unless there are very good reasons to specific – for example, prescribing of controlled drugs, some particular role within the NHS (e.g. the coordinating role and gate keeping role of GPs), or some other statutory duty which rests with a particular professional group (e.g. social work roles). We are not concerned with professional roles per se, but with interventions and care being delivered by healthcare professionals with the relevant competencies and experience.
639.	Dorset Healthcare	1	NICE	1.1.9	12		How do we determine which clients would be held by ASD specialist team and who would be seen in the CMHT and/or	Thank you for this comment – this is an important issue but is for local

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	University Foundation NHS Trust						CLDT? LD Teams should retain responsibility for adults with ASD and LD. The NICE guidance is in opposition to the National Strategy which suggests people with AS are not funnelled into specialist teams. Need clarification on how people are allocated to teams, and better clarity on the function of the specialist team. Autism has a high prevalence rate within the Learning Disability population. The LD teams are experienced in treating and supporting this group of persons with LD. Surely it would make more sense for those with autism and LD to remain within the LD teams rather than be transferred to a separate autism team. Social workers in which team would be required to fund the expensive residential care packages-LD or the specialist autism team? The model suggested/implies the professionals in the specialist ASD MDT will have to be specialists in many areas – LD, ASD'S Forensic, and Mental Health. Is this really practical?	implementation to determine. We do not agree that the guideline is in opposition to national guidance, but even if that were the case NICE's role is to develop recommendations to support best practice. At times this may with national guidance. This model does not imply multi-specialists but is explicit in suggesting that there should be a link between the specialist teams and specialist mental health services and is clear that care for people with autism will be shared between these and other teams.
640.	Somerset Partnership NHS	7	NICE	1.1.9	12/ general	20	The autistic spectrum is extremely wide-ranging. People with severe autism have different practical needs, and also require different interventions to those who function on an high intellectual level. People with higher functioning autism regularly say that they do not wish to be included in services for people with Learning Disabilities. Which service will take responsibility for these Teams, and will people with ASC fulfil eligibility criteria for teams that are not specifically for Mental Health or Learning Disabilities? People with ASC need to be encouraged and enabled to access generic community services where appropriate .There is a danger of deskilling 'non-specialist' professionals and contributing to the exclusion of people with autism from mainstream society.	Thank you for this comment – this is an important issue but is for local implementation to determine.
641.	Somerset Partnership NHS	9	NICE	1.1.9	13	1	Separate Specialist support workers are required for: 1.enabling access to employment and existing specialist support services. 2. to work within FE establishments General support workers are required for: development of social engagement and living skills, promotion of self esteem, and helping generally to support the delivery of the individual's Care Plan.	Thank you for this comment – this is an important issue but is for local implementation to determine.
642.	NCCMH Expert Reviewer	3	NICE	1.1.10	13		however a specialist diagnostic assessment service should include a (properly commissioned) adult psychiatrist or at the	Thank you for your comment, there is scope for this in the recommendation.

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							very least a LD psychiatrist with understanding of comorbid AMH issues?	
643.	NCCMH Expert Reviewer	4	NICE	1.1.10	13		In a similar vein page 13 (1.1.10) – "multidisciplinary autism team should have a key role in providing … support, treatment and care for adults with autism living in specialist residential accommodation " – specialist residential accommodation is highly expensive and currently housing depts. try and look at this with advice from health practitioners but there is only limited accommodation / £ available. If the overall documents focuses on "care should involve abc" without a statement on "funding needs to be addressed where care or housing or other social- health need is absent" then this problem will not be addressed.	Thank you for this comment – this is an important issue but is for local implementation and commissioning to determine.
644.	Dorset Healthcare University Foundation NHS Trust	2	NICE	1.1.10	13		Support accessing housing – where does "fairer access to care" come into this? Who'd fund the specialist teams?	Thank you for this comment – this is an important issue but is for local implementation and commissioning to determine.
645.	Autism West Midlands	16	NICE Version	1.1.10	13		Inclusion of specialist care providers in the specialist community-based multidisciplinary autism team It is essential that the specialist community-based multidisciplinary autism team includes specialist care providers with expert knowledge of care of people with autism. Without that involvement, the multi-disciplinary autism team will lack practical knowledge of care following diagnosis, and the strategy will be weakened by this lack of practical knowledge and experience	Thank you for this comment – this is an important issue but is for local implementation and commissioning to determine.
646.	Somerset County Council	4	NICE version	1.1.10	13 1.1.10	4	This may not be realistic: this would require a lot of co-working. Should a main team coordinate rather than take over sole responsibility for provision? Should include reference to maintaining liaison with the Criminal Justice System, Housing and Employment to ensure a holistic approach to any provision including the training required to ensure delivery of that provision.	Thank you for your comment, we agree but it is not suggested in the recommendations that one team takes over the care for all people with autism.
647.	Hertfordshire Partnership NHS foundation Trust	3	NICE / Full	1.1.10/ 6.4.7.4	145	13	The multi-disciplinary autism team should have a key role in providing…..advice and training to other health and social care professionals on the diagnosis, assessment, care and treatment of adults with autism There is a broad statement of the understanding which staff working with people with autism need on p64, line 39. It would	Thank you for this comment – this is an important issue but is for local implementation to determine. These details are outside the scope for the guideline.

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							be useful to have some ideas about what sort of training is most beneficial for which professionals, since their assessments and interventions contribute so much to the wellbeing of the person with ASC. In practice, there may simply be no helpful data that addresses this point at present. Research into the structure and organisation of specialist autism teams is highlighted as a need (p147, line 30): perhaps the research that is suggested into the role of those teams could include some consideration of what training they can most usefully offer to health and social care professionals.	
648.	AUTISM ALLIANCE UK	29	NICE / Full	1.1.10/6.4.6.4	145	9	6.4.7.4 We do not see how the multidisciplinary autism team can "provide" specialist care and treatment services (second bullet point) without the involvement of specialist providers. The same applies to the seventh bullet point	Thank you for your comment, we agree but it is not suggested in the recommendations that one team takes over the care for all people with autism.
649.	AUTISM ALLIANCE UK	30	NICE / Full	1.1.10/6.4.6.4	145	17	Support to families and carers is typically provided by specialist autism charities. The Autism Alliance supports thousands of families of people with autism. This underlines the importance of including specialist autism providers in the multi-disciplinary autism team	Thank you for your comment, we agree but it is not suggested in the recommendations that one team takes over the care for all people with autism. It is for local commissioners to determine. We see a strong role for a range of providers and this is set out in a number of recommendations we make.
650.	Prison Reform Trust	9	NICE	1.1.10	13	17	1.1.10 Final bullet point: 'training, support and consultation for staff who care for adults with autism in residential and community settings', add: *including staff working in prison.*	Thank you for your comment, all NICE recommendations apply to healthcare professionals working in prisons – we do not therefore think it necessary to make this recommendation which is focused on non-NHS staff who are outside of the remit of the guideline.
651.	British Psychological Society		NICE version	1.1.11 - 1.1.15	13	19	*"Involving families and carers":* Paragraphs 1.1.11 to 1.1.15 consider a wide range of potential situations relating to the involvement of families and carers. However, the situation in which the adult with autism does not have the capacity to consent to the family's involvement is not addressed. This is a frequent dilemma for professionals who work with adults who have significant learning disabilities in addition to autism, and would benefit from further guidance and explicit reference to the Mental Capacity Act 2005 (MCA).	Thank you for your comment, we have amended recommendation 1.1.11 (revised recommendation number 1.1.15) in light of your comment and would also draw your attention to the section on the Mental Capacity Act in the section on person centred care.

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							The BPS recognises that the guidelines are drafted within the MCA framework but we would welcome a new paragraph that reflects the specific issues in relation to people who lack capacity, along the lines of: 1.1.16 If an adult with autism does not have capacity to consent to involve their families in their care, the professionals should ensure that they work within the framework of the Mental Capacity Act 2005 and decision making takes full account of the Code of Practice.	
652.	Nottinghamshire Healthcare NHS Trust	24	NICE /Full	1.1.1 1/4.3 .11.1 /	74	18	It would be useful here to reference the NICE guideline for children and young people with autism (NICE guideline 128).	Thank you for your comment. This is done in the section 6 of the NICE guideline on related guidance.
653.	Autism Rights Group Highland	7	NICE	1.1.1 1	13	19	The section "**Involving families and carers"** should be moved right to the beginning: this is essential to get right from first contact and its importance cannot be stressed enough.	Thank you for your comment, we have adjusted the structure of the guideline in light of your and others' comments and have moved some of the family recommendations near to the front of the guideline.
654.	Somerset County Council	5	NICE version	1.1.1 2	14 1.1. 12	1	Does this tie in to FACS criteria, and if so, would that disadvantage some families/carers?	Thank you for your comment, but we are unable to comment on FACS as it is outside the scope of the guideline.
655.	Ambitious about Autism	3	NICE	1.1.1 2	13 of 50		Young people with autism, in their late teens or early twenties, should be supported to take ownership of decisions about their life and care back from their families where appropriate. We would like this recognised in the guidelines, perhaps with reference to the independent advocates who can provide much needed support in such situations.	Thank you for your comment, we agree and have made reference to advocates in recommendation (see 1.1.4, 1.2.6)
656.	Somerset Partnership NHS	10	NICE	1.1.1 2	13	24	Involvement of family or carers should be encouraged if this deemed to be in the best interests of the person with ASC	Thank you for your comment, we agree and have made a number of recommendations to this effect such as 1.1.11-14 (revised recommendation number 1.1.15-1.1.18).
657.	Somerset Partnership NHS	11	NICE	1.1.1 2	14	1	'make sure that no services are withdrawn, which the person with ASC has been assessed as eligible for	Thank you for your comment, but the GDG felt this was too detailed for a recommendation.
658.	NCCMH Expert Reviewer	5	NICE	1.1.1 3	14		Risk management: ref to specialist mental health teams in managing crises – I think what is meant is generic (non-specialist) general adult mental health by this, but then they need to be involved, commissioned (therefore funded) in some way in specialist assessment rather than picking up the pieces	Thank you for your comment, in the context of NICE guidelines 'specialist' means secondary care and not primary care mental health services.

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							left by an external specialist service. Also their competencies and guidance could be misplaced/ misguided if there is no integration of services at some level, as people with autism will need a different approach and understanding to people with schizophrenia for example. This is highlighted in section 1.9.1 but perhaps a ref to this may be useful here. Ref to outreach services – many of these have now disappeared due to government funding cuts to the NHS.	
659.	Worcestershire Health and Care NHS Trust	1 2	NICE	1.1.1 3	14	5	This is welcomed as clinical practice is showing a number of parents being referred to the adult service following the diagnosis of a child. However none of the adults our service has received an assessment as a carer and as an individual with AS.	Thank you for your comments. We agree this is an important need.
660.	Autism NI	1	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	1 4	Providing verbal and written information could obviate the need for professionals to engage systemically with the families of vulnerable adults. There is a risk that professionals might disregard information coming from family (who are also carers) which because of the patient's capacity may not otherwise be known.	Thank you for your comment.
661.	Autism NI	2	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	1 5	Providing information about autism and its treatment may excuse opting out of attempts to understand systemic contributions to the current situation, which may be ongoing.	Thank you for your comment, this might be the case if the recommendations were only about information, but this is not the case.
662.	Autism NI	3	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	1 6	The capacity of voluntary sector to provide support and time frames should be checked.	Thank you for your comment, but this is outside the scope of the guideline – it is for local determination.
663.	Autism NI	4	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	1 9	This opens the door for professionals to divert families away from the multi-disciplinary input in which they, as carers, should be involved. (see P 65 4.3.7.2 line 2)	Thank you for your comment, however the GDG felt the recommendations do guard against this 1.1.11-14 (revised recommendation number 1.1.15-1.1.18).
664.	Autism NI	5	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	2 1	This needs to be time specific – professionals should ensure that doing so does not disqualify the perspective that family carers offer.	Thank you for your comment but it was the view of the GDG that it would not be helpful to place a time period on this recommendation.
665.	Autism NI	6	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	2 4	A patient's attempt to exclude family who are carers may be motivated by other issues and could mask eg a co-dependency of the patient and key worker or patient enmeshment with key workers.	Thank you for your comment, this may be the case but it is not possible to address these matters in a guideline – it will be a matter for local clinical judgment.
666.	Hertfordshire	1	NICE	1.1.1	73	1	If a person with autism does not want their family or carer(s) to	Thank you for your comment, we agree these

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	Partnership NHS foundation Trust		/ Full	4/ 4.3.1 1.4		3	be involved in their care….. We have encountered some difficulties in circumstances where more able adults who are not diagnosed but are showing features of autism do not accept that they have a need for assessment or support. In those cases, the impetus for service involvement comes from their families, who may be highly anxious and are keen for them to be assessed and to receive support. The dilemma of how to proceed in those circumstances is not covered by the Recommendations about Involving Families and Carers, which refer to care, rather than assessment. At the pre-assessment stage, it may be very difficult to be clear about issues around capacity and to know how best to proceed.	are difficult issues and would have to be a matter for local clinical judgement – it is not possible to deal with this level of specificity in a clinical guideline.
667.	South London and Maudsley NHS Trust	9	NICE / Full	1.1.1 4/ 4.3.1 1.4	73	1 2	The person with autism has a right for their family member not to be told the diagnosis if they do not want this to happen. I've seen this many times (including refusals to allow access to family members for developmental histories).	Thank you for your comment we agree, but providing general information does not involve the disclosure of a diagnosis.
668.	Hampshire Autistic Society	7	NICE / Full	1.1.1 4/4.3 .11.4	73	1 6	Add *All local services including* "generic services that are autism aware".	Thank you for your comment, but this is a staff and not service focused recommendation so it is not possible to include your amendment.
669.	Autism West Midlands	1 9	NICE Versi on	1.1.1 4	14		Confidentiality Our ACWG wanted section 1.1.14 to state whether or in what circumstances parents or carers of adults with autism could receive confidential information about them when the adult with autism does not want their family or carers to be involved. We recommend inclusion of a best practice statement about confidentially in these circumstances.	Thank you for your comment, what you suggest would not routinely be possible. However, we do make reference to the Mental Capacity Act where it might be possible.
670.	Autism West Midlands	1 8	NICE Versi on	1.1.1 4	14		How will parental evidence be used? As a result of the complex issues which arise when adults with autism do not want their family or carer(s) to be involved in their care (ibid: 14, section 1.1.14) more information should be included about what parents or carers can expect if they raise concerns about the adult with autism's care and treatment in these circumstances. We therefore recommend that detail is added to section 1.1.14 about the formal procedures to review parental concerns and to what extent any evidence and information provided by parents or carers would be taken into	Thank you for your comment, we understand the point you are making but the involvement of families will be restricted if consent is not given and it would not be possible to draft a recommendation along the lines you suggest.

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							account in these circumstances.	
671.	Optical Confederation, and the LOC Support Unit	3	NICE	1.2	15	3	Difficulties in diagnosis may be caused by undetected visual problems and hence, to avoid diagnostic overshadowing (i.e. where symptoms may be misinterpreted), an assessment of visual function should be considered and in many cases recommended before assuming particular symptoms or behaviours relate to autism. There is a need to have access to optometrists who are skilled in functional vision assessment and assessing patients with limited or no communication and poor cooperation. Care should be taken to rule out not only severe visual impairment, but also reduced visual acuity due to refractive error, cataract or other pathological causes. Optometric, orthoptic or ophthalmological input is required here too and we would be delighted to work with NICE on any related recommendations.	Thank you for your comment. We have made reference in our recommendations to awareness of visual impairment. It is outside the scope of the guideline to make the detailed recommendations you suggest.
672.	AUTISM ALLIANCE UK	10	NICE /Full	1.2.1 /4.3. 7.5	65	27	“basic” understanding. If people are carrying out assessments of people with autism a “basic” understanding may not be enough and could even be misleading. People with autism often present as more “able” than they are, and the assessments can therefore be vitiated by a wrong perception by the person making the assessment. Where assessments of needs are being made, it is of crucial importance that the assessment is made by someone with specialist understanding of autism, or, at the least, by someone accompanied by a person with specialist understanding of autism. Wrong assessment of needs can store up trouble for the future, including (a) damaging the person with autism and (b) creating the potential for future legal challenges. The need for understanding of the potential discrepancy between intellectual and adaptive functioning is specifically recognised at line 40 of page 65, in the context of care and treatment; but this understanding also needs to be present when assessments are being carried out. This comment is in line with the discussion on page 116 (line 14)	Thank you for your comment, this has now been amended and the term ‘basic’ removed.
673.	Worcestershire Health and Care NHS Trust	15	NICE	1.2.1	19	3	Co-ordination of 24 hour crisis management is welcome but will be difficult to implement. Clinical experience has shown that even after diagnosis crisis teams, A&E and Police dismiss clients with Autism/AS as simply difficult people and ignore their needs. Competing electronic data systems and lack of access to	Thank you for your comment but this is a local implementation issue.

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							theses will make this very difficult to implement properly and fairly.	
674.	Worcestershire Health and Care NHS Trust	1 6	NICE	1.2.1	20	4	Having access to a second opinion in complex cases is welcomed but in most cases will require PCT funding which will be difficult to obtain.	Thank you for your comment but this is a local implementation issue.
675.	Worcestershire Health and Care NHS Trust	1 7	NICE	1.2.1	20	5	This is welcome as long as referrals from non-medically trained staff can be accepted to reduce delays.	Thank you for your comment but this is a local implementation issue.
676.	Institute of Psychiatry, Kings College London	1	NICE / Full	1.2.2 / 5.3.1 2.1	99	2	My comment is that it may be useful to operationalize or identify questions to ask during a clinical interview that might elicit 'persistent difficulties in reciprocal social interaction and communication' (to clarify for non-ASD specialised clinicians)	Thank you for your comment, but this level of detail is outside of the scope of the guideline and is covered in the recommendations from 1.2.4 onwards which recommend a variety of structured assessment measures to address the type of issue you raise.
677.	Hampshire Autistic Society	8	NICE / Full	1.2.2 /5.3. 12.1	99	1	Add a further bullet point "*Regular contact with Criminal Justice System with identified communication disorder issues."*	Thank you for your comment, the GDG were not able to identify sufficient evidence to support its inclusion.
678.	Nottinghamshire Healthcare NHS Trust	2 8	NICE / Full	1.2.2 /5.3. 12.1	99	1	We feel this could usefully be broadened out, as some cases may still be missed with this current definition, particularly women who may present as being socially anxious.	Thank you for your comment, the GDG were not able to identify sufficient evidence to support its inclusion.
679.	Nottinghamshire Healthcare NHS Trust	2 9	NICE / Full	1.2.2 /5.3. 12.1	99	1 0	It may be useful to here to define 'neurodevelopmental disorders' as people's understanding of this may vary. We are also aware that some terminology has changed or become out of vogue (e.g. semantic-pragmatic disorder).	Thank you, we have added some examples in response to your and others' comments.
680.	Sheffield Asperger Syndrome Service	8	NICE	1.2.2	15	1 4	1.2.2 suggests that stereotyped behaviour is a requirement before considering further assessment. This could exclude significant number of people. This criterion should be moved to the list of behaviour just below this paragraph.	Thank you, we have added some examples in response to your and others' comments.
681.	Prison Reform Trust	1 0	NICE	1.2.2	15	1 6	1.2.2 Identification and initial assessment of possible autism: add to, 'one or more of the following': *at risk of anti-social and offending behaviour.*	Thank you, but the GDG were not able to identify sufficient evidence to support its inclusion.
682.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.2 /5.3. 12.1	99	3	The use of 'and stereotypic..' rather than 'or stereotypic..' will exclude atypical autism, particularly as it is unclear whether it includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise. It	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.

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							would be better to make difficulties in social engagement the key alerting symptom and to include stereotypic behaviours and resistance to change in the list of additional features	
683.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.2 /5.3. 12.1	99	8	Given the role of the school heath service it might be better to refer to 'Child Health services' rather than simply 'CAMHS'. It is unclear why an adult might have 'current' contact with CAMHS 'Learning disability services' might be replaced with 'mental health services' to include the other specialities that might be engaged, for example, with an able adult.	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
684.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.2 /5.3. 12.1	99	1 0	It would be helpful to give examples of what is meant by a neurodevelopmental disorder ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
685.	The Royal College of Psychiatrists, Learning Disability Faculty	3 8	NICE /Full	1.2.2 /5.3. 12.1	99	8	Given the role of the school heath service it might be better to refer to 'Child Health services' rather than simply 'CAMHS'. It is unclear why an adult might have 'current' contact with CAMHS 'Learning disability services' might be replaced with 'mental health services' to include the other specialities that might be engaged, for example, with an able adult.	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
686.	The Royal College of Psychiatrists, Learning Disability Faculty	4 0	NICE /Full	1.2.2 /5.3. 12.1	99	1 0	It would be helpful to give examples of what is meant by a neurodevelopmental disorder ('such as for example, ADHD, Developmental Coordination Disorder and Dyslexia')	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
687.	Craegmoor	3	NICE	1.2.2	7	2 3	Previous or current contact with CAMHS or learning disability services – I think adult mental health services should be added to this list.	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
688.	Brighton and Hove City Council	1	NICE versi on	1.2.2	7		Need to ensure identification and assessment takes into account cultural and language needs	Thank you for your comment. This is covered in section on person centred care.
689.	Brighton and Hove City Council	2	NICE versi on	1.2.2 ?	10	1 8	Advice on the best way to communicate with people with autism	Thank you for your comment. This is important point the GDG have tried to reflect throughout the guideline.
690.	Tees, Esk & Wear Valleys NHS	1 5	NICE				Scores less that 7 on the AQ, it should not debar them from further assessment. If this is not clear it will be used as a gate-	Thank you for your comment. Please see recommendation 1.2.3 in the NICE guideline

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	Foundation Trust						keeping tool	which includes 'a high index of suspicion based on clinical judgement' as a basis for offering a comprehensive assessment for autism
691.	British Psychological Society		NICE / Full	1.2.3 /5.3. 12.2	99	g e n er al	The inclusion of a specific screening assessment tool in the guidance, the Autism-Spectrum Quotient-10 (AQ-10), is helpful. We are concerned, however, that the structure of paragraph 5.3.12.2 may lead to an over-reliance on this tool for the "further assessment" of adults with possible autism. In particular, the recommendation to refer on for assessment (where someone has concerns) any adult who scores 6/10 on the AQ-10 is based on a single study (Allison et al., in press). Whilst this study is very large we do not believe it meets the GRADE (Grading of Recommendations: Assessment, Development and Evaluation) Working Group criteria for quality rating. The diagnoses of the adults in this study are self-reported and not validated. The authors cite papers for the validity of parent-reported Autistic Spectrum Disorder (ASD) diagnosis of children but we do not know how well self-reported adult diagnoses stand up against a full clinical assessment. So, whilst the sensitivity (SE) and specificity (SP) and the associated confidence intervals certainly do meet GRADE criteria the quality of this single study cannot do so. The potential 'harm' to services and society of a NICE guideline reporting a recommendation for referral on the basis of a 10-item self-completed questionnaire is considerable. We know of no such recommendation based on a single report with the limitations of the Allison et al. manuscript in the NICE guidelines on mental health. The BPS therefore recommends that, in order to emphasise the importance of clinical judgement in the screening process, Section 5.3.12.2 be revised into two separate sections and re-worded as follows: 5.3.12.2 - If there is a high index of suspicion based on clinical judgement (including, where applicable, compelling evidence from an informant), offer a comprehensive assessment for autism.	Thank you for your comment. The AQ-10 is recommended as a case identification tool which should be considered together with clinical judgement. With regards to methodological quality we are aware of the limitations of a number of the diagnostic test accuracy studies and we have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline). This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. However, despite the recognition of methodological concerns with regards to the AQ data the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, and as such the emphasis was on sensitivity.

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							5.3.12.3 - The Autism-Spectrum Quotient-10 items (AQ-10) is currently being used in research and undergoing validation. It may be useful in support of clinical judgement in the further assessment of adults with possible autism who do not have a moderate or severe intellectual disability. (The current Section 5.3.12.3 would be retained unchanged but would need to be re-numbered as 5.3.12.4).	
692.	NCCMH expert reviewer	5	NICE / Full	1.2.3 /5.3. 12.2	99	1 1	Comment on Recommendation 5.3.12.2: "For the further assessment of adults with possible autism who do not have a moderate or severe intellectual disability, use the Autism-Spectrum Quotient-10 items (AQ-10). (If a person does not speak or read English, read out the AQ-10.) If a person scores above six on the AQ-10, or there is a high index of suspicion based on clinical judgement (including, where applicable, compelling evidence from an informant), offer a comprehensive assessment for autism." Following from the points made above, the specific recommendation pertaining to the Autism-Spectrum Quotient is not supported by review evidence and I advise that it be removed. It has not been evaluated in the population referred to; therefore it is not known what its test characteristics would be there. To include this recommendation would repeat an error made in medicine realised in the 1970s (Ransohoff DF, Feinstein AR. Problems of spectrum and bias in evaluating the efficacy of diagnostic tests. N Engl J Med 1978 Oct 26;299(17):926-30). Page 7 of 50 (1.2.3), short version of the guideline, 'Key priorities for implementation', repeats the same recommendation (page 8 of 50; page 16 of 50, 1.2.3) and should be removed as it is not justified. I would therefore advise that the AQ-20 text, Appendix C, is deleted (page 59 of 50).	Thank you for your comment. The GDG were aware of the limitations of many of the included diagnostic accuracy studies and we have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline) to address these concerns. This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general population screener, and as such the emphasis was on sensitivity over specificity.
693.	Social Care Institute for Excellence	2	NICE / Full	1.2.3 /5.3. 12.2	99	1 4	At least some people who do not read or speak English will not understand the AQ-10 if it is read to them. This seems to need more consideration	Thank you for your comment. This has been amended in the recommendation.
694.	Somerset County Council	6	NICE versi	1.2.3	16 1.2.	1	Use of the AQ10 should be more widely promoted as a positive and timely tool	Thank you for your comment.

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			on		3			
695.	Sheffield Asperger Syndrome Service	9	NICE	1.2.3	15	3	1.2.3 We think the reliance of self reported questionnaire in screening could be seriously misleading. In our experience, this will lead to significant false positive and false negative figures. There are many people who erroneously perceive themselves to be suffering from the disorder to the degree of complete conviction, and another group who do not wish to have the diagnosis despite the overwhelming evidence.	Thank you for your comment. We have added a reliability and validity data table to the case identification review in Chapter 5. This includes inter-rater reliability data where a significant correlation was found between self- and parent-report on the AQ-50.
696.	Somerset Partnership NHS	1	NICE	1.2.3	16	3	Use of AQ -10 rather than the full AQ is welcomed as a way of saving staff time spent on screening for ASC	Thank you for your comment.
697.	Dorset Healthcare University Foundation NHS Trust	3	NICE	1.2.3	16		Where has AQ10 come from? What is it's validity? How is it administered and scored? Wording on "if person doesn't speak/read English – read it out"! Needs to be changed.	Thank you for your comment. You were right to point out that the wording about reading out the AQ-10 needed to be changed. This has now been done. The evidence base for the AQ-10 including the validity of the instrument and further details regarding its administration can be found in Chapter 5 of the full guideline.
698.	The Royal College of Psychiatrists, Learning Disability Faculty	36	NICE /Full	1.2.3 /5.3. 12.1	99	3	The use of 'and stereotypic..' rather than 'or stereotypic..' will exclude atypical autism, particularly as it is unclear whether it includes the development of restricted, circumscribed interests that can manifest in the development of focal expertise. It would be better to make difficulties in social engagement the key alerting symptom and to include stereotypic behaviours and resistance to change in the list of additional features	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
699.	The National Autistic Society	4	NICE /Full	1.2.3 /5.3. 12.2		11 – 17	As part of formulating our response to this consultation, we asked our supporters a number of questions regarding the guideline. A key issue - and something that has been a persistent problem for adults receiving adequate support - concerns diagnosis. To pick out just a few stories: "I was diagnosed as having Aspergers syndrome on 7th January 2009 at age 49. It took over two years to arrange a diagnosis although I (and my sister) had accepted that I showed autistic traits long before this –proved to be all my life when discussed with consultant." Adult with autism "I was diagnosed when I was 42. It took two years from when I asked for a diagnosis until I was actually given one. this is despite the fact that I had tried for years to get help with my social difficulties" Adult with autism	Thank you for your comment. The recommendation states that the AQ-10 should only be considered in cases where there is already a high index of suspicion and it should be interpreted using clinical judgement.

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							I was diagnosed at the age of 23. I had a lot of problems all through my life but they were ignored. I couldn't even get help after a suicide attempt." Adult with autism "I was diagnosed Aspergers at the age of 50 years. It took about 18 months to get the funding through, after which I was seen within about 3 months." Adult with autism The adult autism strategy states that: "Diagnosis is particularly important for adults who have not previously had their condition recognised: their life to date may have been greatly affected by a sense of not fitting in, of not understanding the way they respond to situations or why social settings, for example, are difficult. It is equally important for their families or those who care for and support them…"(p.33) Despite this, we are still seeing very few diagnostic services available on the NHS and, because of this, very long waiting lists. This is why we where so keen to see these guidelines produced and support their recommendations. We are, however, uneasy with the recommendation to use AQ-10 as a form of screening tool for those with suspected autism and without a learning disability. Clearly, we do agree with the GDG that, practically speaking, developing a measure to improve case identification and recognition of adults with autism would be of value in primary care and other settings. We, also agree that that the AQ-10 should not be used for case identification in primary care. Where we disagree, is of the use of AQ-10 for referral in every situation of those without a learning disability. We believe – as with the diagnostic tools discussed below – we must leave the referral for a full assessment up to clinical judgement and expertise. These professionals, as the guideline makes clear in earlier sections, must involve the individuals and families/carers in the process, but the NAS firmly believe that it is inappropriate to declare the AQ-10 as necessary or best practice in all situations – particularly for identification of	

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							autism in older people, women, those with co-morbid mental health conditions and those from BAME communities. As such, the NAS is of the opinion that this guideline should more closely mirror the child autism guideline on recognition, referral and diagnosis of autism[14] and should recommend: Be aware that tools to identify adult with an increased likelihood of autism[15], may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism. Also be aware that: • a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism • a negative score does not rule out autism. The NAS believes that, until we can guarantee the reliability and validity of screening tools, we must leave it up to the professionals' expertise and ensure that they listen to and work with the individuals and families/carers. Furthermore, we are unsure whether the GDG can be certain that the consensus they achieved on this matter is an accurate reflection of the reliability and validity of AQ questionnaires and of the research available.[16] We are concerned that with NICE recommending the use of AQ-10, we will see the tool being misused either through lack of awareness or potentially, in the worst case scenario, to inappropriately protect budgets. There is a real concern as well that we will increasingly see fewer face-to-face assessments and instead adults - or their families/carers - will simply be posted a questionnaire to complete. This would be both	

[14] NICE (2011) *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum*. London http://www.nice.org.uk/nicemedia/live/13572/56428/56428.pdf
[15] such as AQ-10 etc
[16] For instance two pieces of research published in 2011 call into question the use of both AQ questionnaires and some diagnostic tools. The research is:
- Brugha TS, McManus S, Bankart J, et al. *(2011)* Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry;* 68:459–65.
- Brugha TS, McManus S, Smith J, et al. *(2011)* Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. *Psychol Med. 29:1-10.*

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							inappropriate and unhelpful in nearly all situations. The NAS firmly believes that if concerns have been raised about an individual they must be referred through a working diagnostic pathway and ultimately they should be entitled to an assessment. This need not necessarily be a full multidisciplinary assessment, but it is for the multidisciplinary teams to establish a method/procedure – with the professionals, clinicians and autism strategy groups in their area – to ensure that they have a workable diagnostic pathway that will identify appropriate cases to have a full autism assessment or refer individuals onto other teams in the area if not. This may, depending on clinicians experience, knowledge and local decisions, involve the use of AQ-10 – or another tool – but would not necessarily have to be. Clearly, the GDG have reviewed the evidence that is available, and in their opinion they have agreed to go ahead with the recommendation. We would ask, however, that with this important decision – as with the decision to recommend diagnostic tools which will be discussed below – needs further consideration and more research. If the GDG are unconvinced of the AQ-10 ability to identify autism in primary care, how they made the distinction to be able to refer based on the result seems difficult to justify. We in no way intend to undermine the AQ-10 – or other similar tools – they have an important role to play in potential further research and, in the future, in a robust diagnostic pathway. On reflection, however, the NAS believe that the negatives far outweigh the positives of upholding such a tool as 'best practice'.	
700.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.3 /5.3. 12.2	99	1 3	It is unclear what role is being ascribed to the AQ but it would seem to be that, although someone may not meet the criteria in the previous section (5.3.12.1) but has a score of 7+ on the AQ, they should be referred for further assessment – effectively a form of population screening. However, the population being screened is not necessarily the same as that on which the AQ's statistics were originally determined and these findings are contradicted in the large study of the general population	Thank you for your comment. The GDG were aware of the limitations of many of the included diagnostic accuracy studies and we have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline) to address these concerns. This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2

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							described in Brugha, T. S., McManus, S., Smith, J., et al (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. Psychological Medicine, 42, 647-656. (published online July 29). Given this doubt about the AQ's ability to perform this function of selective screening, it should not be given this selective recommendation	methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general population screener, and as such the emphasis was on sensitivity over specificity.
701.	The Royal College of Psychiatrists, Learning Disability Faculty	42	NICE /Full	1.2.3 /5.3. 12.2	99	13	It is unclear what role is being ascribed to the AQ but it would seem to be that, although someone may not meet the criteria in the previous section (5.3.12.1) but has a score of 7+ on the AQ, they should be referred for further assessment – effectively a form of population screening. However, the population being screened is not necessarily the same as that on which the AQ's statistics were originally determined and these findings are contradicted in the large study of the general population described in Brugha, T. S., McManus, S., Smith, J., et al (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. Psychological Medicine, 42, 647-656. (published online July 29). Given this doubt about the AQ's ability to perform this function of selective screening, it should not be given this selective recommendation	Thank you for your comment. The GDG were aware of the limitations of many of the included diagnostic accuracy studies and we have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline) to address these concerns. This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. However, despite the recognition of methodological concerns with regards to the case-control design the GDG decided that these were not sufficient to prohibit recommending the AQ-10 as an aid to case identification, given that the tool is being

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								recommended for case identification of individuals where a suspicion of autism has already been raised on the basis of clinical judgement, rather than as a general population screener, and as such the emphasis was on sensitivity over specificity.
702.	ADRC	7	NICE /Full	1.2.3 /5.3. 12.2	99	1 2	Who would administer the AQ-10? There is a need to consider the results of this in the context of the individual's life and of other mental or physical health issues to avoid false positive and false negative diagnoses. There is a danger that this may be regarded by some as 'proof' either of a diagnosis or that a person does not have autism and therefore an individual may not be referred to appropriate specialist services.	Thank you for your comment. The AQ-10 is a self-report questionnaire and as such it is not relevant to talk about someone administering it. However, the recommendation for the AQ-10 considered that it would be implementable in routine clinical care, including in primary care settings. The recommendation clearly states that the AQ-10 results should be considered together with clinical judgement and therefore scoring below the threshold is not sufficient to rule out referral for further assessment
703.	British Dietetic Association	5	NICE /Full	1.2.4 /5.3. 12.3	99	1 8- 3 4	include persistent inability to nurture him/herself through appropriate dietary including fluid intake	Thank you for your comment, we focus here in core autistic symptoms - although nutrition may be a problem it is not as part of core autistic symptoms and is dealt with elsewhere in the assessment section.
704.	Dorset Healthcare University Foundation NHS Trust	4	NICE	1.2.4	16		Acknowledge the relevance of analysis of the physical environment to include sensory need. However, sensory processing difficulties/ problems warrant separate consideration, not just environmental, alongside physical health and mental health conditions. Repetitive Self Injurious Behaviour needs to be added to the bullet point list	Thank you for your comment issue about the physical environment is dealt with elsewhere, we focus here in core autistic symptoms - although nutrition may be a problem it is not as part of core autistic symptoms and is dealt with elsewhere in the assessment section.
705.	Brighton and Hove City Council	4	NICE versi on	1.2.5	17	5	Delete 'be team based and'	Thank you for your comment, the GDG took view that such assessment was best provided in context of an MDT so would be easier to access (where needed) for the assessment of co-existing conditions and other such problems.
706.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.5	17	2	may require expansion regarding the training and competence requirements of professionals, although this is covered in the full guideline at 4.3	Thank you for your comment but this is a local implementation issue.
707.		9	NICE	1.2.5	121	1	Add a further bullet point "*Individuals Circle of Support.*"	Thank you for your comment, the GDG

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	Hampshire Autistic Society		/ Full	/5.4. 8.1		6		considered this but the term was felt to lack specificity and wider understating to be included.
708.	Royal College of Speech and Language Therapists	1.	NICE /Full	1.2.5 /5.4. 8.1	121	1 9	This reads as though a developmental history is not essential. We feel it is in order to make a differential diagnosis.	Thank you for your comment, we agree that it is best to have family/carer/partners involved but with adults this is not always possible.
709.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.2.5 /5.4. 8.1	121	1 4	It is the view of the Welsh Government and the Network that a comprehensive assessment should include pre and post diagnostic counselling. This is also relevant to those people who, when assessed, are not diagnosed with ASD.	Thank you for your comment. We have added a recommendation on post-diagnostic support.
710.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.5 /5.4. 8.1	122	1 6	Given that the guidelines will also apply to adult mental health, forensic and criminal justice settings, it might be useful to extend the list of examples of disorders by concluding them with 'obsessive-compulsive disorder as well as other personality disorders and traits'. As a comprehensive assessment should explain how symptoms and traits relate to functional need as well as informing the commissioning of the care pathway, the emphasis should be on formulation rather than simply diagnostic labelling	Thank you for your comment we have listed important comorbidities in the assessment recommendations. We agree regarding diagnostic labelling and place emphasis on a broad assessment of need (see recommendation 1.2.7)
711.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.6	17		1.2.6 An initial discussion should address whether, whatever the findings of the assessment, the individual wished for (or would be helped by) a diagnosis of Autism. In someone who already has acquired the label, it should address whether it still applies.	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your comments.
712.	The Royal College of Psychiatrists, Learning Disability Faculty	5 2	Nice	1.2.6	17	1. 2. 6	1.2.6 An initial discussion should address whether, whatever the findings of the assessment, the individual wished for (or would be helped by) a diagnosis of Autism. In someone who already has acquired the label, it should address whether it still applies.	Thank you for your comment. We have amended the recommendation in light of your comment.
713.	Autism Rights Group Highland	8	NICE	1.2.6	17	6 & 1 1	Where permission has been given by the autistic person	Thank you for your comment. We have amended the recommendation to take account of this.
714.	Craegmoor	4	NICE	1.2.7	17	2 2	So good to see the hyper and hypo sensory issues included here and elsewhere throughout the document – Thank you.	Thank you for your comment.
715.	The Royal College of Psychiatrists,	5 1	NICE /Full	1.2.7 &1.2.	121 &1		5.4.8.3 & 5.4.8.5 There is some duplication across these two sections which might be removed.	Thank you for your comment. While we acknowledge that there is some repetition,

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	Learning Disability Faculty			9/5.4 .8.3& 5.4.8 .5	22			the GDG considered that it was worth emphasising that differential diagnoses and coexisting conditions needed to be part of the comprehensive assessment as set out in recommendation 1.2.7. The following recommendation goes onto to list the kinds of conditions that need to be assessed.
716.	ADRC	1 1	NICE /Full	1.2.7 /5.4. 8.3	121	3 6	ADRC welcomes the recommendation for a comprehensive assessment, including direct observation in social situations, and the recognition that a developmental history should be obtained.	Thank you for your comments.
717.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.7 /5.4. 8.3	121 & 122		5.4.8.3 & 5.4.8.5 There is some duplication across these two sections which might be removed.	Thank you for your comment. While we acknowledge that there is some repetition, the GDG considered that it was worth emphasising that differential diagnoses and coexisting conditions needed to be part of the comprehensive assessment as set out in recommendation 1.2.7. The following recommendation goes onto to list the kinds of conditions that need to be assessed.
718.	Ambitious about Autism	4	NICE	1.2.7	17 of 50		During a comprehensive assessment, professionals can benefit from information about previous assessments that may have already been done. Clearly, things change over time, but in line with the Governments plans to create more holistic assessment processes through the proposed Education, Health and Care Plans, we suggest the guidelines reference other assessment processes that may need to be linked to health assessments. We recommend you include reference to statements of special educational needs, and learning disability assessments (section 139a assessments) in the list at 1.2.7. We further suggest a reference to holistic assessment processes across education, health and care is included here, to ensure the guidelines do not go out of date when the new 0-25 Education Health and Care Plans come into force.	Thank you for your comment, we agree and expect as best practice that all healthcare professionals would review other previous assessments where they are available. We have used the term comprehensive – it is more widely used in health and social care and seeks to achieve much of what you have under holistic.
719.	Nottinghamshire Healthcare NHS Trust	3 9	NICE / Full	1.2.7 /5.4. 8.3	121	3 5	A specific recommendation to assess sensory sensitivities is useful. However, as noted previously, it would be also be valuable to review the research on specific tools to assess this and make specific recommendations where indicated. The guideline has limited the scope of sensory presentations to ‘hypo and hyper’; in clinical practise it is much broader and	Thank you for your comment, this is too specific for the guideline and the GDG found no evidence to support it.

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							more complex that this simplistic dichotomy. It may be useful to include in the review: Miller, L. Anzalone, M. et al (2007). Concept evolution in Sensory Integration: A proposed nosology for diagnosis American Journal of Occupational Therapy, 61(2), 135-140. There is a drive for the term 'Sensory Modulation Disorder' to be included in the forthcoming DSM-V (APA) and this is currently being reviewed by the DSM-V Task Force's Disorders of Childhood and Adolescence work committee as a diagnosis in it's own right. Therefore we feel it would useful for the group to consider whether the guideline should consider aligning it's terminology with current developments?	
720.	British Psychological Society		NICE / Full	1.2.7 /5.4. 8.3	121	2 9	For many vulnerable groups in society (e.g. people with a learning disability, asylum seekers, people who have been placed in care as children), details of early developmental history are less likely to be available. We are concerned this may lead to people being unfairly excluded from services on this basis. We would therefore welcome an addition to this sentence as follows: *…early developmental history, where possible (the absence of a developmental history alone should not prevent people from being diagnosed with autism if there is sufficient supporting evidence elsewhere in the comprehensive assessment).*	Thank you for your comment but we think that this is already clear in the recommendation we have made and have acknowledged that it is not always possible to have a developmental history.
721.	South London and Maudsley NHS Trust	1 8	NICE / Full	1.2.8 /5.4. 8.4	122	1	Could you say 'Absence of the use of a diagnostic tool should not be a bar to diagnosis in a clear-cut case. However, diagnostic tools may be considered in less obvious cases, where the diagnosis is disputed, or where these is a relative lack of a detailed developmental history'? That would allay my concern described above.	Thank you for your comment. This recommendation has been amended to clarify that use of these diagnostic tools is intended to aid more complex diagnosis and assessment
722.	Somerset County Council	7	NICE versi on	1.2.8	18 1.2. 8	1	Would it be better to recommend – not just to consider - a nationally agreed diagnostic and assessment tool	Thank you for your comment. However, the evidence base is not strong enough to justify a stronger recommendation.
723.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.8	18		1.2.8 It is unclear why the ADI and DISCO should be excluded. The apparently idiosyncratic nature of this undermines the clinical authority of the guidelines in the eyes of some respondents.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE

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								guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
724.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.8	18	1	Consider RCP semi-structured interview format	Thank you for your comment. However, there is no evidence with regards to the diagnostic accuracy of the RCP semi-structured interview format
725.	Tees, Esk & Wear Valleys NHS Foundation Trust	18	NICE	1.2.8	18		It is noted that the tools are considered appropriate for use in gathering information for clinical assessment, however due to lack of researched evidence they not been included among the suggested aids to diagnosis. This needs clarification It is not clear in the NICE version why the ADI and DISCO be excluded	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
726.	Worcestershire Health and Care NHS Trust	14	NICE	1.2.8	18		The tools recommended all come with costs of buying recoding booklets, training and very prescribed methods of delivery and scoring. Clinical practice has highlighted adults do not wish to put through "tick box" exercises where they do not feel listened to and are not allowed to express their experiences in a way that suits their communication needs. In addition if a person is trained in the recommended methods they take their expensive training and experience with them causing difficulties for recruitment and for people waiting for assessments. Other methods can be used effectively that are lower in cost and that can be shared more easily and effectively with less impact if a team member leaves a service. No examples of these are given e.g. ADI-R.	Thank you for your comment. However, this is outside the scope of the guideline and is a matter for local implementation
727.	The Royal College of Psychiatrists, Learning Disability Faculty	46	NICE	1.2.8	18		1.2.8 It is unclear why the ADI and DISCO should be excluded. The apparently idiosyncratic nature of this undermines the clinical authority of the guidelines in the eyes of a reader.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8

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								and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
728.	Dorset Healthcare University Foundation NHS Trust	5	NICE	1.2.8	18		Research evidence to support ADOS, ASDI etc., is not compelling. Recommending use of these tools over interview is dangerous.	Thank you for your comment. The GDG were aware of the limitations of many of the included diagnostic accuracy studies and we have added a methodological quality review (see sections 5.3.7 and 5.4.4 in the full guideline) to address these concerns. This methodological quality review was based on the QUADAS-2 tool and full QUADAS-2 methodology checklists which evaluate each diagnostic accuracy study can be found in Appendix 16. Subsequently, the GDG considered the diagnostic test accuracy summaries together with the methodological quality reviews. The diagnostic tools recommended are not intended to replace clinical interview but may be considered as an aid for more complex diagnosis (see recommendation 1.2.8 in the NICE guideline) or as a tool to structure clinical assessment (see recommendation 1.2.9 in the NICE guideline)
729.	Tees, Esk & Wear Valleys NHS Foundation Trust	21	NICE	1.2.8	18/19		The common risks could include the risk of breakdown of stable placement (including educational, employment, family) or financially The guidelines will also apply to adult mental health and forensic setting, a wider list of disorders could be included Assessment should explain how symptoms and traits functioning, the emphasis should be on formulation rather than simply diagnostic labelling. This is the emphasis within the TEWV draft pathway that was presented to NICE after being requested, for their consideration in developing the guidelines It is disappointing that there is no reference to the pathway's examined and any good practice already in evidence given such documents were requested and provided	Thank you for your comment. The recommendations emphasise the need for a comprehensive assessment rather than a diagnostic label. However, for the additional points you raise it is not clear to what recommendation you are referring as recommendation 1.2.8 is not relevant to these.
730.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.8 /5.4.8.4	121		5.4.8.4 Instruments are given as examples –it might be clearer to set them in context as: 1) Interview instruments	Thank you for your comment. We have revised these recommendations to take account of your comment and included

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							a) that help take a (developmental) history b) that help a direct assessment of the individual. 2) (self-completion) questionnaires. The repetition of the ADOS-G is confusing as it appears simply to be there to indicate that questionnaires should not be used with people with a significant intellectual disability.	separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
731.	The Royal College of Psychiatrists, Learning Disability Faculty	5 2	NICE /Full	1.2.8 /5.4. 8.4	121		5.4.8.4 Instruments are given as examples –it might be clearer to set them in context as: 3) Interview instruments a) that help take a (developmental) history b) that help a direct assessment of the individual. 4) (self-completion) questionnaires. The repetition of the ADOS-G is confusing as it appears simply to be there to indicate that questionnaires should not be used with people with a significant intellectual disability.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
732.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.2.8 /5.4. 8.4	122	1	We are concerned about the lack of support given to the use of structured interviews such as that developed by the Royal College of Psychiatrists. We are also concerned about the somewhat peremptory dismissal of DISCO as an assessment instrument in favour of such as ADOS which we find to lack face validity to any adult or older teenager – it has been the experience of colleagues in the network that this is inclined to provoke hostility and threatens the whole assessment process. In clinical practice, structured interview frameworks for enabling the eliciting of a detailed developmental history are, in our view, essential to support what remains a clinical diagnosis.	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
733.	ADRC	1 2	NICE /Full	1.2.8 /5.4. 8.4	122	1	ADRC considers that formal assessment tools should always be used. Since no one instrument has been identified as being completely reliable in the assessment of adults with autism, a range of measures should be used. Over-reliance on one analogue measure may increase the risk of false positive and false negative diagnoses.	Thank you for your comment. However, the evidence base is not strong enough to justify a stronger recommendation.
734.	Welsh Government		NICE /Full	1.2.8 /5.4. 8.4	122	1	We are concerned about the lack of support given to the use of structured interviews such as that developed by the Royal College of Psychiatrists. We are also concerned about the somewhat peremptory	Thank you for your comment. We have revised these recommendations to take account of your comment and included separate recommendations to a) assist in

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							dismissal of DISCO as an assessment instrument in favour of assessments such as ADOS which we find to lack face validity to any adult or older teenager – it has been the experience of colleagues in the network that this is inclined to provoke hostility and threatens the whole assessment process. In clinical practice, structured interview frameworks for enabling the eliciting of a detailed developmental history are, in our view, essential to support what remains a clinical diagnosis.	structuring clinical assessment (recommendation 1.2.1 in the NICE guideline) and b) the validity of a diagnosis of autism, see NICE recommendations 1.2.8 and 1.2.9 (revised recommendation numbers: 1.2.8, 1.2.9 & 1.2.10).
735.	Brain-in-Hand Ltd	4	NICE /Full	1.2.8 /5.4. 8.4	122	1	"Consider using a formal assessment tool to aid the diagnosis and assessment," Can the paragraph be strengthened (1) to eliminate the occasions in which replicable tests are not used or ignored and (2) to ensure that a battery of tests be used (rather than a single test) to minimise under/over diagnosis	Thank you for your comment. However, the evidence base is not strong enough to justify a stronger recommendation.
736.	The National Autistic Society	5	NICE /Full	1.2.8 /5.4. 8.4	122	1 – 8	Linked to the above, the NAS believe that it is premature for NICE to recommend the use of ADOS-G, ASDI or RAADS-R. Before expanding on this point, we would like to make it clear that the NAS has long used – and trained others in – the Diagnostic Interview for Social and Communication Disorders (DISCO) tool. To the NAS the value of the DISCO is that it collects information concerning all aspects of each individual's skills, deficits and untypical behaviour, not just the features of autism spectrum disorder. Where possible, it also collects information concerning the person's history in infancy and childhood from an informant who has known the person from birth. Our position, however, is that not one diagnostic tool should be suggested over another, more that this guideline should mirror the child guideline on diagnosis and state: "Do not rely on any autism-specific diagnostic tool alone to diagnose autism." As the GDG acknowledge in the clinical evidence of diagnostic tools: "The psychometric evidence evaluating the reliability and validity of diagnostic instruments in adults with autism is limited." (p.110, line 10-11). In our view, it is too limited to make a recommendation for any one tools' specific use.	Thank you for your comment. The diagnostic tools recommended are not intended to replace clinical judgement but may be considered as an aid for more complex diagnosis (see recommendation 1.2.8 in the NICE guideline) or as a tool to structure clinical assessment (see recommendation 1.2.9 in the NICE guideline) and it is to this latter recommendation where we have added that the DISCO should be considered for this purpose

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							The ADOS-G, ASDI or RAADS-R are useful and we know of many clinicians that use them effectively. We are concerned, however, that by NICE declaring it as best practice before more clinical evidence is available they are making a serious misjudgement. Diagnosis of autism at the moment relies heavily on clinical judgement and expertise of the professional or professionals involved in the process. This is particularly the case when it comes to individuals who present with co-occurring mental health conditions, those with a learning disability, adults with no development history and those with substance misuse problems. Trying to unpick the mental health condition and identify the 'triad' can be extremely challenging. Diagnostic tools are very useful to be able to do this in a structured way, but our position must remain that until we have clear – and consistent - evidence of the clinical effectiveness of a diagnostic tool (or tools) that is more reliable and valid than others, and that these tools work across the spectrum and for those who may be unidentified, it is wrong to define any one tool as being the 'best' available. Although, undoubtedly, we believe it is important that the discussion as to the clinical evidence analysed by the GDG regarding ADOS-G, ASDI or RAADS-R – and the other diagnostic tools - remains in the guideline, we would suggest that the conclusion of this discussion - i.e. that these tools should be used - should be moved out of the recommendation section and into either the review of evidence or in the 'From evidence to recommendation' section. Secondly, we also believe that NICE should recommend as a key priority for further research the use of diagnostic tools to identify autism. This research should look at: • clinical effectiveness; • the professional experience/expertise required to use such tools; and, • how the tools help facilitate a deeper understanding of strengthens, weaknesses and potential support needs of	

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							an individual with autism. To help ensure that these guidelines are consistent with both best practice and clinical knowledge, the NAS would suggest – and would be happy to help arrange for the GDG with NICE's assistance - a schedule of events to explore in more detail the proposed recommendations concerning diagnostic tools - and screening tools mentioned above - and their potential impact on diagnostic services and pre-existing diagnostic pathways. We realise that this would be an unusual step for a GDG and NICE, but this is such an important element of the guideline, the adult autism strategy and the key objectives of the NAS, that we believe special considerations should be given. Without this, we are concerned: • That there is a lack of adequate research to recommend the use of any tool for screening and/or diagnosis that will have a profound impact on diagnostic services and ultimately individuals lives • That until clinicians have a better understanding autism and we have working and established diagnostic pathways, the use of any tool for screening and/or diagnosis is premature • That the use of any tool for screening (and in some cases diagnosis) could be used as a barrier to diagnosis without clinically sound evidence; and, • That the ability of pre-existing screening or diagnostic tools to identify those who do not present with typical autism, such as older people, women, those with co-morbid mental health conditions and those from BAME communities is a major concern.	
737.	The Royal College of Psychiatrists, Learning Disability Faculty	7	NICE /Full	1.2.9 /5.4. 8.5	121	1 3	Overall, the recommendations on assessment and diagnosis seem sensible, balanced and achievable. We welcome the focus on the need for *specialist* assessment teams, and the fact that the guidance avoids being too prescriptive regarding the use of specific instruments.	Thank you for your comments.
738.	British Dietetic Association	8	NICE /Full	1.2.9 /5.4. 8.5	122	1 8	To include nutrition and diet related problems such as nutrient deficiencies, imbalanced diet, over or underweight, diet-related constipation and dehydration, with referral to dietitian for further	Thank you for your comment, we have added a recommendation (1.1.9) that addresses diet.

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							assessment where necessary	
739.	AUTISM ALLIANCE UK	1 9	NICE / Full	1.2.9 /5.4. 8.5	122	1 9	Communication difficulties. It is worth spelling out that communication difficulties can include language difficulties (if English is not the main language) and can also include issues of cultural understanding and/or practice. It may be necessary to bring in an interpreter (who could be a family member) or a Speech and Language Therapist	Thank you for your comment, issues of language and culture are covered in person centred care section of the guideline.
740.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.9	18		1.2.9 Given that the guidelines will also apply to adult mental health, forensic and criminal justice settings, it might be useful to extend the list of examples of disorders by concluding them with 'obsessive-compulsive disorder as well as other personality disorders and traits'. As a comprehensive assessment should explain how symptoms and traits relate to functional need as well as informing the commissioning of the care pathway, the emphasis should be on formulation rather than simply diagnostic labelling	Thank you for your comment we have listed important comorbidities in the assessment recommendations. We agree regarding diagnostic labelling and place emphasis on a broad assessment of need (see recommendation 1.2.7).
741.	The Royal College of Psychiatrists, Learning Disability Faculty	5 6	NICE	1.2.9	18		**1.2.9** Given that the guidelines will also apply to adult mental health, forensic and criminal justice settings, it might be useful to extend the list of examples of disorders by concluding them with 'obsessive-compulsive disorder as well as other personality disorders and traits'. As a comprehensive assessment should explain how symptoms and traits relate to functional need as well as informing the commissioning of the care pathway, the emphasis should be on formulation rather than simply diagnostic labelling	Thank you for your comment we have listed important comorbidities in the assessment recommendations. We agree regarding diagnostic labelling and place emphasis on a broad assessment of need (see recommendation 1.2.7).
742.	Dorset Healthcare University Foundation NHS Trust	6	NICE	1.2.9	18		Seem to be recommending a complete CTLD/CMHT assessment in addition to AS diagnosis. This is not possible within a Specialist AS Team. Clinicians need to bear these recommendations in mind and appropriate referrals/signposting made. Add "sensory processing difficulties including" to hyper-and hypo-sensory sensitivities	Thank you for your comment. We have made this clearer in our revised recommendations. It is not intended that all people with autism or all those assessed by the specialist team would remain under their care. It will be up to local services and commissioners to determine which services are responsible for those who need longer term care.
743.	Sussex Partnership NHS Foundation Trust	1 1	NICE / Full	1.2.1 0/5.4 .8.6	122	2 2	The negative statement "Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment" mmay be usefully rephrased as a positive ie " consider using above to rule out potential differential diagnoses"	Thank you for your comment, we did consider this but felt that your suggestion may lead to a higher level of use of test than the GDG felt was warranted by the evidence.

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744.	AUTISM ALLIANCE UK	20	NICE / Full	1.2.11/ 5.4.8.7	122	32	It is not clear that an assessment team will have the capability to produce a risk management plan unless there is access to/input from a specialist care provider (for whom risk management plans are an everyday part of their work).	Thank you for your comment. We have made this clearer in our revised recommendations. It is not intended that all people with autism or all those assessed by the specialist team would remain under their care. It will be up to local services and commissioners to determine how best to provide crisis services in light of the recommendations we have made.
745.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.11	19		1.2.11 The list of common risks might include the risk of breakdown of any stable placement (including educational, employment) or financial arrangement (e.g. going into debt).	Thank you for your comment, the GDG felt these risks were sufficiently covered in the recommendation.
746.	The Royal College of Psychiatrists, Learning Disability Faculty	54	NICE	1.2.11	19		**1.2.11** The list of common risks might include the risk of breakdown of any stable placement (including educational, employment) or financial arrangement (e.g. going into debt).	Thank you for your comment, the GDG felt these risks were sufficiently covered in the recommendation.
747.	Prison Reform Trust	11	NICE	1.2.11	19	4	1.2.11 During a comprehensive assessment, assess the following risks: add: *at risk of anti-social and offending behaviour.*	Thank you for your comment, the GDG felt these risks were sufficiently covered in the recommendation.
748.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.11/5.4.8.7	122	30-31	5.4.8.7 The list of common risks might include the risk of breakdown of any stable placement (including educational, employment) or financial arrangement (e.g. going into debt).	Thank you for your comment, the GDG felt these risks were sufficiently covered in the recommendation.
749.	British Dietetic Association	9	NICE /Full	1.2.11/5.4.8.7	122	29	self neglect to include poor diet / hydration	Thank you for your comment, the GDG felt this was sufficiently covered by 'self-neglect'.
750.	The Royal College of Psychiatrists, Learning Disability Faculty	53	NICE /Full	1.2.11/5.4.8.7	122	30-31	5.4.8.7 The list of common risks might include the risk of breakdown of any stable placement (including educational, employment) or financial arrangement (e.g. going into debt).	Thank you for your comment, the GDG felt these risks were sufficiently covered in the recommendation.
751.	British Dietetic Association	10	NICE /Full	1.2.11/5.4.8.7	123	29	to include severe poor self esteem	Thank you for your comment, this is not a risk factor and therefore not appropriate to include here.
752.	AUTISM ALLIANCE UK	21	NICE / Full	1.2.12/ 5.4.8.8	123	1	5.4.8.8 Develop a care plan ... it is not clear that a care plan can be developed without input from a specialist care provider	Thank you for your comment, we agree but we fully expect that this would be understood to be the case given existing procedures of risk assessment in NHS and related services.
753.	Hampshire Autistic Society	10	NICE / Full	1.2.12/5.4	123	1	The Care Plan (Support Plan is better terminology as people with autism are not received "care") need to have a *skill*	Thank you for your comment, however the GDG felt it better to use the term 'care plan'

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				.8.8			*development and self management strategy emphasis.*	as this term is used and recognised in the NHS and has well developed procedures for developing them.
754.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.2.1 2/5.4 .8.8	123	4	Where is the carer's assessment and their care plan, especially for the majority of parents who have an adult living at home with them (no specialist residential accommodation being built)?	Thank you for your comment. Recommendations 1.1.13 and 1.1.14 (revised recommendation number 1.1.17 & 1.1.18) both state that carer's should be informed of their right to an assessment, and should be support to access one.
755.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.8	18		1.2.8 Surprised that ADI and DISCO are not mention in the brief guideline	Thank you for your comment, the GDG considered this carefully and have adjusted this recommendation in light of your and others' comments.
756.	Pyramid Educational Consultants	5	NICE	1.2.1 2	19	2 0	As well as creating a crisis management plan we would like to see recommendations for preventative measures that would prevent crises from happening.	Thank you for your comment, we agree and the purpose of a crisis management plan is both to manage and prevent the risk, for example by identifying early warning signs and detailing action to be taken. This is part of routine care in the NHS.
757.	AUTISM ALLIANCE UK	2 2	NICE / Full	1.2.1 3/ 5.4.8 .9	123	5	5.4.8.9 (24-hour crisis management plan). Again, specialist providers need to be included to make this work. This sub-section could probably benefit from further explanation of why a 24-hour crisis management plan is useful/necessary, and could benefit from including indicative criteria, for example "where there is reason to believe that crisis might be imminent ..."	Thank you for your comment, we agree and the purpose of a crisis management plan is both to manage and prevent the risk, for example by identifying early warning signs and detailing action to be taken. This is part of routine care in the NHS. We have amended the evidence to recommendations section in the full guideline to make this clearer.
758.	Hampshire Autistic Society	1 1	NICE / Full	1.2.1 3/5.4 .8.9	123	5	Need to add a further bullet point: *"Key information needed to support the individual in crisis."*	Thank you for your comment. This would be covered in the risk management plan.
759.	Dorset Healthcare University Foundation NHS Trust	7	NICE	1.2.1 3	19		Crisis Team Plan – Concerns about practicalities and funding of resourcing the service. CPA function – over cautious for the majority of people. How will this function?	Thank you for your comments, both the points you raise are matters for local implementation and beyond the scope of the guideline.
760.	The National Autistic Society	6	NICE /Full	1.2.1 3/5.4 .8.9		5 - 1 8	The NAS is fully supportive of the recommendation by the GDG to consider developing a 24hr crisis plans. Through our helpline, we are made aware of the real need for such plans. When individuals with autism are in crisis the outcomes vary considerably depending on the professionals and there	Thank you for your comments, helplines are outside the scope of this guideline. We are unable to create template for care plans as they are for local determination and should be consistent with local plans.

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							experience/knowledge of autism, and the first people to be contacted by the individuals family, carer or support network. It is unfortunately not an uncommon story for adults with autism in crisis to be either sectioned or to come into contact with the criminal justice system. Often this worst case scenario can be avoided and we believe that these crisis plans – as well as the other more structured, preventative, support recommended by this guideline – could make a significant difference. We would recommend, however, that in these plans it should also make recommendations regarding helplines to call – autism specific and non-autism specific – as well as possible sources of information, advice and advocacy. Furthermore, the plan must not solely tell families/carers and individuals with autism what their role in a crisis is, but also give them routes through which they can receive, often urgent, support and advice. We also believe it may be helpful for NICE, with the publication of this guideline, to produce some kind of template or suggested pro-forma for these plans so to avoid unnecessary duplication and give multidisciplinary teams a platform to build on and develop.	
761.	The Royal College of Psychiatrists, Learning Disability Faculty	55	NICE /Full	1.2.13/5.4.8.9	122	16	Given that the guidelines will also apply to adult mental health, forensic and criminal justice settings, it might be useful to extend the list of examples of disorders by concluding them with 'obsessive-compulsive disorder as well as other personality disorders and traits'. As a comprehensive assessment should explain how symptoms and traits relate to functional need as well as informing the commissioning of the care pathway, the emphasis should be on formulation rather than simply diagnostic labelling	Thank you for your comment we have listed important comorbidities in the assessment recommendations. We agree regarding diagnostic labelling and place emphasis on a broad assessment of need (see recommendation 1.2.7).
762.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.13/5.4.8.9	123		5.4.8.9 Crisis and contingency plans are an essential part of risk management where a history of risk exists. The mention of risk escalation signatures is especially important in a group with diminished communication and/or idiosyncratic responses to stress.	Thank you for your comments, we agree.
763.	Welsh Health Boards ASD Assessment &		NICE /Full	1.2.13/5.4.8.9	123	5	This would require engagement of other services such as mental health teams and therefore requires a wider understanding and acceptance of role and responsibilities for	Thank you for your comment. This would be a matter for local implementation. The specialist team is the team referred to in

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	Diagnosis (Adults) Network						adults with ASD. What is “the specialist team” referred to ?	earlier recommendations.
764.	Welsh Government		NICE /Full	1.2.1 3/5.4 .8.9	123	5	This would require engagement of other services such as mental health teams and therefore requires a wider understanding and acceptance of role and responsibilities for adults with ASD. What is “the specialist team” referred to ?	Thank you for your comment. This would be a matter for local implementation. The specialist team is the team referred to in earlier recommendations.
765.	Brighton and Hove City Council	5	NICE versi on	1.2.1 3	19	2 5	Amend ‘the specialist team’ to ‘clinicians and support staff’	Thank you, the recommendation for the autism team was based on a number of factors – the NAO report and assessment of the potential cost-effectiveness’ of such teams, and the expert opinion of the GDG that a number of the recommendations, for example the assessment recommendations would be best provided in the context of a specialist team.
766.	Brighton and Hove City Council	6	NICE versi on	1.2.1 4	20	7	Amend ‘the autism team’ to ‘professionals’	Thank you, the recommendation for the autism team was based on a number of factors – the NAO report and assessment of the potential cost-effectiveness’ of such teams, and the expert opinion of the GDG that a number of the recommendations, for example the assessment recommendations would be best provided in the context of a specialist team.
767.	Dorset Healthcare University Foundation NHS Trust	8	NICE	1.2.1 4	19		Needs clarifying about role of other teams for diagnosis. This implies all diagnosis of autism should be made by the specialist autism team. Professionals in the Learning Disability team are capable of making this diagnosis for their patients.	Thank you for your comments, the GDG feel that it is clear that one role of the specialist team is to provide advice to other teams such as learning disabilities teams.
768.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.2.1 4/5.4 .8.10	123	1 9- 2 9	There is a need for peer group learning and development of diagnostic skills and knowledge	Thank you for your comment. This would be a matter for local implementation.
769.	Welsh Government		NICE /Full	1.2.1 4/5.4 .8.10	123	1 9- 2 9	There is a need for peer group learning and development of diagnostic skills and knowledge	Thank you for your comment. This would be a matter for local implementation.
770.	Northumberland, Tyne & Wear NHS		NICE	1.2.1 5	20		1.2.15 Should genetic investigation be considered where there is simply a strong family history of Autism?	Thank you for your comment, the GDG did not think this addition was necessary nor is

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	Trust							this advised in the *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum* guideline.
771.	Northumberland, Tyne & Wear NHS Trust		NICE	1.2.1 5	20	1 8	1.2.15 We would consider genetic referral if strong FH of autism really?	Thank you for your comment, the GDG did not think this was necessary as it should be as a matter of routine. There may be clinical grounds were this is deemed appropriate but this would be for local clinicians to determine.
772.	The Royal College of Psychiatrists, Learning Disability Faculty	5 8	NICE	1.2.1 5	20		**1.2.15** Should genetic investigation be considered where there is simply a strong family history of Autism?	Thank you for your comment, the GDG did not think this was necessary as it should be as a matter of routine. There may be clinical grounds were this is deemed appropriate but this would be for local clinicians to determine.
773.	NCCMH Expert Reviewer	7	NICE	1.2.1 5	20		ref to specific investigations – I am not sure this is wise, as it implies a protocol driven guideline in which case practitioners may refer to the guideline to drive investigations and management rather than use their already experienced clinical and medical skills. For example, in some cases a patient may be presenting with unusual features warranting an MRI scan which occasionally in my experience shows up a brain tumour, yet MRI was not mentioned (quite rightly as it would not be possible to mention all investigations). So perhaps the fact that the list in this section is merely an example needs to be highlighted more forcefully, then clinicians will continue to use their clinical judgement. (a risk in protocol driven guidelines was highlighted by the Addenbrooks DNR case – see Meikle J. (August 28, 2011) Hospital Sued Over DNR Rule, *The Guardian*, 28.8.2011)	Thank you for your comments, guidelines are not protocols and should not be used as such - they should be used as a guide bit are not a substitute for clinical judgement. The point here was to remove the routine use of a variety of tests which in many cases would services with no purpose, place a burden on patients and be costly to services.
774.	Ambitious about Autism	5	NICE	1.2.1 5	20 of 50		Include 'referral for a learning disability assessment, or alternative form of ensuring access to relevant education, employment or training'.	Thank you for your comment, we would expect this to be part of the assessment method, and assessment might indeed be done in learning disability services.
775.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.1 5/5.4 .8.11	123	3 5	5.4.8.11 Should genetic investigation be considered where there is simply a strong family history of Autism?	Thank you for your comment, the GDG did not think this was necessary as it should be as a matter of routine. There may be clinical grounds were this is deemed appropriate but this would be for local clinicians to determine.
776.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.2.1 5/5.4 .8.11	123		5.4.8.11 The recommendation suggesting "genetic tests, as recommended by the regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or	Thank you for your comments, the GDG did not consider this addition was appropriate.

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							evidence of intellectual disability" may be improved by adding "or a strong family history of autism"	
777.	British Dietetic Association	1 1	NICE /Full	1.2.1 5/5.4 .8.11	123	3 8	to include changes in diet	Thank you for your comment, an additional recommendation has been added to cover issues relating to diet (see the new recommendation 1.1.9).
778.	The Royal College of Psychiatrists, Learning Disability Faculty	5 7	NICE /Full	1.2.1 5/5.4 .8.11	123	3 5	5.4.8.11 Should genetic investigation be considered where there is simply a strong family history of Autism?	Thank you for your comment, the GDG did not think this was necessary as it should be as a matter of routine. There may be clinical grounds were this is deemed appropriate but this would be for local clinicians to determine.
779.	WaASP		NICE guide line	1.3	21	1	We applaud your identification of 'treatment' and 'care' as being the key matters to address.	Thank you for your comments.
780.	Tees, Esk & Wear Valleys NHS Foundation Trust	2 3	NICE	1.3	21		It may be more helpful to comment on a risk of altered sensitivity and idiosyncratic responses	Thank you for your comments but this is too detailed for a clinical guideline.
781.	Royal College of Speech and Language Therapists	2.	NICE /Full	1.3.1 /5.4. 8.12	124	6	Unclear what "duration of autism" means as autism is a developmental disorder so will have existed throughout childhood.	Thank you, we have removed this in light of your comment.
782.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.3.1 /5.4. 8.12	124	6	5.4.8.12 It is not clear what is meant by the 'duration of autism'	Thank you, we have removed this in light of your comment.
783.	British Dietetic Association	1 2	NICE /Full	1.3.1 /5.4. 8.12	124	1 2	To include diet and any nutritional deficiencies that may be caused by physical state e.g. anxiety, side effect of medications, and poor diet	Thank you for your comments but this is too detailed for a clinical guideline.
784.	The Royal College of Psychiatrists, Learning Disability Faculty	5 9	NICE /Full	1.3.1 /5.4. 8.12	124	6	5.4.8.12 It is not clear what is meant by the 'duration of autism'	Thank you, we have removed this in light of your comment.
785.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.3.1 /5.4. 8.12	124	3	The vast majority of any ASD programmes are parent initiated and maintained – they need support to do so.	Thank you for your comment, we not sure this is the case with adults; nevertheless we do recommend the involvement of the family when agreed by the individual.
786.	Royal College of Speech and	1(	NICE	1.3.1	21		Specify "communication needs" alongside physical health	Thank you for your comment, as communication can be a central issue for

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	Language Therapists							people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
787.	Northumberland, Tyne & Wear NHS Trust		NICE	1.3.1	21		1.3.1 It is not clear what is meant by the 'duration of autism'	Thank you for your comment, we have removed this.
788.	Pyramid Educational Consultants	6	NICE	1.3.1	21	5	Consider also whether previous interventions were correctly implemented; advances in interventions since the adult was in education.	Thank you for your comment. Te would expect this to be covered by this bullet point.
789.	Hampshire Autistic Society	1 2	NICE / Full	1.3.1 /5.4. 8.12	124	3	Need to add two further bullet points: *"Recognised existing self management strategies"* and *"Understanding the needs and wishes of the individual"*.	Thank you for your comment, the need to promote the person's autonomy and self management is set out in the 'principles of care' section, which should apply to every step of care for people with autism (see recommendation 1.1.4).
790.	AUTISM ALLIANCE UK	2 3	NICE / Full	1.3.1 /5.4. 8.12	124	2	Identifying the correct treatment and care options for adults with autism. Medical treatment is a matter for medical professionals. Care, we suggest, strongly indicates a need to involve specialist organisations involved in providing care, and, where appropriate, advocacy and brokerage services	Thank you for your comments, the need to develop a comprehensive plan is clear in the guideline. Who is involved will be for local determination.
791.	Nottinghamshire Healthcare NHS Trust	4 0	NICE / Full	1.3.1 /5.4. 8.12	124	6	Given the lifelong nature of autism, we would not consider a question relating the 'duration of autism' to be necessary	Thank you for your comment, we have removed this.
792.	Nottinghamshire Healthcare NHS Trust	4 1	NICE /Full	1.3.2 /5.4. 8.13	124	2 1	As noted previously, it would be useful to reference the evidence relating to environment and give guidance where indicated. Also, we feel it is also useful to note the structure of the environment; and the communication, interaction and empathy skills of the staff team. This needs to range from an environment that is able to adapt to the communication needs of the individual and use approaches such as Intensive Interaction for adults with learning disability; through to interventions such as Social Stories and Comic Strip Conversations for more able individuals.	Thank you for your comments. We have adjusted our recommendations regarding physical environment and staff attitudes in light of your comments.
793.	Hampshire Autistic	1	NICE	1.3.2	124	1	Need to add a further bullet point: *"Ask them how they respond*	Thank you for your comments we think this

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	Society	3	/ Full	/5.4. 8.13		5	*to issues/challenges".*	will be covered by the existing bullet points that cover decision making.
794.	Royal College of Speech and Language Therapists	11	NICE	1.3.2	21		Add "specific communication strategies"	Thank you for your comment, as communication can be a central issue for people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
795.	Northumberland, Tyne & Wear NHS Trust		NICE	1.3.2	21		1.3.2 Rather than limiting the warning to increased sensitivity, it would be more helpful to note that there is a 'greater risk of altered sensitivity and unpredictable responses to the effects of medication or other physical interventions.''	Thank you for your comments, we agree and have adopted your suggested text.
796.	The Royal College of Psychiatrists, Learning Disability Faculty	6 0	NICE	1.3.2	21		**1.3.2** Rather than limiting the warning to increased sensitivity, it would be more helpful to note that there is a 'greater risk of altered sensitivity and unpredictable responses to the effects of medication or other physical interventions.''	Thank you for your comment; we agree and have adopted your suggested text.
797.	Dorset Healthcare University Foundation NHS Trust	9	NICE	1.3.2	P 21		Add to bullet point : the presence and nature of "sensory processing difficulties which includes difficulties with hyper- or hypo-sensory sensitivities and with posture and praxis" and how these may impact on the delivery of the intervention.	Thank you for your comments but this is too detailed for a clinical guideline.
798.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.3.2 /5.4. 8.13	124	1 9- 2 0	5.4.8.13 Sensitivity to effects (not just side/adverse effects) may be decreased as well as increased – e.g. ineffectiveness of tranquillisers, decreased awareness of pain increasing the risk of injury in physical intervention.	Thank you for your suggestion, but this is too detailed for a clinical guideline, however we do this think recommendation has been improved in light of your other comments.
799.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.3.2 /5.4. 8.13	124	2 6	This might explicitly include 'predictability' as well as 'clarity, structure and routine'	Thank you for your comment; we added 'predictability' as you have suggested.
800.	The Royal College of Psychiatrists, Learning Disability Faculty	6 1	NICE /Full	1.3.2 /5.4. 8.13	124	2 6	This might explicitly include 'predictability' as well as 'clarity, structure and routine'	Thank you for your comment; we added 'predictability' as you have suggested.
801.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.3.2 /5.4. 8.13	124		Within the list of aspects to assess in adults good to see acknowledgement of hyper- and hypo-sensory sensitivities which we know continue into adulthood and can be limiting to adults' participation ability in education/employment and other aspects of community life.	Thank you for your comments.
802.	Northumberland, Tyne & Wear NHS		NICE /Full	1.3.3 /5.4.	124	2 9	It might it be helpful to add that the clinician should always consider providing information in written form as well.	Thank you for your comment; we make it clear elsewhere in the guideline that

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	Trust			8.14				information should be in written and form (see 1.1.4).
803.	The Royal College of Psychiatrists, Learning Disability Faculty	62	NICE /Full	1.3.3 /5.4. 8.14	124	29	It might it be helpful to add that the clinician should always consider providing information in written form as well.	Thank you for your comment; we make it clear elsewhere in the guideline that information should be in written and form (see 1.1.4).
804.	Worcestershire Health and Care NHS Trust	18	NICE	1.3.3	22		Clients with AS do not fit into neat time limited interventions often needed extended time for interventions to be successful.	Thank you for your comment, we agree and have indicated at key points the need for long term care and support along the care pathway, see recommendations 1.9.1-7 (revised recommendation numbers: 1.8.1-1.8.7)
805.	Northumberland, Tyne & Wear NHS Trust		NICE	1.3.4	22		1.3.4 a passport may be helpful and should be offered; it may be problematic to require service users to carry cards if they refuse with capacity, or where there are capacity issues	Thank you for your comment. We have revised the recommendation following yours and others' comments to say 'advise the person to carry the health passport at all times'.
806.	Worcestershire Health and Care NHS Trust	19	NICE	1.3.4	22		Many clients with AS do not wish to disclose let alone carry a 'health passport' though it would be beneficial if they did. Example of good practice would have been helpful.	Thank you for your comment, a person may of course decide not do so. WE will draw this to the attention of the NICE Implementation team who may add this to their clinical case scenarios.
807.	Dorset Healthcare University Foundation NHS Trust	10	NICE	1.3.4 – 1.3.6	22		This part of the guidance is mainly LD and not relevant to adults who are higher functioning. Facilitated groups: With a decrease in staffing across health and social care it is unlikely that there will be scope to develop regular, skilled group work and this would realistically have to be commissioned through the voluntary sector with attention being given to the level of skills and experience of the facilitators.	Thank you for your comment, the nature of service provision will be for local commissioners to decide.
808.	Autism West Midlands	20	NICE Version	1.3.4	22		Disclosure and the health passport Although our ACWG thought the 'health passport' would be useful and many of them carry an autism attention card already, they thought section 1.3.4 should include information about disclosing that you have autism. On the one hand they saw the advantage of accessing more appropriate support by	Thank you for your comment. This recommendation has been revised to remove the 'language of compulsion'. The recommendation now advises that a health passport should be carried, rather than stating that it definitely should be.

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							disclosure through the use of a health passport but were nervous about being stigmatised. The “stigmatisation” issue has been raised with us by a police force in the West Midlands in relation to children and young people. They are concerned that the word “autism” on a card may result in stigmatisation and bullying by the peer group. We are working with them on this issue. The stigmatisation concern is a matter of general concern. We are also concerned that the language of compulsion used in 1.3.4 – i.e. that ‘health passport should be carried by the person with autism at all times’ (NICE 2011b: 22) - may make adults with autism anxious and even think that it is necessary for them to proffer this information outside the treatment and care context. We recommend that section 1.3.4 includes additional information about how an adult with autism can apply for the health passport; that guidance is given about the appropriate use of it, and that there is some discussion of the benefits or otherwise of disclosure. This is especially relevant given that the guideline later refers to the relevance of ‘interventions to develop anti-victimisation skills’ (NICE 2011b: 24, section 1.4.7)	
809.	Somerset County Council	8	NICE version	1.3.4	22 1.3.4	9	Build in links to the local Criminal Justice System to integrate understanding and use of any such systems	Thank you for your comments – we address some of the issue you raise in recommendation 1.9.3 (revised recommendation number 1.8.3).
810.	The National Autistic Society	7	NICE /Full	1.3.4 /5.4. 8.15		1-4	The NAS is intrigued by the recommendation regarding adults with autism using ‘health passports’, but we feel more information is needed for this recommendation to reach its full potential. The NAS is aware of the use of health passports[17] and hospital passports[18] for adults with a learning disability. We have also	Thank you for your comment. We have amended the recommendation in light of your comments. We will draw your other points to the attention of the NICE implementation team.

[17] http://www.healthpassport.co.uk/upload/health%20pass%20cs4%20final%20june3.pdf

[18] http://www.croydonhealthservices.nhs.uk/Downloads/Patient%20Information/Learning%20Disability%20Hospital%20Passport.pdf

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							seen examples of adults with autism using small laminated cards which detail their support preferences – an example of such a card is in use in Peterborough. All of these three 'passports' serve very different roles. All have benefits, but none is necessarily ideal in every situation. For instance, the 'hospital passport' which details medication, support requirements and personal preferences, is a large document and not entirely practical to be carried at all times – as recommended. Passports like those in use in Peterborough, however, can be very useful to alert people to the adjustments needed to support an individual, but does not have the breadth of information potentially required. 'Passports' can be fantastic empowering documents that give the individuals a sense of security and gives professionals useful tips on how to make adjustments and ensure that their patient is well looked after. We would encourage the GDG to expand on the recommendation and detail what they would expect to see in this passport in more detail. We would also suggest that NICE should produce, when the guideline is published, an example passport(s) so that we can all ensure that there is consistent practice across the country.	
811.	Royal College of Speech and Language Therapists	3.	NICE /Full	1.3.4 /5.4. 8.15	125	1	Health passports should be offered if appropriate and it should be individual choice as guidance reads as though it must be offered. In our experience most people with ASD and no learning disability would not want a health passport.	Thank you for your comment. We have revised the recommendation following yours and others' comments to say 'advise the person to carry the health passport at all times'.
812.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.3.4 /5.4. 8.15	125		Important to see acknowledgement of environment in adult care plans, for example, whether it is suitably adapted for people with autism, in particular those with hyper- or hypo-sensory sensitivities.	Thank you for your comment, in light of your and others' comments we have added a further recommendation regarding the physical environment.
813.	Worcestershire Health and Care NHS Trust	20	NICE	1.3.5	22		Each of these would be useful but all have resource implications for services to support them. Very few exist and non-locally that are sufficiently resourced to meet the vast range of issues that clients have.	Thank you for your comment, this is a matter for local implementation but NICE will produce costing guidance separate from guideline to aid implementation.
814.	Nottinghamshire	4	NICE	1.3.6	125	6	It would be valuable to understand why 'functional analysis' as	Thank you for your comment, 'functional

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	Healthcare NHS Trust	2	/Full	/5.4. 8.16			a specific assessment model was recommended and give further information regarding specific tools to perform this. The guidance could usefully make reference here to the Royal College of Psychiatry/British Psychological Society recommendations of Challenging Behaviour (CR144 2007).	analysis' is recommended here for challenging behaviour, not the overall assessment. It would not be appropriate to reference this guidance in a recommendation.
815.	The National Autistic Society	2 4	NICE /Full	1.3.6 /5.4. 8.16		1 5	We would recommend that when professionals look behind the causes of challenging behaviour and decide on treatment and/or care interventions, it is helpful for them to have in mind that the behaviour could be an individual's attempt to communicate a particular problem. The guideline does do this in other places, but you may want to consider adding: *…needs that the person is attempting to meet (or to communicate) by performing the behaviour.*	Thank you, we feel this is covered by our recommendations on the assessment of challenging behaviour.
816.	Hampshire Autistic Society	1 4	NICE / Full	1.3.6 /5.4. 8.16	125	5	Need to add a further bullet point: *"Discussions with the individual and those important to the individual – to gain a better understanding of the nature/causations of the behaviour".*	Thank you for your comment, we agree with this but it will form part of the functional analysis, and the wider comprehensive assessment and therefore we do not feel it necessary to make further additions.
817.	British Psychological Society		NICE / Full	1.3.6 /5.4. 8.16	125	6	*Recommendation 5.4.8.16:* The BPS welcomes the importance given to the need to perform a functional analysis on any specific problem behaviours. However we recommend that this paragraph should include an additional bullet point to emphasise the importance of the context within which the behaviour occurs. This is recommended as good professional practice when working with adults whose behaviour presents challenges (British Psychological Society, 2004): • *Observation and description, in a range of environments, of:* - *the likely setting events (temperature, noise, changed environment, etc.) that are relevant and important to the individual* - *the internal and external stimuli…*	Thank you for your comment, we feel this is covered by our recommendations on challenging behaviour, and have also added a further recommendation regarding the physical environment.
818.	British Psychological		NICE / Full	1.3.6 /5.4.	125	1 3	*Recommendation 5.4.8.16:* Good professional practice (British Psychological Society,	Thank you for your comments, we agree but feel this is too detailed for a clinical guideline

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	Society			8.16			2004) recommends that trends in the wider context in which the behaviour occurs is also important. We suggest that this bullet point is amended to read: • *review of the observational data to identify trends in behaviour, occurrence, environmental and other setting events that increase the likelihood of the individual responding to trigger situations, stimuli that may be evoking …*	and is already covered by our existing recommendations.
819.	British Psychological Society		NICE / Full	1.3.6 /5.4. 8.16	125	1 7	The BPS welcomes the emphasis on changing behaviour through "addressing the causes and function(s) of problem behaviour(s)", but would like to see a greater emphasis on *prevention* by amending this paragraph sentence to the following: *Use the analysis to set up environments that are more likely to support positive behaviours and to target interventions at addressing the causes and function(s) of problem behaviour(s).*	Thank you for your comments, we agree but feel this is too detailed for a clinical guideline and is already covered by our existing recommendations.
820.	South London and Maudsley NHS Trust	1 9	NICE / Full	1.3.6 /5.4. 8.16	125	6	The preferred term these days is applied behavioural analysis, not functional analysis.	Thank you for your comment. We accept that there is no agreement on the definition of terms between different clinical and academic groups. However, the GDG decided to use the term 'functional analysis' as it is in wide use in the NHS. In order to be clear about the nature of any psychological intervention the GDG specify the nature and content of those interventions in the recommendations in order to avoid any confusion in the use of different terms to describe these interventions.
821.	Northumberland, Tyne & Wear NHS Trust		NICE	1.3.6	22	1 6	1.3.6 refers to assessment and intervention re challenging behaviour and needs to be linked into an wider framework to guide interventions that have a positive value base with sound theoretical underpinnings (e.g. positive behaviour support). Suggest this be brought into psychosocial interventions section as it links with some of the interventions outlined there (e.g. 1.4.6 interventions to develop daily living skills).	Thank you for your comments, we did consider this but felt it would not work and therefore kept challenging behaviour separate to avoid confusion.
822.	Pyramid Educational	7	NICE	1.3.6	22	1 7	We're glad to see this explicitly stated.	Thank you for your comments.

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	Consultants							
823.	Autism Rights Group Highland	9	NICE	1.3.6	23	1	Care must be taken to ensure that any behaviour modification is to the benefit of the autistic person: that they will be happier after intervention and that they genuinely require intervention. Intervention should never be for the ease of others eg to make a person more compliant rather than to meet the needs of that person, or to save time and or / money in a care setting.	Thank you for your comments, we agree with your point but these are about good professional and ethical practices and outside of guideline scope.
824.	Royal College of Speech and Language Therapists	4.	NICE /Full	1.3.2 /5.4. 8.13	124	1 6	Also need to take into account persons level of understanding and preferred modality of communication, e.g. communication aid	Thank you for your comment, as communication can be a central issue for people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
825.	Worcestershire Health and Care NHS Trust	7	NICE	1.3.6	8 and 22	P ar a 3	Challenging Behaviours. Completing a proper and useful functional analysis is very difficult to complete outside of school, care home and residential facilities and is often not possible for adults with IQ's over 70 and live independently or with family. There is no suggestion about obtaining consent to this recording when the person has capacity and contradicts the advice about respect.	Thank you for your comments, we agree with your point but these are about good professional and ethical practices and outside of guideline scope.
826.	Royal College of Speech and Language Therapists	12	NICE	1.4	23		There is a failure to consider the communication needs of the individual. This section needs to highlight the need to adapt interventions to meet communication needs of the individual(as per in 1.5.3. on page 26)	Thank you for your comment, as communication can be a central issue for people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
827.	Prison Reform Trust	1 2	NICE	1.4	23	5	1.4 Psychosocial interventions for autism should be routinely available for prisoners and offenders on the autism spectrum. These should include restorative justice interventions and interventions to develop skills to reduce/stop anti-social and offending behaviour.	Thank you for your comments, this guideline has not reviewed the evidence for prison populations, although the recommendations may be relevant to those working within prison/forensic services, and is unfortunately outside the scope of this guideline.
828.	Pyramid Educational Consultants	8	NICE	1.4	23	6	There isn't a specific listing for communication skills. While social interaction is listed, this could be interpreted as social skills training, while some adults need training in more basic communication skills before the social skills training. We recommend basic expressive communication programmes should address: the ability to ask for reinforcers; the ability to	Thank you, however we could identify no evidence for what you suggest and you provide none in your comment.

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							say yes or no to objects and experiences; the ability to ask for help and a break. Receptive skills we recommend everyone learn include transitioning effectively; learning to respond to wait and no; learning to follow directions and learning to follow a schedule. These skills often reduce difficult behaviours, and we recommend teaching these before more advanced social skills.	
829.	Worcestershire Health and Care NHS Trust	21	NICE	1.4	23-25		The range of interventions is welcomed but would in most cases not required highly qualified staff but a large number of lower grade staff with skills in working with people with Autism/AS. However the concern remains on resourcing staff numbers and not relying on volunteers or support groups to deliver these interventions.	Thank you for your comment. This would be a matter for local implementation.
830.	Northumberland, Tyne & Wear NHS Trust		NICE	1.4	24		There should be mention of anxiety management – techniques (including realization training) and strategies. Both this and anger management require the development of emotional literacy (with the help of a Speech and language therapist) and may usefully be dealt with under the heading of emotional management.	Thank you, however we could identify no evidence for what you suggest and you provide none in your comment.
831.	Autism Rights Group Highland	10	NICE	1.4.4	23	6	Whole section: **Interventions to improve social interaction** Social interaction should never be forced or presumed to be what the autistic person actually wants. Education focussing on NT social behaviour rather than perceived deficits in Autistic social behaviour can be used to teach about differences in a non- judgemental way, the autistic person can then chose (possibly with support) what they would like to act upon. It shouldn't be assumed that the Autistic person wants to change to emulate NT behaviours; they should not be given negative feelings towards Autistic behaviours; it is not acceptable to say NT = good, autistic = broken.	Thank you for your comments, we agree and this is a matter for discussion with the person and obtaining informed consent – this is outside the scope of the guideline.
832.	Tees, Esk & Wear Valleys NHS Foundation Trust	29	NICE	1.4	24		There should be consideration of wider therapeutic input including anxiety management - which clinically is the most common presentation. There should also be expressed direction to consider provision of emotional literacy etc	Thank you for your comments, we agree anxiety should be treated and suggest that it is provided and informed by existing NICE guidance, see 1.5.1 (revised number 1.6.2) and the new recommendations 1.6.4.
833.	Hampshire Autistic Society	6	NICE / Full	1.3.5 /4.3. 7.8	66	7	Need to reference "*Autism Partnership Board's and join planning/commissioning groups for autism*".	Thank you for your comments. We were unsure which recommendation you are referring to here as this is not appropriate for this section.
834.	The Royal College	7	NICE	1.4	24		There should be mention of anxiety management – techniques	Thank you for your comments, we agree

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	of Psychiatrists, Learning Disability Faculty	5					(including realization training) and strategies. Both this and anger management require the development of emotional literacy (with the help of a SALT) and may usefully be dealt with under the heading of emotional management.	anxiety should be treated and suggest that it is provided and informed by existing NICE guidance, see 1.5.1 (revised number 1.6.2) and the new recommendations 1.6.4.
835.	Hampshire Autistic Society	2 7	NICE / Full	1.4.1 2/7.8 .8.2	234	1 7	Need to add to this section: • *Proactive work with Employers – engage to understand and promote positives of individuals with autism.* • *Job Centre – autism awareness training and support.*	Thank you for your comment. However we are unable to make recommendations outside the NHS.
836.	Sheffield Asperger Syndrome Service	1 7	NICE	1.4.2	23		1.4.2. details a number of things which should be included in "Group-based social learning programmes" – there is no mention of in-situ practice and support however. This is something which is crucial for skill generalization from group settings to the 'real world'.	Thank you for your comment, we agree this may be helpful but we think this is sufficiently covered by the recommendations. Guidelines should be used in conjunction with clinical judgment and when delivering an intervention clinicians should consult relevant manuals which should make this clear
837.	Craegmoor	5	NICE	1.4.3	23	1 8	Good to see the value of social learning programs and that it is recognised sometimes these will need to be delivered on a one to one basis to start with for those who find group based activities very difficult.	Thank you for your comments.
838.	Somerset Partnership NHS	1 2	NICE	1.4.4	23	2 4	Structured leisure activity programmes often need to take place on an individual, rather than group basis.	Thank you for your comment. The recommendation has been amended in light of this comment.
839.	Dorset Healthcare University Foundation NHS Trust	1 1	NICE	1.4.4	23		Voluntary Sector – not health/social care Structured leisure activity programmes for all ranges of intellectual ability: It is unlikely to achieve this as the levels of intellectual abilities within autism are wide ranging. A person with Asperger's Syndrome is likely to reject the idea of joining a group of people with autism and learning disability. Generally, how is this to be applied in the workplace?	Thank you for your comment. The recommendation has been amended in light of this comment.
840.	Somerset County Council	9	NICE versi on	1.4.4 and 1.4.5	23 1.4. 4 and 1.4. 5	2 1	Should there be reference to one-to-one leisure activities as well as group activities, as appropriate to the individual's needs/interests	Thank you for your comment. The recommendation has been amended in light of this comment.
841.	NCCMH Expert Reviewer	8	NICE	1.6.1 3	29		Antipsychotics for treatment of irritability, aggression and self-harm – given that atypical antipsychotics cause long term health problems including QT prolongation (cardiac conduction defects), diabetes, weight gain, metabolic syndrome, I am concerned about this as a general guideline. It would be	Thank you for your comment, the recommendation is limited to challenging behaviour as there is not the evidence base for self-harm. We have added clear recommendations about the duration of use.

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							important to mention that other (eg behavioural/ psychological) approaches need to be tried first and I would agree with what appears to be a question in the brackets, that there has to be robust evidence in place to support this as an assertion. Also in borderline PD, dialectical behaviour therapy has a better proven track record in emotional dysregulation causing self-harm, irritability and aggression than medication. There are similarities between amygdala hyperarousal (+ reduced prefrontal feedback) in borderline PD and autism that have yet to be compared / explored in research.	
842.	Hampshire Autistic Society	22	NICE / Full	1.4.6 /7.4. 7.1	187	15	Add "*that are based on a clear understanding of the individual and their autism".*	Thank you for your comment. This is covered in the general principles of care section.
843.	Pyramid Educational Consultants	9	NICE	1.4.6	24	2	Activities for daily living, or even an independence skills category should be placed above leisure skills in this section.	Thank you for your comment. Following your and others' comments we have restructured this section.
844.	Somerset County Council	10	NICE version	1.4.7 and 1.4.8	24 1.4.7 and 1.4.8	7	Should include reference to Hate Crime and its reporting within the Criminal Justice System, and other agencies that would need to be involved.	Thank you for your comments. This is outside the scope of the guideline.
845.	The National Autistic Society	17	NICE /Full	1.4.8 /7.5. 7.5		26 - 33	The NAS believes that the GDG have really got to grips with many of the key issues faced by adults with autism from all walks of life. The recommendation regarding anti-victimisation interventions is just the type of innovative recommendation that could really make a difference to peoples lives. We would suggest, however, that to coincide with the publication of this guideline, examples of courses that are currently being run, and potentially a list of organisations that offer these courses, should be compiled. This would help professionals in health and social care, as well as individuals and their families/carers, to access these classes if needs be. The NAS would also be keen to help and add this information to the autism services directory,[19] the UK's most	Thank you for your comment. It would not be appropriate for NICE to endorse particular courses. Also, as this document may not potentially be updated for another 4 years it would be out of date and confusing for someone reading this guideline in 2016.

[19] http://www.autism.org.uk/directory.aspx

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							comprehensive directory of services and support for people with an autism spectrum disorder, their families, and people who work with them.	
846.	Dorset Healthcare University Foundation NHS Trust	1 2	NICE	1.4.8 – 1.4.1 2	23		Is this to be applied to work place? Anger Management – not available in other adult services (outside of LD) – HUGE resource implications. Supported employment programme: This is already being offered through the Job Centre Plus and their Disability Advisor Service who will have the specialist contacts within the employer services. In the current climate of high unemployment it is unlikely that specialist autism teams will have the expertise or time to deal with employment issues on top of running a very complex and demanding service. Consider Interventions to develop and improve sensory processing: develop self regulation strategies, consider the environment and develop posture and praxis skills.	Thank you for your comments this is outside of scope of the guideline, but NICE will do a costing impact analysis to aid implementation. NICE guidelines should set high standards of care and should not be limited by costs where evidence of benefit is available.
847.	Specialist Autism Services	2	NICE /Full	1.4.1 3/7.3 .7.1	181	1 3	Perhaps refer to Royal College of Speech & Language Therapist publications : The Resource Manual for the Commission and Planning or Resources for ASD (2009) Clinical Guidelines (2005) ALD Position Paper (2010)	Thank you for your comment, however it would not be appropriate to refer to this document in the recommendations.
848.	Specialist Autism Services	3	NICE /Full	1.4.1 3/7.3 .7.1	181	1 3	What of those with co-morbitity? i.e. Dyslexia, Dyspraxia, Disfluency, Dysphagia .	Thank you for your comment, please see the full guideline section 7.3 for further information as to why we have made this recommendation.
849.	Hampshire Autistic Society	2 6	NICE / Full	1.4.9 /7.5. 7.6	197	3 7	Add *"and gain an understanding of the potential causations of anger".*	Thank you for your comment, this recommendation is about the delivery of an intervention and so your suggestion would not fit here.
850.	Northumberland, Tyne & Wear NHS Trust		NICE	1.4.9	24	1 4	At 1.4.9 some would recommend CBT base for anger management interventions as this is where the evidence base is in developmental disabilities and anger (cf Taylor & Novaco; Wilner)	Thank you for your comment. The GDG avoided the use of the term CBT as this can mean different things to different people and doesn't necessarily adequately convey the Novaco approach on which the evidence is based. The GDG therefore decided that to avoid confusion caused by this term it would be more suitable to outline the components of the anger management intervention and these reflect the evidence base.
851.	Autism Rights	1	NICE	1.4.1	25	1	All of this should be done with negotiation with person	Thank you for your comment, we agree and

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	Group Highland	1		1				have set this out in the ‘general principles of care’ section.
852.	Ambitious about Autism	6	NICE	1.4.1 1	25 of 50		Supported employment programmes are not the only way to support adults with autism into employment! This section must include reference to consideration of a range of specialist and mainstream career development options, including: further education colleges, higher education providers, apprenticeships, internships, social enterprises, training programmes and any other local learning providers.	Thank you for your comment. This may be the case but the only evidence we were only able to recommend IPS as that was where the evidence was.
853.	The National Autistic Society	1 8	NICE /Full	1.4.1 2/7.8 .8.2		2 0	The NAS is extremely supportive of the recommendation that adults with autism should have access to supported employment programmes. One of the key ambitions of the NAS is that people with autism should have the same training and employment opportunities as non-disabled people. We know from our Prospects service that giving this type of support to adults with autism can drastically improve people’s lives. We also know, however, that this support has to be right or it can lead to some serious issues. One example came to our attention during the consultation exercise which highlights the problem of offering employment support that is not appropriately adjusted: *“I was assigned a Disability Employment Advisor and referred to the Work Choice scheme which, for my area, is run by [employment provider] - the problem [employment provider] was a lack of understanding about Asperger Syndrome and they treated me like I had learning difficulties (in fact, [employment provider] made my depression and anxiety worse and made a small contribution to a recent three week stay in hospital).”* **Adult with autism.** The NAS believe that this guideline will help ensure not only with adults with autism have better access to employment support, but also receive support that meets their needs. We would suggest, however, that it might not be feasible for employment services to offer ‘training for the identified work role’ in every situation. As the GDG will appreciate the range and scope of the jobs potentially available to adults with autism is incredibly varied.	Thank you for your comment. This may be the case but the only evidence we were only able to recommend IPS as that was where the evidence was.

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							For example, our Prospect service has helped individuals find employment in major banks in a range of technical posts. It is not feasible for them to necessarily assist in training for the identified work role above what would be covered by the recommendation that employment services should offer ‘advice to employers about making reasonable adjustments to the workplace’. We would suggest therefore, that line 20 should state that supported employment programmes should typically include: • Social skills training, workplace expectations advice; work-related behaviours and communication strategies.	
854.	The National Autistic Society	19	NICE /Full	1.4.12/7.8.8.2		24	In a similar point to the one above, we believe that due to the range of jobs and potential locations that adults with autism may be employed in, it would be wise to temper expectations as to what is possible for employment support services to offer. Although we fully appreciate the need for such support: *“I feel the need to improve some key skills such as assertiveness, which may come through workplace training.”* **Adult with autism.** Our experience is that is it not always necessary or appropriate to offer workplace support. As such, we would recommend that line 24 should read: • access to continuing specialist support for the person after they start work , if required	Thank you for your comment. This may be the case but the only evidence we were only able to recommend IPS as that was where the evidence was.
855.	The National Autistic Society	20	NICE /Full	1.4.12/7.8.8.2		25	Our Prospects service works extensively with employers to help with the recruitment, training and retention of staff with autism. This experience has taught us that as well as offering support for the employer before and after an individual starts work, it is also vital to provide autism awareness training and advice for the employer and staff working with the individual. Indeed, this is likely to be the most important factor in determining the success or failure of the appointment. Clearly, it would depend on the employer, individual and position as to exactly who receives this training and advice, but	Thank you, we have amended the recommendation in light of your comment.

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							we believe this should be something that any employment support provider should be able to arrange as standard. As such, we would recommend that line 25 should read: • Autism awareness training and advice for the employer before and after the person starts work.	
856.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.4.1 2/7.8 .82	234	2 5	Employer support - broaden to ASD training for him/work colleagues = ASD sensitive environment. Add advice on how to manage financially, as most will be out of work for long periods, surviving on a limited income.	Thank you, we have amended the recommendation in light of your comment.
857.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.4.1 3/7.3 .7.1	181	7. 3. 7	The language of the recommendation "do not offer facilitated communication to adults with autism.", is rather stark. We have positive clinical experience of the use of e.g. timetable and pictorial choice cards and welcome the support that is given to visual aids elsewhere e.g page 197 at 7.5.7.3. Perhaps the term "facilitated communication" is used in some restricted sense at 7.3.7, we feel there is room for confusion here, please clarify.	Thank you for your comment, the use term 'facilitated communication' refers to a very specific recommendation rather than the wider things you list here. We have added a description of this to the glossary to avoid confusion.
858.	Royal College of Speech and Language Therapists		NICE	1.4.1 3	25		Is there a typo in 1.4.13 where it says "do not offer"?	Thank you for your comment, the use term 'facilitated communication' refers to a very specific recommendation which has been shown to be damaging to people with autism. We have added a description of this to the glossary to avoid confusion.
859.	Hampshire Autistic Society	1 5	NICE / Full	1.7.2 /5.4. 8.18	125	3 4	Need to add a further bullet point: Need to *"Understand the individual to be able to contextualise the behaviour"*.	Thank you for your comments. We feel this is covered by the assessment recommendations and the general principles of care.
860.	Somerset County Council	1 1	NICE versi on	1.4.1 4	25– extr a		There needs to be a specific reference to the Criminal Justice System as a mode of intervention	Thank you for your comment, it would not be appropriate to take up your suggestion here as the CJS is a service setting not a mode of intervention.
861.	Dorset Healthcare University Foundation NHS Trust	1 3	NICE	1.5 and 1.5.3	26		Very contradictory – flips between CMHT's and Specialist Team – Not clear. Need better clarity about developing AS expertise in mainstream services (CTLD's/CMHT's)	Thank you for your comments, we found you suggestion somewhat difficult to follow but we assume it refers to the role of the specialist team. However we should point out that one role for the specialist team is to advise on

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							Allowance for Treatment taking longer	management of Autism in CMHTs and similar services. We therefore do not think the recommendations are contradictory.
862.	Nottinghamshire Healthcare NHS Trust	6 0	NICE / Full	1.5.1 /7.5. 7.1	197	2	Given the concerns the group has expressed about CBT it seems pertinent here to 'consider but be mindful' of potential therapeutic issues, rather than a blanket 'offer a range of interventions'	Thank you for your comment. 'Consider' encompasses being mindful by its very nature, so we feel this would be unnecessary.
863.	South London and Maudsley NHS Trust	2 3	NICE / Full	1.5.1 /7.5. 7.1	197	2	This is an absence of evidence isn't evidence of absence thing. Could you be a bit stronger than you have been, and say that there is no evidence that standard treatments as recommended by NICE don't work where there is also a diagnosis of autism? My experience is that people with ASDs are denied treatments on the basis of their diagnosis of autism (Colleague: 'there's no point - It's just an autistic ritual').	Thank you for your comment. We understand and sympathise with your point but we think some caution is required as we have little evidence of direct effectiveness in this disorder.
864.	The National Autistic Society	1 6	NICE /Full	1.5.2 /7.5. 7.2		6	Again, similar to the point above about training, we would recommend that the word 'basic' is removed. Individuals working with adults with autism should have an understanding of autism that is best described as above basic.	Thank you for your comment, on reflection, and in response to yours and others' comments, the term 'basic' has been removed from this recommendation.
865.	Queen's University Belfast,	8	NICE / Full	1.5.3 /7.5. 7.3 7.9.2	197 236 237	1 9 9- 1 3 2	I find some of the language that is used very dated and objectionable, eg using a deficit model and being culturally not inclusive e.g., using terms as 'plain English', using 'mother' synonymously with 'parents or carers' (page numbers are only some examples there are too many to identify all) etc.	Thank you for your comment, we do not think the language is objectionable and no other stakeholder has raised this point. The GDG was comprised of senior figures in the field of autism in the UK – they are the authors of this guideline and they did not view the language as dated or objectionable, nor was this issue raised by internal NICE reviewers. Additionally, we did not use the term 'mother' synonymously with 'parents or carers'. The term 'mother' is only used in the full guideline when discussing studies in which the participants were mothers, and therefore it was fully appropriate and accurate to use that term.
866.	Hampshire Autistic Society	2 4	NICE / Full	1.5.3 /7.5. 7.3	197	1 7	Add *"tailored to the needs of the individual and focussing on the development of self management strategies".*	Thank you for your comment, the need to promote the person's autonomy and self management is set out in the 'principles of care' section, which should apply to every step of care for people with autism (see recommendation 1.1.4).
867.	Hampshire Autistic	2	NICE	1.5.3	197	1	Add *"Understand individuals' learning methodology".*	Thank you for your comment. We found no

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	Society	5	/ Full	/7.5. 7.3		8		evidence for the self-management strategies.
868.	Northumberland, Tyne & Wear NHS Trust		NICE	1.5.3	26		1.5.3 Augmented communication is limited to a research recommendation. (Section 4.3 on page 41) However, in the form of, for example, picture exchange and object exchange as well as visual information in TEACCH, has a wide usage currently and needs more exploration and guidance. This section might be expanded accordingly	Thank you for your comment. We agree that augmentative and alternative communication interventions are potentially important and this is why they have been included as a research recommendation. However, at the moment there is no evidence to suggest that these interventions cause significant benefit or significant harm and as such a recommendation cannot be justified.
869.	The Royal College of Psychiatrists, Learning Disability Faculty	7 3	NICE	1.5.3	26		1.5.3 Augmented communication is limited to a research recommendation. (Section 4.3 on page 41) However, in the form of, for example, picture exchange and object exchange as well as visual information in TEACCH, has a wide usage currently and needs more exploration and guidance. This section might be expanded accordingly	Thank you for your comment. We agree that augmentative and alternative communication interventions are potentially important and this is why they have been included as a research recommendation. However, at the moment there is no evidence to suggest that these interventions cause significant benefit or significant harm and as such a recommendation cannot be justified.
870.	Worcestershire Health and Care NHS Trust	2 2	NICE	1.6	27- 30		Guidance on the use of medication is very welcome and it appears to be useful for GP's and Psychiatrists.	Thank you for your comments.
871.	Welsh Government		NICE /Full	1.6.1 /8.2. 7.1	266	3	Need to be more specific about who constitutes a suitably qualified and experienced professional	Thank you for your comment. This would be a matter for local implementation.
872.	British Psychological Society		NICE / Full	1.6.1 /8.2. 7.1	267	3	The BPS welcomes the guidance that the benefits of any biomedical intervention should be regularly reviewed but would like to see the first bullet point strengthened by removal of the word "preferably". The BPS does not believe that a biomedical intervention should be used with the aim of changing a target behaviour unless there is an explicit means of determining whether the behaviour does change. We would therefore like to see this sentence read as follows: • *the benefits of the intervention using a formal rating of the target behaviour(s).*	Thank you for your comment. The use of the term preferably relates not to monitoring itself – this is responsibility of all healthcare professionals - but that for some problems no formal scale will exist so we have changed to 'where feasible' to clarify this.
873.	British Dietetic Association	2 8	NICE /Full	1.6.5 /8.12 .7.1	320	1 9	This statement seems much too strong in light of previous lines – p319: 30 – 'To summarise, the evidence for restrictive diets in children with autism is promising.'	Thank you for your comment. This statement has been amended in the evidence to recommendations section in the full guideline.

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							Suggested change: There is insufficient evidence to make a recommendation on the use of dietary modifications, vitamins and minerals in autism, however, emerging evidence is promising, and these interventions are relatively low risk. Dietary modifications could be trialled on an individual patient basis only under the advice and supervision of a registered dietitian. Screening for Coeliac disease is recommended prior to trial of gluten exclusion. Dietary assessment carried out by registered dietitians, alongside relevant blood testing, can identify nutritional deficiencies. Nutritional supplements are often needed to correct deficiencies, whilst dietetic advice on dietary improvements can prevent them recurring. High dose vitamin and or mineral supplementation should be considered a pharmaceutical trial and monitored as such, with care not to exceed safe upper limits as set by the Department of Health. Longer term high dose supplementation is only justified when clear clinical improvement is seen due to relatively unknown risks of long term high dose supplementation. -- To be clear – the way the recommendation is currently worded could mean that adults who are already following a dietary modification are forced to come off it even if it is seen to help (e.g. when living in supported homes). Clinical practice shows us that dietary modifications do help a proportion of children and adults with autism. The mechanism of this is unknown – it is probable that excluding foods that are causing headaches/tummy aches or exacerbating hyperactivity then result in improvements in problematic autistic behaviours. Dietitians are best placed to advise on the appropriateness of dietary modification on an individual case basis – e.g. for an underweight person who has an already self-restricted (fussy) diet, further restriction would not usually be considered, however for someone who eats well and has behaviour to indicate possible gastro discomfort, a trial of dietary exclusion would be indicated.	However, the recommendation remains unchanged based on GDG interpretation of the evidence base.

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874.	WaASP		NICE guide line	1.6.6	28	2 2	Many AS patients sleep by day and are awake all night. Many parents give multivitamin supplements to counter the lack of daylight exposure. It would be helpful to clarify whether this practise is at odds with your recommendation to avoid B6 etc	Thank you for your comment. However, there is no evidence on which to make any recommendations about this.
875.	NCCMH Expert Reviewer	9	NICE / Full	1.6.7 /8.9. 7.1	299	4	You may wish to amend your advice that atomoxetine be considered for use, given the recent medication product warning circulated to all UK doctors (about 'Strattera') that atomoxetine can cause or worsen hypertension.	Thank you for your comment. The recommendation on hyperactivity and use of atomoxetine has now been removed.
876.	Northumberland, Tyne & Wear NHS Trust		NICE	1.6.7	28-29		1.6.7 The recommendation for the use made for the use of atomoxetene on the basis that 13% dropped out of a study of 16 children (ages 5-14 years) of normal IQ (Posey 2006) in comparison to an 18% drop out from a study of 72 children of a mixed ability range (RUPP 2005). The difference in attrition rate is not statistically significant and the extrapolation to adults dubious, particularly as it is acknowledged that paediatric prescribing differs substantially. Nor is there any comment about the conjoint use of neuroleptics with methylphenidate although the practice is frequent and Posey (2006) mentions its potential. The recommendation to use atomoxetene on the basis of a higher adherence rate should be removed although it may remain as a drug that, in children, has been shown to be as effective.	Thank you for your comment. The recommendation on hyperactivity and use of atomoxetine has now been removed.
877.	The Royal College of Psychiatrists, Learning Disability Faculty	8 0	NICE	1.6.7	28-29		**1.6.7** The recommendation for the use made for the use of atomoxetene on the basis that 13% dropped out of a study of 16 children (ages 5-14 years) of normal IQ (Posey 2006) in comparison to an 18% drop out from a study of 72 children of a mixed ability range (RUPP 2005). The difference in attrition rate is not statistically significant and the extrapolation to adults dubious, particularly as it is acknowledged that paediatric prescribing differs substantially. Nor is there any comment about the conjoint use of neuroleptics with methylphenidate although the practice is frequent and Posey (2006) mentions its potential. **The recommendation to use atomoxetene on the basis of a higher adherence rate should be removed** although it may remain as a drug that, in children, has been shown to be as effective.	Thank you for your comment. The recommendation on hyperactivity and use of atomoxetine has now been removed.
878.	Northumberland, Tyne & Wear NHS		NICE /Full	1.6.1 0/8.1	324		The evaluation of testosterone based interventions suggestst the comment that although co morbid hypersexuality may	Thank you for your comment. We do not recommend testosterone regulation for the

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	Trust			4.7.1			occasionally be managed with oral cyproterone acetate or similar antilibidinals where the historical nature of the disorder presents clear sexualised risks, we do not suggest their use for core autism	treatment of the core symptoms of autism.
879.	NCCMH Expert Reviewer	10	NICE / Full	1.6.12-13/ 8.2.8.1-2	267	17	In SIGN 98 we highlighted the evidence that risperidone can cause increased prolactin levels as a specific side effect (section 6.2, page 22; good practice point). I understand that aripiprazole has a prolactin lowering effect. Whilst we don't fully know what increased prolactin does to a patient as a side effect (unless there are external signs such as gynaecomastia etc) it makes clinicians increasingly wary of using risperidone and more inclined to consider aripiprazole in the under 18s. This is advice from Professor Paramala Santosh at Great Ormond Street. Did you look for this kind of detailed evidence re antipsychotic use for ASD in adults?	Thank you for your comment. However, there was no evidence for increased prolactin levels associated with risperidone in the evidence reviewed. However, a general intervention recommendation is included that potential adverse effects of any intervention should be regularly reviewed.
880.	British Psychological Society		NICE / Full	1.6.13/8.2.8.2	267	20	The BPS is concerned that the recommendation in Section 8.2.8.2 about the use of antipsychotic medication places insufficient emphasis on the use of a full functional analysis as part of a multidisciplinary formulation that provides the rationale for the use of antipsychotic medication. (cont'd/…) There are very few Randomised Control Trials (RCTs) identified in the draft guideline. The review of the Tyrer (2008) RCT (p.256, line 10; p.259, line 27) appears to demonstrate that placebo is as effective as antipsychotic medication in the treatment of challenging behaviour. Given the evidence from Tyrer, the BPS would like to see a recommendation that the role of antipsychotics should be limited to the treatment of psychosis rather than of challenging behaviours.	Thank you for your comment. However, we disagree that the recommendations do not place emphasis on functional analysis. In fact, this is a key recommendation for the assessment of challenging behaviour. We also disagree with your interpretation of the TYRER2008 study, as when we included mean and standard deviation scores in meta-analysis, the study failed to provide evidence for significant treatment effects with risperidone. However, a significant treatment effect was found for haloperidol in comparison with placebo for symptom severity/improvement.
881.	The Royal College of Psychiatrists, Learning Disability Faculty	9	NICE /Full	1.6.13/8.2.8.2	267	18	This recommendation seems to arise from an unduly medical model of autism. The studies assessed generally focus on challenging behaviour without considering the underlying cause, and the draft NICE guidance has, to some extent, fallen in to the same trap. Most autism specialists would argue that low dose Risperidone especially DOES have a positive effect on core symptoms, but to accept this requires a conceptual shift to a position where it is acknowledged that anxiety is a core symptom of autism and may underpin other symptoms.	Thank you for your comments, anxiety is not accepted as core symptom of autism and there was no high quality evidence to support the use of resperidone in the management of anxiety. Therefore we could not make a recommendation. We do also in our recommendations address the issue of underlying causes in challenging behaviour; see recommendation 1.7.1 (revised recommendation number 1.2.20).
882.	NCCMH Expert	1	NICE	1.6.1	309	7	As I understand the evidence (from Professor Fred Volkmar),	Thank you for your comment. However, the

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	Reviewer	1	/ Full	4-15/ 8.11. 7.1-2			there are well-designed studies that show that SSRIs are effective in reducing rigid / inflexible behaviour patterns in ASD in children and adolescents (but not in anxiety per se). Did you examine this link (i.e. of possible efficacy of SSRIs in reducing behavioural rigidity?)	evidence you discuss would not have been included as the age of the sample was below 17 years of age.
883.	Northumberland, Tyne & Wear NHS Trust		NICE	1.7	30		For 1.7.Challenging behaviours see earlier points. Include in Psychosocial interventions and include framework for positive value base.	Thank you for your comment. This is set out in person centred care and the general principles sections.
884.	Dorset Healthcare University Foundation NHS Trust	1 4	NICE	1.7	30		Primarily relevant to LD, not high functioning ASD	Thank you for your comment. We agree that the majority of challenging behaviour is in people with LD but we also think the principles set out can apply across the autism spectrum.
885.	Worcestershire Health and Care NHS Trust	2 3	NICE	1.7	30- 32		This section reads as though it is designed for people with Autism who have a learning disability rather than adults with AS. Implementing an intervention suggested outside of a residential setting would be very difficult to achieve. For adults with AS challenging behaviour could surround a long held obsessions that may be highly resistant to change. Other behaviour may require constant monitoring for long periods to enable change to occur. Within current resourcing the goals outlined cannot be obtained. For example changing a person's environment may not be possible i.e. they live in the parents' house and the changes will affect them and other family members. What is needed is dedicated advice on how this type of work can be implemented for people with AS.	Thank you for your comment. We agree that the majority of challenging behaviour is in people with LD but we also think the principles set out can apply across the autism spectrum and they also include consideration of environmental factors and co-existing conditions.
886.	AUTISM ALLIANCE UK	2 4	NICE / Full	1.7.1 / 5.4.8 .17	125	1 9	Assessment of challenging behaviour. This may be outside the expertise of clinicians and it is therefore important to include specialist providers who deal, on a day to day basis, with challenging behaviour	Thank you for your comments we would expect specialist teams to be well placed to address these problems.
887.	British Psychological Society		NICE / Full	1.7.1 /5.4. 8.17	125	2 0	The BPS welcomes the importance given to integrating any assessment of challenging behaviour into a comprehensive assessment of the person. A detailed person-centred plan and an understanding of how the adult with autism makes sense of their environment and of those around them is essential. Such an understanding should lead to the design of an individualised, supportive environment in which the likelihood of challenging behaviour is "designed out". *(cont'd/…)* We would like to see a greater emphasis of this approach to	Thank you for your comment, we agree with this comment and believe that the guideline refers to relevant issues at several points but we have added a specific point about challenging behaviours to the general recommendation about physical environment at the beginning of the guideline.

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							preventative support as an introductory section to recommendation 5.4.8.17	
888.	British Psychological Society		NICE / Full	1.7.1 /5.4. 8.17	125	2 4	*Recommendation 5.4.8.17:* The BPS welcomes the importance given to the need that an assessment of challenging behaviour should be integrated into a comprehensive assessment and that the professional should perform a functional analysis on any specific problem behaviours. However, we recommend that this paragraph should include an additional point to emphasise the importance of the context within which the behaviour occurs. This is recommended as good professional practice when working with adults whose behaviour presents challenges (British Psychological Society, 2004).	Thank you for your comments; we believe we have dealt with this in our recommendations regarding the assessment for challenging behaviour, functional analysis and general recommendations about challenging behaviour.
889.	Nottinghamshire Healthcare NHS Trust	4 4	NICE / Full	1.7.1 /5.4. 8.17	125	3 2	It would be useful to add here assessment of the communication environment, in addition to specific communication difficulties the individual may have.	Thank you for your comment, as communication can be a central issue for people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
890.	The National Autistic Society	2 1	NICE /Full	1.7.1 /5.4. 8.17		2 0- 3 3	The NAS support the GDGs recommendations concerning challenging behaviour, in particular the suggestions made in 7.4.8. One area that NICE may wish to consider adding into the section regarding assessing individuals with challenging behaviour is looking at the impact this challenging behaviour is having on the families/carers. A quote from our consultation is indicative of the problems families that are pushed to the limit by the lack of support they receive: *"[My son's] behaviour became so difficult that we could no longer cope and at one stage he was living in entirely unsuitable emergency B&B accommodation with no proper supervision"* **Parent of adult with autism** Clearly, the assessment should look at the social environment, but the team should also consider the impact this is having on	Thank you for your comments, we agree and have covered this in the assessment recommendations and the recommendations covering the involvement of families, carers and partners.

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							the family and refer as appropriate. We know that the recommendation is made later on (7.9.7.1), but it may be helpful to emphasise the point here.	
891.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.7.1 /5.4. 8.17	125	1 9	The use of the term Challenging behaviour is not entirely consistent with good practice as laid out in the RCPsych CR144 report (referenced above). CR144 lays out clear principles and guidance for assessment, formulation and diagnosis of individuals presenting behavioural challenges and has specific guidance for adults with ASD.	Thank you for your comment, the GDG took an evidence based approach to treatment of challenging behavior in autism. To some extent it will therefore be different from CR144. It is difficult to comment further because you do not specify where you see the problems.
892.	British Dietetic Association	1 3	NICE /Full	1.7.1 /5.4. 8.17	125	2 6	to include poor diet or hydration	Thank you for your comment, an additional recommendation has been added to cover issues relating to diet (see the new recommendation 1.1.9).
893.	Welsh Government		NICE /Full	1.7.1 /5.4. 8.17	125	1 9	The use of the term Challenging behaviour is not entirely consistent with good practice as laid out in the RCPsych CR144 report (referenced above). CR144 lays out clear principles and guidance for assessment, formulation and diagnosis of individuals presenting behavioural challenges and has specific guidance for adults with ASD.	Thank you for your comment, the GDG took an evidence based approach to treatment of challenging behavior in autism. To some extent it will therefore be different from CR144. It is difficult to comment further because you do not specify where you see the problems.
894.	British Dietetic Association	1 4	NICE /Full	1.7.1 /5.4. 8.18	125	3 8	To include nutrition and diet related problems	Thank you for your comment, an additional recommendation has been added to cover issues relating to diet (see the new recommendation 1.1.9).
895.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.7.2 /5.4. 8.18	125	3 8	It might be useful to add some of the more frequent causes of physical distress – toothache, earache, hay-fever	Thank you, the GDG did not feel this level of detail was needed.
896.	The Royal College of Psychiatrists, Learning Disability Faculty	6 3	NICE /Full	1.7.2 /5.4. 8.18	125	3 8	It might be useful to add some of the more frequent causes of physical distress – toothache, earache, hay-fever	Thank you, the GDG did not feel this level of detail was needed.
897.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.7.2 /5.4. 8.18	125	3 4	Melt-downs may be triggered by family members who have not had training in delivering low energy environments - provide them with skills to create an enabling home situation.	Thank you for your comments, the GDG felt this was covered in recommendation 1.7.2 (revised recommendation number 1.5.1).
898.	British Psychological		NICE / Full	1.7.2 /5.4.	125	3 4	*Recommendation 5.4.8.18:*	Thank you for your comments, the GDG felt this was covered in recommendation 1.7.2

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	Society			8.18			Good professional practice (British Psychological Society, 2004) recommends that assessment should include the wider context in which the behaviour occurs, as this is also important. We suggest that this recommendation is amended to read: *Address any identified factors that may act as setting events or may trigger or maintain challenging behaviour ...*	(revised recommendation number 1.5.1).
899.	British Psychological Society		NICE / Full	1.7.2 /5.4. 8.18	126	1	The BPS welcomes the guidance on changing the environment in circumstances where the problems are related to the environment. This is an effective approach for adults with autism who also have a learning disability. We would like to see some additional examples that have particular relevance to adults with learning disabilities. We suggest the following addition to this paragraph: *… changes to the physical environment or accommodations such as wearing earplugs or dark glasses, setting up low arousal environments, reviewing who they live with or the characteristics of the person who provides support*.	Thank you for your comments; we have amended this in light of yours and others' comments.
900.	Sheffield Asperger Syndrome Service	1 8	NICE	1.7.3	31	1 3	1.7.3 "the physical and social environment" should also mention the "sensory environment" when considering and trying to make sense of challenging behaviour	Thank you for your comments; we have amended this in light of yours and others' comments.
901.	Royal College of Speech and Language Therapists	6.	NICE	1.7.3	31		Add "communication ability of the individual"	Thank you for your comment, as communication can be a central issue for people with autism this is covered in a number of other recommendations, see1.1.11, 1.2.2, 1.2.7, 1.2.9 & 1.7.1 (revised recommendation numbers: 1.1.15, 1.2.2, 1.2.7, 1.2.10 & 1.2.20).
902.	Pyramid Educational Consultants	1 0	NICE	1.7.3	31	7	A lack of communication skills can cause challenging behaviours, so please include a bullet point to suggest treatment/intervention to improve communication skills if these aren't presently effective or appropriate for independent living in the community.	Thank you, we have not specified any interventions but expect a functional analysis might indentify this and an intervention developed to address this.
903.	British Psychological Society		NICE / Full	1.7.3 /7.4. 8.1	187	1 7	The BPS is concerned that there is insufficient consideration of "preventative strategies", with an apparent reliance on "reactive strategies" in this section. Current professional practice gives a greater emphasis to avoiding/preventing the onset of challenging behaviour (British Psychological Society, 2004; (Royal College of Psychiatrists, British Psychological Society &	Thank you, we have amended guideline to take into account preventative strategies. There are also a number of recommendations in the guideline which relate both directly and indirectly to this issue, and we feel that if fully implemented would

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							Royal College of Speech and Language Therapists, 2007), rather than relying on responding to such behaviour when it occurs. We would welcome greater emphasis being paid to this aspect of interventions and suggest that the first sentence of section 7.4.8.1 is amended to read: Emphasis should be given to the development of "preventative approaches" to challenging behaviour by supporting the person in suitable environments using carers who adopt person-centred approaches and fully understand the person and their autism. Despite the best efforts to create appropriately supportive environments, some people will still display behaviours that are challenging to those around them. Clearly described "reactive strategies" should be available to guide staff and carers in the event that the person displays the behaviours in spite of the preventative strategies. Base the choice of interventions …	lead to a reduction in challenging behaviour.
904.	South London and Maudsley NHS Trust	2 2	NICE / Full	1.7.3 /7.4. 8.1	187	2 0	Applied behavioural analysis, not functional analysis	Thank you for your comment. We accept that there is no agreement on the definition of terms between different clinical and academic groups. However, the GDG decided to use the term 'functional analysis' as it is in wide use in the NHS. In order to be clear about the nature of any psychological intervention the GDG specify the nature and content of those interventions in the recommendations in order to avoid any confusion in the use of different terms to describe these interventions.
905.	British Psychological Society		NICE / Full	1.7.3 -4 /7.4. 8.1-2	187	1 6	*Section 7.4.8:* The BPS strongly advises that, in line with our current professional guidance (British Psychological Society, 2004; (Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists, 2007), there should be a new section between the current 7.4.8.1 and 7.4.8.2 that describes the importance of "preventative strategies" that "design in" appropriate environmental supports (including the physical building, compatibility issues, appropriate levels of arousal, communication methods,	Thank you, we have adjusted other recommendations to take account of this as we think this should be part of a general approach of the service not just focused on challenging behaviour.

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							consistent support planning, etc.).	
906.	Welsh Government		NICE /Full	1.7.3 /7.4. 8.1	187	2 4	Again reference should be made to RCPsych CR144 (see above)	Thank you for comment, it would not be appropriate to refer to this document in a clinical recommendation.
907.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.7.4 /7.4. 8.2	187	2 4	Again reference should be made to RCPsych CR144 (see above)	Thank you for comment, it would not be appropriate to refer to this document in a clinical recommendation.
908.	Nottinghamshire Healthcare NHS Trust	5 9	NICE / Full	1.7.4 /7.4. 8.2	187	3 7	A cross reference from challenging behaviour to communication is needed here – perhaps a recommendation including an understanding of the person's speech, language, communication and interaction needs, as well as equal weight given to the communication and interaction skills of other people in the environment.	Thank you but this has been a general approach to assessment throughout the guideline and we need to avoid being repetitive.
909.	Institute of Psychiatry, Kings College London	2	NICE / Full	1.7.4 /7.4. 8.2	187	2 7	To add the recommendation that the behaviour or relevant clinical phenomena should be subject to appropriate systematic measurement pre and post the behavioural intervention to provide objectivity about whether the agreed outcomes are or are not being met.	Thank you, we have adjusted the recommendation in light of your comment.
910.	British Psychological Society		NICE / Full	1.7.4 /7.4. 8.2	187	2 4	Recommendation 7.4.8.2 appears to be setting out guidelines for the development of reactive strategies based upon behavioural principles. These are not entirely consistent with Department of Health (2007) and professional guidance for such interventions (British Psychological Society, 2004; Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists, 2007). We therefore suggest that a number of changes be made to this recommendation, as follows: *Offer psychosocial interventions based on behavioural principles, and informed by a functional analysis of behaviour and an integrated formulation that sets out the rationale for the intervention as initial treatment for the management of challenging behaviour. Interventions should:* • *clearly identify the behaviours with agreed outcomes* • *clearly link to outcomes that aim to improve quality of life*	Thank you, we have adjusted the recommendation in light of your comment.

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							• *identify and modify specific factors about the environment, communications or interactions with other people that may trigger or maintain the behaviour* • *have a clearly defined intervention strategy that is based upon an integrated formulation that sets out the rationale for the intervention* • *if the intervention includes changes that are made as a consequence of the behaviour occurring, ensure that it is clearly described how carers should respond on demonstration of the desired behaviour* • *have a specified timescale to meet treatment goals (modifying intervention strategies that do not lead to change within a specified time).*	
911.	Pyramid Educational Consultants	1 1	NICE	1.7.4	31	1 7	We're pleased that behavioural principles are recommended in the guidelines so clearly.	Thank you for your comment.
912.	Worcestershire Health and Care NHS Trust	2 4	NICE	1.8	32		Support for families is very welcome but will require greater co-operation across all areas of health and social care. In our area there is no respite provision for adults. This would be very useful but again how can it be resourced.	Thank you for your comment. This is a matter for local implementation.
913.	Hampshire Autistic Society	2 3	NICE / Full	1.7.4 /7.4. 8.2	187	2 4	Add a further bullet point: *"Focus on self management strategies for the individual*".	Thank you for your comment, the need to promote the person's autonomy and self management is set out in the 'principles of care' section, which should apply to every step of care for people with autism (see recommendation 1.1.4).
914.	Dorset Healthcare University Foundation NHS Trust	1 5	NICE	1.8	32		Where are sensory interventions? Need to consider voluntary sector	Thank you for your comment, the interventions recommended were based on the evidence found.
915.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.7.5 /8.2. 9.1	267	2 4	Again reference should be made to the RCPsych CR144 which contains guidelines on the use of medication for challenging behaviour – also the DATABID guidelines produce by University of Birmingham.	Thank you for your comment, it would not be appropriate in a NICE guideline to reference other guidance which we have not formally reviewed – to review these would be outside the scope.
916.	British Psychological Society		NICE / Full	1.7.5 /8.2. 9.1	267	2 5	The BPS would find it helpful for it to be re-emphasised here that, as stated in Section 7.4.8.2 (p.187), psychosocial interventions should be offered as the initial treatment for challenging behaviour. We therefore recommend that the first	Thank you for your comment, significant revisions have been made to this recommendation following your and others' comments.

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							sentence of Section 7.8.4.2 be repeated at the start of Section 8.2.9.1, using the form of words we have recommended in Point 21, above: *Offer psychosocial interventions based on behavioural principles, and informed by a functional analysis of behaviour and an integrated formulation that sets out the rationale for the intervention as initial treatment for the management of challenging behaviour.*	
917.	British Psychological Society		NICE / Full	1.7.5 /8.2. 9.1	267	2 6	There is some ambiguity about the opening sentence that could be interpreted as providing advice that psychotropic medication should always be used. The BPS does not believe that this is the intended guidance and therefore suggests modifying this sentence to read: *Psychotropic (anxiolytic, antidepressant or antipsychotic) medication should normally only be used in conjunction with psychosocial interventions. Only consider psychotropic medication as the main treatment approach when:* • *psychosocial …*	Thank you for your comment. We have revised the recommendation in light of your and others' comments.
918.	Northumberland, Tyne & Wear NHS Trust		NICE	1.7.5	32		Include family approaches in psychosocial interventions.	Thank you, however we could identify no evidence for what you suggest and you provide none in your comment.
919.	Association Directors of Adult Social Services	2 1	NICE /Full	1.8.1 /7.9. 7.1	240	3 9	Need to state that a Carers Assessment is an entitlement to the main carer, rather than 'offer families and carer an assessment of their own needs".	Thank you for your comment. Recommendations 1.1.13 and 1.1.14 (revised recommendation number 1.1.17 & 1.1.18) both state that carer's should be informed of their right to an assessment, and should be support to access one.
920.	Hampshire Autistic Society	2 8	NICE / Full	1.8.1 /7.9. 7.1	241	4	Add: *"with clear choices / options for the future*".	Thank you for your comment, however this recommendation is about services, the point you make is about service users and therefore would not be an appropriate addition here.
921.	Autism Rights Group Highland	1 2	NICE	1.8.2	33	1	no mention of partners; parent support groups are not appropriate for this group.	Thank you for your comment. We have added partners to this and other recommendations focused on families and carers.
922.	Hampshire Autistic Society	2 9	NICE / Full	1.8.2 /7.9.	241	7	Add: *"and generic autism aware services*".	Thank you for your comment, the GDG felt this point is sufficiently covered by the

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				7.2				existing recommendation.
923.	AUTISM ALLIANCE UK	3 1	NICE / Full	1.9.1 / 6.4.7 .5	146	3 1	6.4.7.8 We are not entirely sure of the wording here, but we fully support the concept that someone with autism has a single point of contact and that, within reason, this contact is the case-coordinator. Having a single point of referral is ambiguous: if we take the example of a specialist autism and diagnostic centre (where one exists) this could be the single point to which people are referred for specialist services; but the referrals are likely to come from various sources, including GPs, the criminal justice system, etc. Specialist centres may (as is the case with at least one such centre) not accept self-referrals unless there is a pre-existing diagnosis. This recommendation would benefit from being lengthened and explained further	Thank you for your comment, but we feel the wording as it stands is clear and would not benefit from expansion.
924.	The National Autistic Society	1 2	NICE /Full	1.9.1 /6.4. 7.5		2 3 – 3 4	Linked to the point above about prevention, we believe care pathways should highlight their role in preventing people going into crisis. A key goal of these pathways should be to ensure people receive the support they require, before their support needs escalate. The NAS believe it would be helpful for the GDG to add into this section a line stating pathways should be: *Encouraging services to act early to ensure the needs of adults with autism – and their families and carers – do not escalate.*	Thank you for your comment, this point is already covered in recommendation 1.2.13 (revised recommendation number 1.2.15).
925.	Dorset Healthcare University Foundation NHS Trust	1 6	NICE	1.9.1	33		Development of pathways: Needs to include clear routes for access to appropriate mainstream services. Care Pathways: Access to social care services in the way this is anticipated is restricted by locally agreed eligibility criteria and not everyone who has autism would necessarily meet these and be entitled to care management provisions and support.	Thank you for your comment, what you set out is regrettable but is a matter for local implementation. Unfortunately eligibility criteria are outside our scope.
926.	Prison Reform Trust	1 3	NICE	1.9.1	33	1 3	1.9.1 Developing local care pathways: pathways should be flexible, such that they can continue during an individual's contact with criminal justice services, including for individuals remanded into, or sentenced to, prison.	Thank you for your comment, this is important and we feel it is already set out in the guideline.
927.	Nottinghamshire Healthcare NHS Trust	4 5	NICE /Full	1.9.2 /6.4. 7.6	146	1 4	It would be useful for the guideline to expand on transitional issues and how to address these. It would also be useful to make reference here to the NICE guideline for children and young people with autism (2011) and DoH (2011) Implementing Fulfilling and Rewarding Lives.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the*

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								autism spectrum'. We have amended the preface of the full guideline to highlight the links between the documents.
928.	ADRC	8	NICE /Full	1.9.2 /6.4. 7.6	146	6	ADRC welcomes the recommendation to develop a clear policy and protocols as part of a local autism care pathway.	Thank you for your comment.
929.	Ambitious about Autism	7	NICE	1.9.2	34 of 50		This section must reflect the multi-agency approach that is suggested elsewhere in the guideline. We recommend the word 'care' is taken out of the 4th bullet point, so that it refers to 'the integrated delivery of services across all settings' rather than just care settings. We think the 5th bullet point, around transition, could be strengthened by referring to the need for strong links between adult and childrens services, and the need to use data from childrens services to strategically plan services for the adults who will be coming through the system.	Thank you for your comments. We agree the issue of transition is an important one, and will be dealt with in the forthcoming NICE guideline '*Autism: the management and support of children and young people on the autism spectrum'.* We have amended the preface of the full guideline to highlight the links between the documents.
930.	Hampshire Autistic Society	1 7	NICE / Full	1.9.2 /6.4. 7.6	146	2	Autism Strategy *and "delivery"* groups should be......	Thank you for your comment, we do not cover or use delivery groups in this guideline so will not include it.
931.	WaASP		NICE guide line	1.9.2	34	3	See our point 4 above – we recommend that the lead professional be a psychologist.	Thank you for your comment. This is a matter for local implementation.
932.	Prison Reform Trust	1 4	NICE	1.9.2	34	1 0	1.9.2 Organisation and delivery of care: the development of national criminal justice liaison and diversion services by 2014 means there is a better chance that people who come into contact with criminal justice services will have their support needs recognised and met, including people on the autism spectrum. It would be helpful, therefore, to include *'criminal justice, including liaison and diversion and Appropriate Adult services'* in the 3rd bullet point, to read: 'making sure the relevant professionals (health and social care, housing, employment, *criminal justice, including liaison and diversion and Appropriate Adult services* and the third sector) are aware…'	Thank you for your comment, however this degree of specificity has not been accorded to other groups and would therefore unbalance the recommendations.
933.	Autism West Midlands	6	NICE /Full	1.9.3 /6.4. 7.7	146	1 7- 3 0	The list at 6.4.7.7 is largely of groups with protected characteristics. Sexual orientation is notably missing from the list and we suggest that it should be included.	Thank you for your comment. We have included transgender people but there was no evidence of under-recognition of autism in other sexual groups.
934.	Somerset County Council	1 3	NICE versi	1.9.3	35 1.9.	4	Should mention partner/spouse specifically as a different perspective may be needed	Thank you for your comment. We have amended the whole guideline to include

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			on		3			partners with families and carers.
935.	WaASP		NICE guide line	1.9.3	34	2 6	We are aware of the higher prevalence of AS among men. Nevertheless the specification of 'women' to be included seems a little odd, as expressed. Of course women must be included. Equally, must men.	Thank you for your comment, the reason we have picked out women is due to the under diagnosis of them.
936.	Somerset County Council	1 2	NICE versi on	1.9.3	34 1.9. 3	2 7	Should have a separate section regarding gay/lesbian/bi	Thank you for your comment. We have included transgender people but there was no evidence of under-recognition of autism in other sexual groups.
937.	Somerset Partnership NHS	1 3	NICE	1.9.3	34	1 8	People from gay, lesbian and bi communities need to be included. Also partners with autism	Thank you for your comment. We have included transgender people but there was no evidence of under-recognition of autism in other sexual groups.
938.	Autism Rights Group Highland	1 3	NICE	1.9.7	36	1	The autism strategy group should include autistic peoples organisations ((ie organisations run and controlled by autistic people).	Thank you for your comment. This is a matter for local implementation.
939.	Dorset Healthcare University Foundation NHS Trust	1 7	NICE	1.9.7	36		"minimise the need for transition between different services or providers": surely the way to minimise transfer would be for persons with autism and LD to stay within the LD teams rather than transfer to a specialist autism team.	Thank you for your comment, this may be the case but that is not the point of this recommendation which is about the effective operation of the care pathway.
940.	ADRC	1 4	NICE /Full	1.9.7 /6.4. 7.12	147	1 6	ADRC welcomes the recommendation that services should be built around the care pathway and not the pathway around the service.	Thank you for your comments.
941.	Cochrane Collaboration Developmental, Psychosocial and Learning Problems Group		NICE /Full	1.9.8 /6.4. 7.8	146	1 3	System currently mitigates against self-referral - only deterioration into crisis and comorbid mental health problems open diagnostic doors.	Thank you for your comment. We hope this guideline will improve this situation.
942.	WaASP		NICE guide line	1.9.8	36	1 5	Does your inclusion of 'self-referral' include self-referral for diagnosis?	Thank you for your comment, yes it does.
943.	Worcestershire Health and Care NHS Trust	2 5	NICE	1.9.8	36		Self referral should not be encouraged as the individuals will not have had any screening or know the type of information that is required. It also could lead to risks not being highlighted that referrals though GP, etc would identify.	Thank you for your comment. We are not sure this will be the case. People with autism have had obstacles which have got in the way of effective services provision, and other self –referral system such as in IAPT have not generated the problems you describe. Services may develop triage systems which will address your concerns.

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944.	Dorset Healthcare University Foundation NHS Trust	1 8	NICE	1.9.8	36		Self referral to Specialist Team not appropriate – needs to be through the GP. Self-referral would result in over-referral from people who are seeking a diagnosis as an alternative to another diagnosis, and for whom an objective screen through a GP would be appropriate first.	Thank you for your comment. We are not sure this will be the case. People with autism have had obstacles which have got in the way of effective services provision, and other self –referral system such as in IAPT have not generated the problems you describe. Services may develop triage systems which will address your concerns.
945.	Somerset County Council	1 4	NICE versi on	1.9.8	36 1.9. 8	1 3	Should there be a screening service before referral, such as the Community Mental Health Team? There are issues with capacity: would there be resources made available to establish a discrete team to deal with this to avoid a client being passed around?	Thank you for your comment. This would be a local implementation issue.
946.	Nottinghamshire Healthcare NHS Trust	4 6	NICE / Full	1.9.8 / 6.4.7 .8	146	3 1	We are unsure about the suggestion for self-referral, particularly where there will be high demand for services, and a need to gate keep.	Thank you for your comment. We are not sure this will be the case. People with autism have had obstacles which have got in the way of effective services provision, and other self –referral system such as in IAPT have not generated the problems you describe. Services may develop triage systems which will address your concerns.
947.	South London and Maudsley NHS Trust	2 0	NICE / Full	1.9.8 / 6.4.7 .8	146	3 1	Don't agree. Should be general psychiatric services – which should be in a position to make the diagnosis in an obvious case, as I have indicated above. There should then be referral on within local services, ideally to a team as you describe, for the people with a possible partial phenotype or where the diagnosis is for some reason complex or disputed. Also, if you are talking about a single point of referral, you are going to increase the case load to this 'hub' which will require more resources (because the diagnoses in obvious cases are not being made in CMHTs). We need to live 'in the real world' on this one; in the current NHS climate, these resources will not be made available, so fewer diagnoses will be made. Sometimes people will be referred with 'please see and assess' – with no suggestion that the referral is for assessment for autism. Are you suggesting that this person should be referred on from a 'general assessor' (e.g. a consultant psychiatrist) even where the diagnosis is obvious and supported by a good	Thank you for your comment. We have amended our recommendations to be clear about the roles of the specialist and generalist services. Our recommendation for a single point of referral is to ensure that individuals who need specialist assessment or treatment are referred on to specialist services where they might be most effectively assessed and treated. Currently many adults with autism are not identified nor referred for specialist assessment. The requirement in the Autism Act suggests that local commissioners will not be able to avoid supporting provision of services and it is this context that the recommendation is made. Clinical guidelines set out standards that

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							developmental history. You are also requiring those who refer (often GPs) to adopt a different pattern of referral for a specific disorder (when they would be used to simply referring to the CMHT) and this will also be an 'informatic' bar to referral leading to decreased rates of diagnosis. I also disagree with the single point of referral idea on a general ground. Differentials between different behavioural/psychiatric disorders are often unclear in clinical practice within the whole sphere of our work. Where they are, appropriate avenues should be sought to clarify issues (eg referral to someone with special expertise/tools). There is no logic in making people with autism a special case (unless you think the need to acquire developmental information or ask an informant makes them different – with which I would disagree).	should be aspired to and funding issues should not reduce the expectations made by these guidelines. Local services should determine the precise protocol for the operation of the single referral point.
948.	Sussex Partnership NHS Foundation Trust	7	NICE / Full	1.9.8 /6.4. 7.8	146	3 1	We feel the recommendation for self-referral to specialist services would create very long waiting lists without investment in sufficient triage practitioners.	Thank you for your comment, this may be the case but it will be for local services to address. Given the very poor general provision of services for people with autism the guideline may well result in increased demand for services.
949.	AUTISM ALLIANCE UK	3 2	NICE / Full	1.9.8 /6.4. 7.8	147	3 1	Research recommendation. We endorse this recommendation, though we would suggest substituting the word "outcomes" for the word "care". Separately, there needs to be objective longitudinal research into outcomes for people with autism. As an Alliance of specialist autism charities, we believe – based on long experience and on much anecdotal evidence – that early specialist intervention has benefits in the quality of life for the person with autism and, in the medium and longer term, to public funds. We would be more than happy to assist in a properly established longitudinal study.	Thank you for your comment but the purpose of research is assess the potential impact of an intervention, and so it is important to measure outcomes.
950.	Brighton and Hove City Council	7	NICE versi on	1.9.9	36	1 5	Amend 'the specialist autism team' to 'autism specialists'	Thank you for your comment, the GDG took view that such assessment was best provided in context of an MDT so would be easier to access (where needed) for the assessment of co-existing conditions and other such problems.
951.	Nottinghamshire	2	NICE	1.9.9	66	3	Multiple references are made throughout the guidance in	Thank you for your comment. We have

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	Healthcare NHS Trust	0	/Full	/4.3.8			relation to suitable environments for adults with autism. It would be useful to include any related to research and specific environmental modification guidance concluded from the research evidence.	added a new recommendation on adaptations to the physical environment (1.1.8).
952.	Dorset Healthcare University Foundation NHS Trust	19	NICE	1.9.10	36		Case co-ordination – huge issue if Specialist Team is small. If co-existing issues (LD or MH), they should be case-coordinated by that team.	Thank you for your comment. This is a matter for local implementation.
953.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.1.10/6.4.7.4	145	9	The multidisciplinary team should be a real (as against 'virtual') team whose members should be able to meet and work together on common tasks.	Thank you for your comment, we agree.
954.	Northumberland, Tyne & Wear NHS Trust		NICE /Full	1.1.10/6.4.7.4	145	9	There must be concern that establishing a multidisciplinary autism team will encourage the local adult mental health services to avoid taking responsibility for developing their knowledge of and expertise in autism. It would be helpful to emphasise that the presence of autism does not absolve adult mental health from its responsibility to provide an effective service for all	Thank you for your comment, one of key roles of the Specialist team is to develop local staff skills including those in CMHTs.
955.	The Royal College of Psychiatrists, Learning Disability Faculty	67	NICE /Full	1.1.10/6.4.7.4	145	9	**6.4.7.4** The multidisciplinary team should be a real (as against 'virtual') team whose members should be able to meet and work together on common tasks.	Thank you for your comment, we agree.
956.	The Royal College of Psychiatrists, Learning Disability Faculty	69	NICE /Full	1.1.10/6.4.7.4	145	9	**6.4.7.4** There must be concern that establishing a multidisciplinary autism team will encourage the local adult mental health services to avoid taking responsibility for developing their knowledge of and expertise in autism. It would be helpful to emphasise that the presence of autism does not absolve adult mental health from its responsibility to provide an effective service for all	Thank you for your comment, one of key roles of the Specialist team is to develop local staff skills including those in CMHTs.
957.	British Dietetic Association	4	NICE /Full	1.1.14/4.3.11.4	73	12-27	this seems a contradiction in terms – if the Autistic person does not want his family involved then why the following points as this would be disrespecting his/her wishes for which there may be justified reasons!	Thank you for your comment we agree, but providing general information does not involve the disclosure of a diagnosis.
958.	Somerset County Council	15	NICE version	1.9.11	37 1.9.11	5	Recognise that issues will also apply to those in Extra Care Housing which need to be specifically addressed	Thank you for your comment.
959.	Craegmoor	6	NICE	1.9.11	37	7	Where a small community based unit is referred to I think it would be beneficial to state the number of beds that is considered small….ie 3 / 4 to prevent a 5 /6 bedded unit being built on and extended and becoming a 12 bedded unit in the	Thank you for your comment. We have amended the recommendation to specify this in light of your comments.

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							community……	
960.	Northumberland, Tyne & Wear NHS Trust		NICE	1.9.1 1	37	5	Consider use of short term inpatient assessment and treatment for minority. Potentially include short break/respite social care..	Thank you, however we could identify no evidence for what you suggest and you provide none in your comment.
961.	Autism Rights Group Highland	1 4	NICE	1.9.1 1	37	6	Care should be taken that people are placed with others that they genuinely want to live with, or if they chose to live alone this should be respected.	Thank you for your comment, we agree and this should be part of a person centred care approach.
962.	South London and Maudsley NHS Trust	2 1	NICE / Full	1.9.1 1/ 6.5.1 0.1	167	1	I suggest 'training in awareness signs of co-morbid mental health difficulties' given the rates of MH problems in this group of people?	Thank you for your comment, unfortunately the specifics of training is outside the scope of our guideline.
963.	AUTISM ALLIANCE UK	3 8	NICE / Full	1.9.1 1/ 6.5.1 0.1	167	3-5	Environment: people with autism may very well benefit from a structured environment, but the level of this varies, and it is not safe to assume that everyone with autism has the same needs. This recommendation could be seen to perpetuate the concept – recognised as being wrong – that people with autism are a homogeneous group. It could contribute to a 'one size fits all' mentality amongst commissioners, which could potentially be damaging to people with autism. Collaborative approach: it would be sensible to note (in the recommendation) the importance of bespoke communication and understanding tools that can facilitate effective communication with people with autism. Without an awareness of people's needs in relation to expressive and receptive language and the knowledge to check understanding, the collaborative approach – even with good intentions – can produce misleading results and poor outcomes. Development and maintenance of interpersonal and community living skills: development of these skills requires trained and caring staff who know how to support somebody to acquire a skill or strategy that can then be used independently. Staff need to be aware of what skills and strategies are useful to a person with autism and how to support their development. To do this they also need to be self aware and be able to change their own approaches (because people's needs are different) and be aware of the disabling consequences of over direction. We believe that this recommendation, as written, is worryingly loose, because good intentions are not a substitute for trained staff using appropriate strategies.	Thank you for your comment, this recommendation is based on the evidence we have. As you say needs to be varied according to each individual.
964.	Hampshire Autistic	1	NICE	1.9.1	167	6	Add *"and support the individual to develop strategies of self*	Thank you for your comment, the need to

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	Society	8	/ Full	1/6.5 .10.1			*management and skill development"*.	promote the person's autonomy and self management is set out in the 'principles of care' section, which should apply to every step of care for people with autism (see recommendation 1.1.4).
965.	AUTISM ALLIANCE UK	3 7	NICE / Full	1.9.1 1/6.5 .10.1	167	2	"If residential care is needed for adults with autism it should usually be provided in a small community-based unit". As noted earlier, the evidence for this recommendation comes exclusively from services which are not autism-specific. That makes the recommendation unsound. People with autism may experience sensory differences which can make smaller or larger environments better or worse for the particular individual. The concentration should be on what works for the individual (accepting that all people with autism are different), rather than on a schematic model which will suit some (but not all) people with autism. We also note that the right to choose is embodied within the Mental Capacity Act.	Thank you for your comment. The GDG considered very carefully whether or not to extrapolate from a learning disabilities population when considering recommendations for residential care. Given the significant proportion of people with autism and learning disabilities in residential care the GDG considered this an appropriate extrapolation in line with the agreed methods. In developing the recommendations for this section the GGD had in mind the needs of people with autism with all ranges of intellectual ability.
966.	Hampshire Autistic Society	1	NICE / Full	1.9.1 1-14/ 6.5.1 0.1-4	Ge ner al		Our major comment on the generally excellent NICE draft guideline is the lack of inclusion of expert providers in the two major groups set out in the guideline: the local multi-agency strategy group and the specialist community-based multidisciplinary autism team. We do not see how these groups can work effectively without including specialist providers. Without labouring the point too far, the generally very strong draft guideline is self-evidently weakest in Section 6: Principles and practice for the effective organisation and delivery of care. This is partly because of the acknowledged lack of outcome-based evidence, but partly, we would suggest, because of the low representation of specialist providers in the guideline development group. The draft guideline states on two occasions that the group contains "a representative from a service organisation". That is not in any sense to criticise the representative or the service organisation, but it does indicate a less than comprehensive understanding of the practical aspects of specialist care. In particular, the recommendations on page 167 [6.5.10 Recommendations] are basic in the extreme. We would view	Thank you for your comments. The GDG are content with the membership of these groups. At a local level additional staff from a range of organisation may be appointed in addition to the core group we recommend, but this is more appropriate as a local decision and not one for the GDG. The guideline states that there was *a representative from a service user organisation* and not a service provider organisation.

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							these as a very low baseline. It is not clear from the recommendations that a residential environment as described goes far enough in enabling and developing the skills of the person with autism. Our other major concern is the assumption that the Care Quality Commission (CQC) will monitor the effective implementation of the guideline. CQC has a vast and multi-faceted remit, and therefore it is not a criticism to state, as is the case, that CQC has not demonstrated significant knowledge or capability in the field of autism; and nor is it, at least at present, able to demonstrate expertise in reviewing organisational structures or the implementation of complex proposals across different agencies. The proposal to add the review of the guideline to CQC's already massive remit would take it into areas which are beyond its capability. We would therefore recommend the National Audit Office (NAO) as a better choice of monitor. The NAO has the intellectual grasp and the ability to see both the wood and the trees to carry out this task, and has also demonstrated substantial knowledge and understanding of autism. The NAO will presumably wish, in any event, to review the way in which the guideline is being implemented, and therefore work done by CQC might duplicate work by NAO at unnecessary cost to public funds. Our main additional recommendation is that research needs to be carried out on outcomes for people with autism. This is difficult to structure, because of the varying nature of autism and the highly variable needs of the different client groups within the spectrum. Nonetheless, it should be possible to identify cohorts and conduct longitudinal studies identifying progress, or lack of progress, in increases/decreases in medication, increases/decreases in episodes of challenging behaviour; and the extent to which adults who have previously been sectioned are able to live outside secure accommodation or are sectioned again. These are (in one sense) elementary numerical measures. However, they should be guides to the efficacy of practice in different care/support environments. In other words, they will help to show what works.	The general principles of care section sets out very clearly that these issues should be addressed in every setting. The CQC has a formal role in the monitoring of all care settings – it is not within the remit of the guideline to suggest a revision of this role. Please see our previous comment and do note the GDG included members with considerable experience of working with residential services. Thank you, we will consider this comment when developing our research recommendations but what you set out is a broad strategy for research and does not fit with a specific research recommendation. All of our research recommendations have been explicit about the focus on outcomes.
967.	British		NICE	1.9.1	167	5	Recommendations 6.5.10.1 to 6.5.10.4 appear to be promoting	Thank you for your comment, we agree and

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	Psychological Society		/ Full	1-14/ 6.5.1 0.1-4			a model of 'residential care' and describe care models in terms such as "units". It is expected that, increasingly, people who require support will live in supported living options with input from Personal Assistants. The BPS recognises that the research literature on which these recommendations are made pre-date Supported Living, but we feel that this model should be mentioned as a form of individualised small scale housing in the community. We therefore recommend that these sections are amended to reflect these changes. The BPS supports the guidelines about how support should be provided.	have amended the recommendation to be clear that some people would live in individual accommodation with the option of considerable support.
968.	AUTISM ALLIANCE UK	35	NICE / Full	1.9.1 1-14/ 6.5.1 0.1-4	167	1-25	Recommendations. We question the unevidenced preference for small community-based units. Our experience is that the key factor in successful outcomes is skilled staff in a caring environment. It is possible to have a caring environment with good outcomes in services caring for 20 residents. Conversely, it is possible to have very bad outcomes in services caring for four or five residents. Size is one factor, but is not a conclusive factor. We would recommend a complete review of these recommendations and would be happy to give more detailed views in any revision process. More detailed comments are given below.	Thank you for your comment. The preference for small community-based units is based on the review of the learning disabilities evidence. We accept that good outcomes can be obtained in large units but the GDG took the view that it was more likely to be the case that good outcomes would be obtained in small units. The GDG noted that there was no evidence to support the provision of larger units specifically for people with autism and in their expert opinion smaller unit were to be preferred. We have revised the evidence to recommendations section to more fully reflect these issues.
969.	AUTISM ALLIANCE UK	36	NICE / Full	1.9.1 1-14/ 6.5.1 0.1-4	167	1-25	Detailed comments Environment and the groupings of people are less important than understanding by staff of the individual person with autism. Staff understanding of the individual should be informed by the thinking patterns of the individual, the communication preferences of the individual and the sensory differences of the individual. As autism is a heterogeneous condition, this will vary from person to person. Thinking patterns of people with autism differ considerably from the neurotypical population. This makes the support they require very different from the rest of the population. The nature of autism makes extrapolation from the experiences and	Thank you for your comment. However, staff training is outside the scope of this guideline and is a matter for local implementation.

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							outcomes of other groups of little value, and very possibly of negative value. Services for people with autism should explicitly recognise the susceptibility of the autism population to over direction. Over-direction can have disabling consequences for the person with autism, who may, as a result, fall far short of his or her potential. It is of crucial importance that services for people with autism go beyond "containment" and focus on "enablement". Services for people with autism should also avoid an over-concentration on behaviour, and should instead concentrate on analysing the underlying causes of the behaviour (which can include the sensory environment and the behaviour of staff).	
970.	AUTISM ALLIANCE UK	42	NICE / Full	1.9.1 1-14/ 6.5.1 0.1-4	167	1-23	Key considerations for the Guideline Development Group to consider • Autism affects people uniquely • It is 'detail' that distinguishes a good autism service • People with autism are extremely vulnerable to over-direction and control • The consequences of this are often unseen or misunderstood • There is a lack of understanding of the issues relating to communication • There is often an over focus on behaviour • There is a lack of knowledge of effective practice for people with autism • The thinking patterns of people with autism are not understood and are not factored into commissioning or service delivery • There is an over focus on a disabling model of autism: i.e. what people cannot do, rather than recognising skills and strengths and utilising these to offset areas of difficulty.	Thank you for your comment, we agree these are important issue but think many of these issues are dealt with in the guideline. We should point out that the majority of GDG members are active practitioners in the field.

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							The recommendations would benefit from practitioner involvement and a more detailed picture of the approaches, systems and culture necessary to deliver an effective service to people with autism.	
971.	The National Autistic Society	1 4	NICE /Full	1.9.1 1/6.5 .10.1		3	The NAS support the recommendation that, for those that need it, individuals with autism in residential care should be placed in small community-based units. We would recommend that the word 'local' is also added to this sentence. In our experience, many local authorities and PCTs place people with autism in unnecessary out-of-area residential and inpatient services. The National Audit Office's research on services for adults with autism found that 50% of authorities commissioned some services out of area. However, over 90 per cent were unable to give figures for expenditure on out-of-area inpatient services for adults with autism, and over two thirds were not able to estimate their expenditure on out-of-area residential care for adults with autism. This is unacceptable. On average, out-of-area placements will often be considerably more costly than local placements. • A study of high-cost (over £70,000 per annum) services for people with learning difficulties and challenging behaviour in five London boroughs in 2006 found that the mean cost of out-of-borough placements was £106,000 (range £70,000 to £258,000), compared with a mean cost for in-borough placements of £98,000 (range £70,000 to £195,000). • A 2006 study in the West Midlands found that the average annual cost for those with complex mental health needs placed out-of-area was £98,000, compared with an average in-area cost of £75,000. The average out-of-area cost for those with severe learning disabilities was £47,000, compared with an average in-area cost of £43,000.	Thank you for your comment we have amended the recommendation in line with your suggestion.

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							Furthermore, there are obvious negative implications to placing adults with autism in a local authority away from where their friends and family live and the community that they are familiar with. While the NAS acknowledges that in some cases people with especially complex needs require specialist resources that it may not be reasonably expected for all local authorities to provide, the percentage of adults being placed out-of-area due to a lack of basic autism provision is too high, and is both unnecessarily expensive and a burden on individuals and their families. In a similar vein, we also believe that although it is right to talk about those that need support in residential setting, this guideline should recommend that it is preferable for individuals to be supported to live independently in the community or in supported living accommodation.	
972.	Nottinghamshire Healthcare NHS Trust	50	NICE /Full	1.9.12/6.5.10.2	167	14	Again it would be useful to consider recommendations from research regarding what these environments should look like (e.g. Brand, A (2010) 'Living in the Community. Housing Design for Adults with Autism').	Thank you for your comment. We agree this could be a useful document for future researchers in the area.
973.	The National Autistic Society	15	NICE /Full	1.9.12/6.5.10.2		8	Again, we strongly support the recommendations in this area. Our only suggestion would be to also add the word 'personal' to this sentence. As this guideline emphasises so well, individuals need to be supported in a personal way and be able to make choices about their care and support. It may be helpful, therefore, to re-emphasise the point here.	Thank you for your comment. We feel that the point you raise is covered by this recommendation's focus on autonomy and choice.
974.	AUTISM ALLIANCE UK	39	NICE / Full	1.9.12/ 6.5.10.2	167	7-9	Residential care environments should include activities that are structured and purposeful, clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomous action. We recognise that this approach will be helpful to many people with autism. However, "many" is not the same as "all". The recommendation again appears to be based on the wrong assumption that people with autism are a homogeneous group. There is also no explicit mention of involving service users in choosing their activities: the recommendation as drafted could be met by a rigid timetable of activities deemed to be suitable	Thank you for your comment, the recommendations on residential service should not be seen in isolation the full range of interventions in this guideline, and the wider principles set out at the beginning of the guideline. People with autism living in supported accommodation of any kind should not in any way limit their access to these interventions.

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							for the person with autism. This may simply be a drafting issue – especially given the mention of choice and autonomy later in the same sentence. It is important to ensure, as far as practicable, that service users are involved in the choice of activities; and that activities are structured around preferences and interests, and make use of the learning opportunities that such activities afford. There should also be acknowledgement of the difficulties faced by people with autism in making choices and of the staff skills necessary to facilitate choices.	
975.	Hampshire Autistic Society	19	NICE / Full	1.9.12/6.5.10.2	167	7	Add "to enable the individual to take control of their lives".	Thank you for your comment, this is not specific to residential services but is dealt with in the section on general principles of care.
976.	Craegmoor	7	NICE	1.9.12	37	14	Where it says a time table to promote choice etc I think there needs to be an additional comment about how difficult and stressful choice can often be and how many people with autism will just go for the predictable or the best known option……learning to choose takes time and also choice needs to be offered when people are calm. There is a lot of rhetoric about choice in both LD and MH services and though it is of course important for people with Autism it must be handled with care or we can be in danger of causing anxiety through the choices offered.	Thank you for your comment, the recommendations on residential service should not be seen in isolation the full range of interventions in this guideline, and the wider principles set out at the beginning of the guideline. People with autism living in supported accommodation of any kind should not in any way limit their access to these interventions.
977.	Pyramid Educational Consultants	12	NICE	1.9.12	37	12	This should also include activities to teach the adult with autism to be independent in their lives.	Thank you for your comment, this is not specific to residential services but is dealt with in the section on general principles of care.
978.	Autism Rights Group Highland	15	NICE	1.9.12	37	15	and allow the autistic person to choose how to use their spare time if they want to do nothing thats fine	Thank you for your comment. We do not think this is necessary as this should be part of standard care.
979.	Ambitious about Autism	8	NICE	1.9.12	37 of 50		Residential settings must also provide access to education and training options for all people with autism.	Thank you for your comment, the recommendations on residential services should not be seen in isolation the full range of interventions in this guideline, which should address the issue that you raise.
980.	AUTISM ALLIANCE UK	40	NICE / Full	1.9.13/	167	10-	Residential care environments should have designated areas for different activities in order to provide visual cues about	Thank you for your comment. We have introduced a new recommendation about the

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				6.5.1 0.3		1 7	expected behaviour, adaptations made to the physical environment (especially lighting, sound insulation and furnishings) to accommodate people with hyper- and hypo-sensory sensitivities inside and outside spaces where the person with autism can be alone (for example if they are over-stimulated) Designated areas We repeat the comment that people with autism are not a homogeneous group. For some people with autism designated areas will be useful. For others, they are not needed. Behaviour We have concerns about a focus on behaviour. As noted earlier, a concentration on the causes behind behaviour is necessary. This can, in our experience, reduce the number of incidents, improve life skills, and improve the quality of life for the person with autism. Applying neurotypical expectations to people with autism can be confusing and damaging. Adaptations These should be considered and applied where appropriate. Some people with autism will not need them.	design of the physical environment to take your point into account.
981.	Autism Rights Group Highland	1 6	NICE	1.9.1 3	37	2 4	Staff should be constantly aware that this is a home and treat as such, they are going into someone eles private space and should be respectful, should not treat as a workplace place and home second.	Thank you for your comment, we agree.
982.	Welsh Health Boards ASD Assessment & Diagnosis (Adults) Network		NICE /Full	1.9.1 3/6.5 .10.3	167	1 1	Only if necessary for the individual. This should not be able to read in such a way as promotes 'autism' environments for everyone – many individuals with autism can live in ordinary houses with a range of co-habitees, companions.	Thank you for your comment, we agree. The recommendation has been amended to specify: *"adaptations to the physical environment for people with hyper- and hypo-sensitivities".*
983.	Welsh Government		NICE /Full	1.9.1 3/6.5 .10.3	167	1 1	Only if necessary for the individual. This should not be able to be read in such a way as promotes 'autism' environments for everyone – many individuals with autism can live in ordinary houses with a range of co-habitees, companions.	Thank you for your comment, we agree. The recommendation has been amended to specify: *"adaptations to the physical environment for people with hyper- and hypo-sensitivities".*
984.	Dorset Healthcare University Foundation NHS Trust	2 0	NICE	1.9.1 4	36		Training on sensory understanding and needs for staff in residential care environments.	Thank you for your comment, however this is outside the scope of the guideline.
985.	Pyramid Educational Consultants	1 3	NICE	1.9.1 4	38	4	There is no mention of staff commitment to build skills in people with autism.	Thank you for your comment, the recommendations on residential service should not be seen in isolation the full range

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								of interventions in this guideline, and the wider principles set out at the beginning of the guideline. People with autism living in supported accommodation of any kind should not in any way limit their access this support.
986.	Nottinghamshire Healthcare NHS Trust	5 1	NICE / Full	1.9.1 4/ 6.5.1 0.4	167	2 3	We feel it would be important to add that staff should have the ability to adapt their own communication and interaction skills to suit the person being supported.	Thank you for your comment, however this is outside the scope of the guideline.
987.	AUTISM ALLIANCE UK	4 1	NICE / Full	1.9.1 4/ 6.5.1 0.4	167	1 8- 2 2	Staff in residential care environments should be trained in assessing and supporting the needs of adults with autism, demonstrate high levels of consistency and predictability, but with some flexibility to allow change and choice, [and] have a positive commitment to involving families and carers. Training: the focus of training should be on understanding the person with autism, and how most effectively to support them. A focus on practice development and on self reflection (among staff) has the best impact on outcomes and on the acquisition of skills and strategies. High levels of consistency and predictability: the degree of predictability may need to vary from person to person. It is important that there is consistency of approach from the whole support team. Flexibility to allow choice and change: we fully agree, but would comment that skilled staff are needed to support choice and change Involving families and carers: we fully agree.	Thank you for your comment, this is outside the scope, however we do specify that staff should be adequately trained.
988.	Hampshire Autistic Society	2 1	NICE / Full	1.9.1 4/6.5 .10.4	167	1 9	Add two further bullet points: *“Be committed to the individual gaining control of their lives and environment”* and *“Be able to develop strategies for self-management and skill development that take account of the individuals’ style of learning”.*	Thank you for your comment, the recommendations on residential service should not be seen in isolation from the wider principles set out at the beginning of the guideline. People with autism living in supported accommodation of any kind should not in any way limit their access to this support.
989.	Northumberland,		NICE	1.1.1	73	1	4.3.11.4 “if a person with autism does not want their family or	Thank you for your comment, the GDG felt

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	Tyne & Wear NHS Trust		/Full	4/4.3 .11.4		2	carers to be involved in care" • Number of omissions here I think. • Clarify to what extent not at all – or not to some degree • Attempting to negotiate an acceptable degree of involvement • Questions of capacity and best interests should be considered.	your points were adequately covered by the recommendation.
990.	Autism Rights Group Highland	1 7	NICE	1.9.1 4	38	3	If the Autistic person has given permission	Thank you for your comment, the GDG felt this was sufficiently covered in the recommendations.
991.	Worcestershire Health and Care NHS Trust	2 6	NICE	4.1	39-40		Whilst the development of self help tools for anxiety for people with Autism/AS the clinical usefulness of these would be very small and only help a very limited number of people. Clinical experience has shown that many people with AS have very high levels of anxiety that requires long term intervention with ongoing face to face support e.g. graded exposure that computer based or self help books cannot provide. In addition clients with AS will often counter anti anxiety work negatively quoting possible but highly unlikely events as evidence to resist change. Self help guide will not be able to tackle this type of difficulty. In the majority cases	Thank you, we appreciate your comment and have made a further research recommendation about formal psychological interventions.
992.	Autism Rights Group Highland	1 8	NICE	4.1	40	5	More accurately: negative interaction with Society	Thank you for your comment, however we are unable to respond fully to this as we are unsure what you are referring to.
993.	WaASP		NICE guide line	4.1	41	1	Your reiteration of the uncertainly about the composition of the autism team prompts us to draw you attention again to our points 4 and 7 above – psychologist-led.	Thank you for your comment, however we are unable to respond fully to this as we are unsure what you are referring to.
994.	Dorset Healthcare University Foundation NHS Trust	2 1	NICE	4.2	40		Huge risks in developing a team with LD and HFA clients – needs are completely different, and for adults with LD and Autism, primary professional skills need to come through LD experts with a good understanding of autism, not ASD experts with little understanding of LD!	Thank you for your comment, this research is intended in part to address your concern but we should also point out that it is not intended that the specialist team will be responsible for the care of all people, with autism primary care, social care, learning disabilities and mental health services will all have a role to play.
995.	Autism Rights Group Highland	1 9	NICE	4.2	41	1	"High Functioning" is an offensive term and should not be used.	Thank you for your comment. We have changed the term 'high functioning' to 'those who have an IQ of 70 or above'
996.	Royal College of Speech and	7.	NICE	4.3	41		We would like to see a mention of speech and language therapists' role to help people evaluate the effectiveness of	Thank you for your comment, this will be for the research team to determine.

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	Language Therapists						communication aids.	
997.	Pyramid Educational Consultants	14	NICE	4.3	41	14	Augmented communication devices. Limiting the research to ‘devices’ could be seen as research that is purely aimed at high-tech devices. We would like it to be clear that low tech devices, e.g. PECS books, should be included in the study as well to provide evidence about the effectiveness of all augmented or alternative communication aids and techniques.	Thank you for your comment, we have amended the recommendation in light of your comment.
998.	Autism Rights Group Highland	20	NICE	4.3	42	7	this is an area where autistic peoples organisations could be involved in research: Community Based Participatory Research, for example, Autreach IT	Thank you for your comment, we agree it would be good practice to involve services users and this is now a requirement for many funding bodies (e.g. NIHR).
999.	Autism Rights Group Highland	21	NICE	Appendix A	46	1	We would like to see representative of an autistic led organisation here, such as ARGH	Thank you for your comment. It is not possible to add members to the GDG at this stage as all GDG members need to be part of the whole process of development.
1000	Department of Health		General	General			Thank you for the opportunity to comment on the draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation. Many thanks and best wishes	
1001	Medicines and Healthcare products Regulatory Agency		General	General			Thank you for your recent enquiry to the MHRA. We don't think there's very much here that falls within the scope of MHRA's work. Therefore, we won't be commenting on this guideline. Please contact us again if you need further assistance with this, or any other queries.	

These organisations were approached but did not respond:

Stakeholders that were approached but did not respond to consultation
Abertawe Bro Morgannwg University Health Board
Action for Aspergers
Adult Autism Additional Support Team
Alder Hey Children's NHS Foundation Trust

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Asperger East Anglia
Assert
Association for Cognitive Analytic
Association for Dance Movement Psychotherapy UK
Association for Psychoanalytic Psychotherapy in the NHS
Association of Dance Movement Therapy UK
Association of Optometrists
Association of Professional Music Therapists
Autism in Mind
Autism North East
Autism Outreach
Autism Plus
Autistic Rights Movement UK, The
Autonomy Self Help Group
Barchester Healthcare
Belfast Health and Social Care Trust
Bradford District Care Trust
Breakspear Medical Group Ltd
Bridgewater CHC
Bright Futures Autism Limited
British Association for Counselling and Psychotherapy
British Association for Psychopharmacology
British Association of Art Therapists
British Association of Behavioural and Cognitive Psychotherapies
British Association of Drama Therapists
British Association of Music Therapy
British Association of Social Workers
British Medical Association
British Medical Journal
British National Formulary
British Society of Neuroradiologists
Calderdale and Huddersfield NHS Trust
Camden and Islington NHS Foundation Trust
Camden Link
Care Quality Commission (CQC)
Central London Community Healthcare
Challenging Behaviour Foundation
CIS' ters
Citizens Commission on Human Rights

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Coeliac UK
College of Mental Health Pharmacists
College of Mental Health Pharmacy
College of Occupational Therapists
COMMUNITY INTEGRATED CARE
Contact
Critical Psychiatry Network
Department for Communities and Local Government
Department for Education
Department of Health, Social Services and Public Safety - Northern Ireland
Developmental Adult Neuro-Diversity Association
Dimensions
Disabilities Trust, The
Dorset Mental Health Forum
Dorset Primary Care Trust
Dravet Syndrome UK
Ealing Hospital NHS Trust
East and North Hertfordshire NHS Trust
Energy Therapy World-Wide Net
English Community Care Association
Epilepsy Action
Equalities National Council
Estia Centre, The
Faculty of Dental Surgery
Faculty of Occupational Medicine
Federation of Ophthalmic and Dispensing Opticians
Five Boroughs Partnership NHS Trust
Foundation for People with Learning Disabilities
Friends of Landau Kleffner Syndrome
Gender Identity Research and Education Society
George Eliot Hospital NHS Trust
Glencare
Gloucestershire Hospitals NHS Foundation Trust
Gloucestershire LINk
Great Western Hospitals NHS Foundation Trust
Greater Manchester and Cheshire Cardiac and Stroke Network
Greater Manchester West Mental Health NHS Foundation Trust
Hafal

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Halton & St. Helens Primary Care Trust
Hammersmith and Fulham Primary Care Trust
Hampshire Partnership NHS Trust
Handicapped Families Council
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Healthcare Inspectorate Wales
Hindu Council UK
Humber NHS Foundation Trust
Huntercombe Group
Information Centre for Health and Social Care
Kent and Medway NHS and Social Care Partnership Trust
Knowsley Health and Wellbeing
Knowsley Primary Care Trust
Lambeth Community Health
Lancashire Care NHS Foundation Trust
Leeds Partnerships NHS Foundation Trust
Leeds Primary Care Trust (aka NHS Leeds)
Leicestershire Partnership NHS Trust
Liverpool Community Health
Liverpool Primary Care Trust
Liverpool University Dental Hospital
London Autistic Rights Movement
Mencap
Mersey Care NHS Trust
Mild Professional Home Ltd
Mind Wise New Vision
Ministry of Defence
Mother and Child Foundation
National Association for Gifted Children
National Attention Deficit Disorder Information and Support Service
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Institute for Health Research Health Technology Assessment Programme
National Patient Safety Agency
National Public Health Service for Wales
National Treatment Agency for Substance Misuse
NCC Women & Childrens Health

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NeuroDiversity International(NDI)/NeuroDiversity Self-Advocacy Network
NHS Bournemouth and Poole
NHS Bristol
NHS Clinical Knowledge Summaries
NHS Confederation
NHS Connecting for Health
NHS Nottinghamshire County
NHS Plus
NHS Sheffield
NHS Warwickshire Primary Care Trust
NHS West Essex
NHS Worcestershire
NICE technical lead
NICE TLOC GDG
North Essex Mental Health Partnership Trust
North Essex Partnership Foundation Trust
North Staffordshire Combined Healthcare NHS Trust
Novartis Pharmaceuticals
Oxford Health NHS Foundation Trust
Oxleas NHS Foundation Trust
Parents' Education as Autism Therapists
Pathological Demand Avoidance Syndrome Contact Group
Patient Assembly
PERIGON Healthcare Ltd
Pfizer
Pilgrim Projects
POhWER
Public Health Wales NHS Trust
Qbtech Ltd
Rainbows Childrens Hospice
RASDN - HSC.Board/Public Health Agency
Research Autism
Ridgeway Partnership
Rotherham Primary Care Trust
Royal Berkshire NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners in Wales
Royal College of Midwives

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Royal College of Paediatrics and Child Health
Royal College of Paediatrics and Child Health , Gastroenetrology, Hepatology and Nutrition
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists in Scotland
Royal College of Psychiatrists in Wales
Royal College of Radiologists
Royal College of Surgeons of England
Royal National Institute of Blind People
Royal Pharmaceutical Society
Royal Society of Medicine
Ruskin Mill Educational Trust
Safeguarding the Rights of Children with Autism
SCHOOL AND PUBLIC HEALTH NURSES ASSOCIATION
Scottish Intercollegiate Guidelines Network
Sensory Integration Network
Sheffield Bullying Observatory
Sheffield Health and Social Care NHS Foundation Trust
Sheffield Teaching Hospitals NHS Foundation Trust
SNDRi
Solent Healthcare
South Asian Health Foundation
South Essex Partnership NHS Foundation Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
South West London and St George's Mental Health NHS Trust
Southwark Council
St Andrew's Hospital
Stroud Court Community Trust
Surrey and Border Partnership Trust
Swansea University
Talking Mats research and development center
Tavistock & Portman NHS Foundation Trust
The Autism Centre, Sheffield Hallam University
The Kingwood Trust
The National LGB&T Partnership
The Princess Royal Trust for Carers
The Rotherham NHS Foundation Trust
The University of Glamorgan
Tizard Centre

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Tourettes Action UK
Treating Autism
Tunstall Healthcare UK Ltd
Turning Point
UK Young Autism Project
Unite - the Union
United Kingdom Council for Psychotherapy
University Centre for Excellence in Developmental Disabilities
University of Birmingham
University of Edinburgh
University of Nottingham
University of Wales, Bangor
Warwickshire County Council
Welsh Scientific Advisory Committee
Western Cheshire Primary Care Trust
Western Health and Social Care Trust
Wigan Council
Worcestershire Acute Hospitals Trust
York Hospitals NHS Foundation Trust

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