National Institute for Health and Clinical Excellence

Autistic spectrum disorders in adults
Scope Consultation Table
23 April – 21 May 2010

No	**Type**	**Stakeholder**	**Section No**	**Comments** Please insert each new comment in a new row.	**Developer's Response** Please respond to each comment
1	SH	ASSERT (B&H)	1	The term "management" could be misinterpreted as suggesting that autism is an illness that needs to be controlled or reduced. A more appropriate word would be "support" or "medical support" (as this relates to clinical guidelines rather than social or care services). This is a better way of expressing that emphasis should be on accepting that autism is part of who people are and the priority is to help them be the best that they can be, and to adhere to the Social Model of Disability.	Thank you for this comment – whilst we appreciate your concerns we still believe that management is the most appropriate term given the scope of the guideline which will relate not only directly to health care but also to pathways into social and residential care. We take management also to include a wide range of activities, including possibly self-management, and do not think it is at odds with a social model of disability.
2	SH	ASSERT (B&H)	1.2	Please see above. Suggested improved wording: "To produce a clinical guideline on the support of adults with autistic spectrum conditions."	Thank for this suggestion but we do not think that such a title would be consistent with the content of the scope document and would therefore be potentially misleading.
3	SH	ASSERT (B&H)	2.1c	The current wording is quite derogatory and fails to differentiate between being able to do something but finding it significantly more difficult than neuro-typicals, and not being able to do it at all. It also does not reflect the fact that there can be positive elements to autism Suggested improved wording: "Other features commonly found are difficulty with cognitive and behavioural flexibility, altered sensory sensitivity (which can have both advantages and	Thank you for this suggestion – we have incorporated your comments into a revised draft

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				disadvantages), sensory processing difficulties, stereotyped mannerisms, emotional regulation difficulties, and a narrow yet highly focused range of interests and activities.”	
4	SH	ASSERT (B&H)	2.1d	Reference to medical professionals taking into account the Social Model of disability when considering impairments and impact on person’s functioning is **necessary** as while someone may be able to function so well in certain situations as to not be considered eligible for diagnosis, the reality of the way society operates and discriminates may well represent a substantial impact upon the individual’s functioning.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
5	SH	ASSERT (B&H)	2.1f	More specific reference should be made to the fact that people on the autistic spectrum with an IQ above 70 fall in the ‘gap’ between mental health and learning disability services, often being considered ineligible for neither. Reference should also be made to the fact that many people are misdiagnosed and the fact that most medical professionals still have poor and inadequate knowledge of autistic spectrum conditions. Please also include reference to the fact that autism is a misunderstood, misrepresented and ‘hidden’ disability means that people on the spectrum are far more likely to experience bullying, ridicule, humiliation and discrimination.	Thank you for this comment. A key purpose of adopting the term spectrum is to ensure that the guideline gives consideration to pole across the range of cognitive abilities. We note your other comments but do feel that these issues are already adequately dealt with in the section on current need for the guideline.
6	SH	ASSERT (B&H)	2.2a	Please could you elaborate on what specifically you are referring to when you say ‘genetic counselling’?	Genetic counselling is a procedure in which a person or relatives, at risk of an inherited disorder, are informed about the nature of and the consequences of having the disorder, the probability of developing it or transmitting it to their children, and the options open to them (including family planning) in order to prevent or ameliorate it.
7	SH	ASSERT (B&H)	2.2b	In outlining the ‘ideal’ scenario, there is no reference to the autistic individual having a say in the support and	Thank you for your comment, we agree that the autistic individual should be involved in the decisions about

				care they receive. This should be facilitated as necessary by alternative augmentative communication, or other communication facilitation/support as required. All autistic individuals should have a say in any plan for future support or interventions for them. They should also be made aware of the positive elements of autism and of the autistic rights and pride movements for the sake of their own self-esteem, sense of identity and to give them true choice over their future. For example, use of Dr. Attwood's '"Discovery" criteria should be considered. Please see http://everist.org/archives/asp/Discovering_Asper.htm http://www.timesonline.co.uk/tol/comment/columnists/magnus_linklater/article5496799.ece	their care and have amended this section to reflect your suggestion. Thank you for the comment – all NICE guidance is grounded in a person centred approach to care and as such places strong emphasis in the involvement of people with the disorder playing a central role in negotiating the nature of their care. This will be the case in this guideline. We will consider the evidence as to how this might best be achieved for people with ASC.
8	SH	ASSERT (B&H)	2.2c	We would suggest adding the recommendation that further research needs to be done into the value of biomedical interventions and genetic counselling to ascertain how helpful this is in facilitating autistic individuals to fulfil their potential. There are numerous theories and supposed 'cures' and 'treatments' with little or no scientific basis and these should not be used until it can be proven that they are of genuine benefit and are safe.	Thank you for your comment. It is not the purpose of the scope to make recommendations. The development of clinical guidelines often highlights the need for further research and we make research recommendations accordingly within the guideline.
9	SH	ASSERT (B&H)	2.2f	It should also be added that current 'information-sharing' rarely, if ever, includes information on positive elements of autism, autistic self-advocacy, the Social Model of Disability, and disability rights.	Thank you for your comment, we will consider this when developing the guideline.
10	SH	ASSERT (B&H)	2.2i	We would suggest adding that discrimination, misunderstanding, refusal by employers to fulfil their	Thank you for your comment. This is a clinical guideline and NICE are unable to make

				legal obligations to make ‘reasonable adjustments’, and supported employment schemes whose staff do not understand autism, or who use a ‘one size fits all’ method not appropriate to those who are autistic, contribute significantly to difficulties in sustaining long-term employment. It is also necessary to acknowledge that not all people on the autistic spectrum will be able to sustain employment, but ensuring that these individuals can still have “Happy and fulfilling lives” as per the title of the Department of Health’s Autism Strategy.	recommendations to non-NHS organisations.
11	SH	ASSERT (B&H)	2.2k	We would recommend that you contact an appropriate user-led organisation to check that ‘gender identity problems’ is the correct and non-offensive wording to those who would identify themselves as being in this group.	Thank you for this comment – this is a widely used and understood term in the NHS. We will work with NICE to see if user-led organisations that have a specific interest in the area can be recruited as stakeholders.
12	SH	ASSERT (B&H)	3.1.1c	We would recommend that you contact an appropriate user-led organisation to check that ‘gender identity disorders’ is the correct and non-offensive wording to individuals who would identify in this group.	As this comment is a duplicate please see comment 11 for the response.
13	SH	ASSERT (B&H)	3.2c	It would be useful, if possible, to address the many inappropriately qualified individuals and organisations who are offering diagnosis or ‘pre-diagnostic assessment’, both within statutory services and also outside of or as an ‘add-on’ to statutory services, particularly where statutory services refers to outside organisations/individuals and/or allows them to advertise and promote there services on statutory service property and information networks.	Thank you for your comment. We will be looking at how to improve joint working.
14	SH	ASSERT (B&H)	3.3.1b	Please elaborate on what you are referring to when you say ‘genetic and biomedical techniques’? How will strengths and skills be identified and how will it be ensured that these are preserved and valued (but not used as an excuse to refuse or reduce support)?	A purpose of the guideline is to examine whether genetic or other biomedical markers would aid diagnosis and assessment. This may inform but is not a way of addressing the strengths and skills of an individual.

				Identifying strengths and skills is important but it must be made clear that the purpose of this is to tailor support to enable the individual to fulfil their potential and not used to force or push them into inappropriate employment or training or to steer them towards unsuitable accommodation or support packages. It is necessary to note that people on the spectrum can have difficulty with accurate ‘self-reporting’ and also struggle to predict consequences. Without adequate information, detail and explanation, autistic individuals might appear to agree to something which is actually completely unsuitable.	
15	SH	ASSERT (B&H)	3.3.1c	Please note that ABA is highly controversial and people on the spectrum may well not want this therapy and should have the right to refuse this without being penalised or discharged. http://www.springerlink.com/content/vnx08r94v2p3n703/ http://www.sentex.net/~nexus23/naa_vic.html http://www.sentex.net/~nexus23/naa_fac.html Please also note that CBT must be tailored and adapted to suit people on the spectrum. Dr. Tony Attwood has stated that ‘conventional’ psychological therapies can be useless or even damaging for people on the spectrum. Other psychological therapies should also be available as CBT is not appropriate for everyone and the bias that has been shown towards CBT is concerning. http://bjp.rcpsych.org/cgi/content/abstract/196/3/173 http://books.google.co.uk/books?id=qJZmsp3ZVG8C&pg=PA160&lpg=PA160&dq=attwood+asperger+therapy+damaging&source=bl&ots=lDtuiMwGxq&sig=wmzNM87Q_Q2e5GqdlgDbQ2xsWmA&hl=en&ei=W5PwS4XVKJHy0gSm6NjfBw&sa=X&oi=book_result&ct=result&	Thank you for your comment. The purpose of this guideline is to assess the efficacy of interventions using the available evidence base. One matter we will consider will be the means to ensure that any intervention (including psychological treatment or support) is delivered in a manner which supports its effective delivery for a person with ASC.

				resnum=3&ved=0CCEQ6AEwAg#v=onepage&q=therapy&f=false Assert does not condone any ‘therapy’ that seeks to suppress, discourage or punish any non-harmful autistic behaviours or traits, or remove or disregard autistic skills, strengths and talents**.** It should be noted that while mentoring, befriending and social groups can be useful, some people on the spectrum prefer not to socialise, and this should be respected. Support should be available for all types and levels of job, from entry level to senior level. This support should also exist for people who are only able to work part time and people who want to work on a freelance / self-employed basis. It is important to recognise that employment may not be possible for some people on the spectrum.	
16	SH	ASSERT (B&H)	3.3.1d	Only as long as these do not cause side effects that the individual on the spectrum cannot cope with or suppress any non-harmful autistic behaviours or autistic strengths / talents The scope must also cover how this will be monitored to ensure that people on the spectrum are not made to endure side effects that are detrimental to their quality of life. Autistic individuals must have the right to refuse or be taken off medication they are not happy with without being (or threat of being) penalised or discharged. It is also necessary to allow for the fact that individuals on the spectrum experience difficulty with ‘self-reporting’ skills and due to sensory issues (such as under-sensitivity to pain) may also have difficulty	Thank you for these comments the side effects of medication will be considered.

				identifying more serious side effects. The unusual pharmacokinetic effects experienced by people on the spectrum must also be acknowledged and taken into consideration when prescribing medication. ***Please also see comment 22 regarding 3.5***	
17	SH	ASSERT (B&H)	3.3.1e	In the case of dietary interventions that involve more expensive foods, these should be available on prescription (in the same way as for Coeliac disease) in order to ensure autistic individuals are not financially penalised. Discussion about this should form part of the “key issues”. http://www.coeliac.org.uk/healthcare-professionals/prescriptions	Thank you for this comment. This is outside of the scope and matter for the NHS to consider.
18	SH	ASSERT (B&H)	3.3.1f	This should include support from autistic advocates and sources that give positive information about autistic traits. (Current information tends to focus on the ‘deficiencies’ only). All information must be provided in formats accessible to the individual on (or suspected to be on) the autistic spectrum e.g. Easy Read format, alternative colours, sans serif text, audio etc.	Thank you for this comment – we will consider this in the development of the guideline.
19	SH	ASSERT (B&H)	3.3.1g	Suggested change to wording: “The organisation and delivery of care, and care pathways for the effective components of support and treatment of co-existing conditions (including transition planning), based on an ethos of multi-professional working and with the wishes and realization of potential of the autistic individual being paramount.” We would also recommend that user-led organizations as well as autistic individuals, have ongoing involvement at all levels to provide information, support, ‘expert patient’ input etc. to medical	Thank you for your suggestion. We have not taken up your suggestion as we are concerned to develop pathways for Autistic Spectrum Conditions not only for co-occurring conditions. The role of user-led organisations will be considered in detail by the GDG.

				professionals.	
20	SH	ASSERT (B&H)	3.4a & 3.4b	This must include identifying, recognising, preserving and encouraging the positive elements of autism, including any special skills, talents or abilities (including savantism where applicable).	Thank you, we have revised the outcomes in light of other comments but we have not adopted your suggestions which describe a general approach to ASC rather than the specific indicators covered in the outcomes section.
21	SH	ASSERT (B&H)	3.4d	This MUST be within the context of the social model and inclusive/accessible design. Difficulties in functioning in social/occupational/educational settings are often exacerbated (or even solely caused) by sensorily inaccessible environments and information, discrimination, misunderstanding, etc. Viewing difficulties in functioning as a problem within the individual is inaccurate, insulting and discriminatory. It is essential that a key outcome is for NICE guidelines to contribute as far as possible to improved access, and recommendations for 'autism friendly' environments, communication and information in accessible formats.	Thank you for this comment –the issues that you raise will be considered by the GDG when considering the relevant evidence.
22	SH	ASSERT (B&H)	3.5	The difficulty here is that issues that are well recognised and acknowledged by both professionals and individuals on the spectrum may not be represented in research. For example, many people on the spectrum experience unusual pharmacokinetic effects such as unexpected or severe side effects, responding to unusually high or low dosage levels, paradoxical reactions etc. This has implications in prescribing and monitoring recommendations. This could also mean that medications that are blacklisted, because 'cheaper	Thank you for this comment which does not relate directly to the content of section 3.5 However, we will draw these comments to the attention of the GDG.

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				medications that work just as well are available,' could actually be necessary for people on the spectrum due to their unusual reactions – so perhaps it is necessary to consider removing certain medications from blacklists for people on the spectrum. While research and evidence are important, if something is widely anecdotally recognised by both professionals and autistics, this must be accepted by economists. Evidence must, primarily, be from autistics themselves regarding what does and doesn't help them and whether or not the positives of a particular therapy outweigh the negatives. Relying on testimony from the medical world and/or carers only may lead to these people recommending or endorsing things that they see as making autistics 'easier to control' or 'less difficult' which are not the same as identifying and recognising those therapies that actually benefit autistics themselves.	
23	SH	ASSERT (B&H)	5	Please make sure all of your documents are available in accessible formats.	NICE's equality scheme sets out how they are meeting their obligations in promoting equality and eliminating discrimination (see http://www.nice.org.uk/aboutnice/howwework/NICEEqualityScheme.jsp). To ensure that our guidance is accessible to the people who need to use it, NICE publishes a document of service users and carers called 'Understanding NICE Guidance' (UNG) in the following formats: • Printed A4 leaflets and booklets. • PDF on NICE website (these files can be read at enlarged size). • Word version on NICE website (this enables outside organisations to easily incorporate the information into

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					their own publications). • Audio files (Browse Aloud). • Large print versions for particular subjects, such as guidance for people who are visually impaired. • Braille versions (on request). In addition, the NICE website can be converted into a high contrast version for people with visual impairments. NICE will consider other formats as appropriate, taking into account the resources available.
24	SH	ASSERT (B&H)	General	The scope should also include recommendations for future research and a set review date for the guidelines currently in development, e.g. 2015.	Thank you for your comment. It is not the purpose of the scope to make recommendations. The development of clinical guidelines often highlights the need for further research and we make research recommendations accordingly within the guideline.
25	SH	Association for Family Therapy and Systemic Practice	General	We are pleased to comment on the draft scope, because AFT represents professionals who work with families who live with complex problems. Some are employed as UKCP registered Family Therapists, whilst others use their training and skills within their roles such as clinical psychologists, community psychiatric nurses social workers. While few will be working in services for adults with autism spectrum conditions, it may be one of the problems that a family has to manage that emerges in systemic couple and family therapy. Systemic therapy can also be offered to individuals who wish to find ways to deal with relationship issues, including their disappointment about the effects of autism on interactions and relationships. More details can be found on the website www.aft.org.uk	Thank you for your comments.

26	SH	Association for Family Therapy and Systemic Practice	2.2b 2.2f	The follow up support for adults who are diagnosed with autism is important. Some family members seek family therapy after their child is given a diagnosis of Asperger's or autism, and then recognise the possibility that their partner may also this diagnosis. Partners would benefit from access to support and psychological therapies, whether this may be systemic individual or couple therapy	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
27	SH	Association for Family Therapy and Systemic Practice	2.2h	Providing services during the transition to adult services is important, especially when the young person with autism has behavioural problems. But this highlights the value of having access to professionals and services that understand autism in adult mental health services and who can provide long term support, and interventions when needed..	Thank you for your comment. We shall be addressing the transition between children's and adults' services in this guideline.
28	SH	Association for Family Therapy and Systemic Practice	3.3.1c	Suggest that this should include psychological therapies for families / carers, to provide support to parents and partners, build on their strengths, as well as helping them to find solutions to the difficulties they live with. Some may benefit from couple counselling or therapy.	Thank you for your comment, the needs of carers will also be addressed in this guideline, as outlined in 3.3.1 f).
29	SH	Association of Professional Music Therapists	2.1b	The third impairment in the triad is an impairment in imaginative play, often replaced by restricted,repetitive and stereotyped patterns of behaviour.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
30	SH	Association of Professional Music Therapists	3.2b	I work in an NHS Creative Therapy Team where we provide Arts Psychotherapies to adults, addressing their mental health needs. We see people with or without Learning Disabilities, and many of my clients have an Autistic Spectrum Condition.	Thank you for your comments.
31	SH	Association of Professional Music Therapists	3.3.1c	This is probably the category that Music Therapy fits into, though it would be better termed psychological or psychotherapeutic.	Thank you for your comment. All relevant interventions will be looked at – the list in 3.3.1 c) is not exhaustive and it is not possible to list all interventions here.
32	SH	Association of Professional Music Therapists	3.4	We could make significant contributions to areas b), c), d) and e) and be part of f)	Please send us any studies you feel will be relevant to this guideline.
33	SH	Association of Professional Music Therapists	general	Music Therapy has a strong evidence base in Autism (see for example Research Autism's review www.researchautism.co.uk) It is very effective in	Thank you for your comment - the list of possible interventions are offered as examples – if we find evidence of sufficient quality we will consider it in the

				addressing the triad of impairments and in helping people with ASCs address mental health problems. We have much to contribute to the develop of appropriate healthcare services for people with ASCs and would very much like to be involved at every stage of this development.	guideline.
34	SH	Autism Cymru	2.2g <u>and</u> <u>general</u>	You have made the statement 'in-line with the autism strategy'. However, the autism strategy to which this comment refers applies only to England. There is no acknowledgement anywhere in this document to the Welsh Assembly Government's all-age autism strategy which has been in place since 2008. Further in January 2010 Ministers in WAG announced an additional £1.7m from 2010-13 to go directly to establishing services with autism living in Wales including the development of an all-Wales approach to the assessment, diagnosis and post-diagnostic support of adults with autism - which will include the provision of a managed clinical diagnostic network. (otherwise it looks good!)	Thank you for your comment and for pointing out this admission. We have amended the scope to make reference to this strategy.
35	SH	Autism Rights Group Highland	general	The words "care" and "carers" (for adults) are unhelpful as they suggest a "cared for" person rather than an autonomous adult. Support / supporters / PA's are more useful terms.	Thank you for this comment but we disagree. Some people with autism are severely disabled and need considerable care and support. We therefore consider the term carer to be appropriate.
36	SH	Autism Rights Group Highland	general	I'd like them to consider autistic people as real people who have a place in society, that means taking into account our lives as parents, employees, students etc sometimes they attempt this but it always seem to have an artificial edge, as though we're not really part of society. This also means that they need to think about the practicalities of attending appointments: childcare or other help to attend, plus flexible appointment times.	Thank you for this comment – we will draw it to the attention of the GDG.
37	SH	Autism Rights Group Highland	general	I'd also like to see before assessment a full explanation of how a diagnosis may affect a persons life : work etc along with the legal duty (or not) to disclose. Some form of counselling but from a positive practical viewpoint. I want people to feel supported and fully	This will be considered as part of our review of assessment methods.

				aware.	
38	SH	Autism Rights Group Highland	general	There is no mention of the most recent ideas relating to autistic women and the theory that they may present differently. Also, no mention of connections between ASC and addiction, (just seen they do in 4.4 but I think it needs highlighting still).	Thank you – we feel the issue is sufficiently highlighted in 4.4
39	SH	Autism Rights Group Highland	general	All of the language is very medical, I know it's the NHS but even so I don't like "treatment" or "management" as terms that refer to me or my children.	Thank you but you will appreciate that this is a guideline for the NHS
40	SH	Autism Rights Group Highland	general	There is also no mention of living circumstances: to live in a place where we are happy and secure should be here and is just as relevant (if not more so) to those that require the most support (even 24 hour support) in group homes or other settings.	Thank you but we consider this issue to be outside the scope.
41	SH	Autism Rights Group Highland	general	-Glad scope recognised 'DIAGNOSTIC OVERSHADOWING' of symptoms hidden under other health labels but this may need better examples within the guideline as we know what it means.	Thank you for this comment.
42	SH	Autism Rights Group Highland	general	Even though it does not do 0-18 years, I hope there will be a good practice recommendation that a tie into the NICE guideline for children will be made to recognise good transitions to adulthood planning.	Thank you for your comment. We shall be addressing the transition between children's and adults' services in this guideline.
43	SH	Autism Rights Group Highland	3.2k	"...Supporting people with autism through adulthood' focusing particularly on the transition from adolescence to adulthood." Once again they say they are going to help adults and then focus on the transition into adulthood still leaving adults with a very small if any service. They need to provide a service for everyone if there is a service for adults there would be a service for the adolescent's to move into.	We are unable to comment on or amend studies conducted by other agencies (i.e. National Audit Office).
44	SH	Autism Rights Group Highland	4.1.3c	I don't like the list of psychosocial interventions: they come from the perspective that we are broken and need to be fixed which is wrong and damaging to self esteem. Social skills training in an unnatural setting is a waste of time and money also. Enriching socialisation activities that people want to engage in are far better; increased opportunities to interact with others just as the general population do: with shared	This list is not exhaustive but does include a number of commonly used interventions. Where interventions are identified that address the issue you raise we will evaluate them.

				interests etc should be fostered and access to these should be enabled.	
45	SH	Autism Rights Group Highland	4.1.3e	any helpline should be available to all, so not just phone, include email, instant messaging, post etc	Thank you – the list is indicative and not exhaustive – other methods may be considered.
46	SH	Autism Rights Group Highland	4.4	Outcomes a bit poor: Having employment present is good but it should be accompanied by education, leisure (measure of happiness or somesuch) and family life (however an individual would define that). It's important that they don't try to "normalise" people as one persons' version of "normal" never suits another. Also, sexual health and relationship and health screening should be included even if it's just a good practice recommendation.	Thank you - we have significantly revised this section in light of yours and others' comments.
47	SH	Autism Rights Group Highland	8d	Consider side effects and unusual dosages or reaction times for medication. Take into consideration the different ways autistic people metabolise medications, so for instance some people made need very little anaesthetic and equally others may need a lot more. Some drugs may have completely unexpected reactions such as something that keeps people awake can make autistic people sleepy and also antipsychotics making us psychotic.	Thank you for your comment, we will consider this when developing the guideline.
48	SH	Autism Rights Group Highland	3.3.1	Sensory profiling should be considered	We will consider sensory issues as part of the review of assessment methods.
49	SH	Autistic Rights Movement UK	2.1b	The bullet-pointed definition given here; • qualitative impairments in social interaction • qualitative impairments in communication • restricted, repetitive and stereotyped patterns of behaviour, interests and activities. is a reworking of the "Triad of Impairments" rather than a summation of DSM-IV. The Triad is routinely used in official documents (including governmental guidance) as a definition of autism.	Thank you for this comment - in this section we are setting out the current position in relation to the diagnosis and assessment of ACS. We therefore think it appropriate to cover the three bullet points you highlight. Whilst the guideline will cover assessment and diagnosis it is beyond the scope of the guideline to consider changes to diagnostic criteria – others e.g. the working groups on DSM-V are considering this issue.

				It is no such thing. In its original form (as formulated by Lorna Wing in the 1970s) it was intended to be a “thumbnail sketch” to assist teachers dealing with autistic pupils. (The constantly re-written third part was originally “lack of imaginative play”.) It was never intended to be the general definition it has since become. The NICE GDG ought to seize the opportunity to formulate a more useful alternative.	
50	SH	Autistic Rights Movement UK	2.1c	The above point is supported by this rather poorly written sentence. Some of the “features” it mentions are further rewordings of various versions of the Triad. More importantly, “altered sensory sensitivity” and “sensory processing difficulties” are never included in the Triad despite being a core feature of autism. Most autistic people experience some sort of sensory “atypicality”.	Thank you for this comment we have amended 2.1.c
51	SH	Autistic Rights Movement UK	2.1d	The “features” of “autism” present not a continuum but a series of continua. The “autism spectrum” is only a metaphor, and one of questionable usefulness at that. Difficult as it is to generalise about such a heterogeneous group of people, it is reasonable to suggest that the overwhelming majority of autistic people have a “jagged ability profile”. They tend to be very good at some things and very poor at others. This fact makes the use of the terms “high-functioning” and “low-functioning” highly inappropriate.	Thank you for this comment. We agree that autism does not present as a disorder with a core set of abilities (or deficits) which vary in strength in a consistent manner and this view has informed the guideline. However, we do believe that the terms continuum and functioning have some utility and are also in widespread use.
52	SH	Autistic Rights Movement UK	2.1e	“Atypical autism” is a separate diagnostic category to PPD-NOS. They are two of the six PDDs in DSM-IV. Generally speaking, this document is a good example of the difficulties of language surrounding the subject of autism. Hopefully the work of the GDG will go some way	Thank for this comment. We are aware of the limitations of the current diagnostic systems and that is why we have adopted the term autistic spectrum condition (which will include the diagnoses of atypical autism and PPD-NOS).

				towards addressing some of these difficulties.	
53	SH	Autistic Rights Movement UK	2.1f	The "diagnostic overshadowing" mentioned "cuts both ways". Not only is autism mistaken for something else or overlooked because of the presence of something else but the presence of autism (or, more accurately, the presence of a diagnosis of autism) can lead to other co-existing conditions remaining undiagnosed. Often these "missing" diagnoses would be extremely helpful to the individual concerned in terms of accessing services and otherwise.	Thank you for this comment we have amended this section to take account of your comment.
54	SH	Autistic Rights Movement UK	2.2	We would like to see neuro-imaging become a standard part of the diagnostic procedure. We want referral for full metabolic screening immediately post-diagnosis. We want referral for assessment of other "neuro-diverse" conditions (dyspraxia, dyslexia, ADHD, Tourette's Syndrome) immediately post-diagnosis.	Thank you for this comment, we will consider these methods along with a range of other assessment methods in the development of the guideline.
55	SH	Autistic Rights Movement UK	3.1.1	Serious consideration should be given to the needs of autistic people over the age of 65. Consideration should also be given to co-morbidity of autism and dementia (including early-onset dementia).	Thank you for your comment. We will add the issues surrounding older people to our scope.
56	SH	Autistic Rights Movement UK	3.1.1a	This sentence comes perilously close to committing the error made in the National Audit Office report of June 2009 (mentioned at 2.1.f), that of confusing the concept of "low-functioning autism" with the concept of "autism with an accompanying learning disability" (and the concept of "high-functioning autism" with the concept of "autism without an accompanying learning disability). "Low-functioning" does not mean "with an IQ of 70 or below".	Thank you – we note your comment and will bring it to the attention of the guideline development group – we do not think we need to amend the text.
57	SH	Autistic Rights Movement UK	3.1.1b	It might be clearer to state "all 'pervasive developmental disorders' including autism". Or simply list all six of them (as contained in DSM-IV).	Thank you we will consider the full detail of the diagnostic systems in the GDG – what is in the scope is by way of example or indication. We do not think it would be helpful to list the full range of the diagnostic categories
58	SH	Autistic Rights Movement	3.1.1c	Clear distinctions ought to be made here between	Thank you for this comment. We will consider each

		UK		different types of "coexisting conditions". Mental health conditions – depression, eating disorders, personality disorders, anxiety disorders. Neuro-developmental disorders other than autism – dyspraxia, dyslexia, ADHD, Tourette's Syndrome. "Sensory sensitivity" is really a part of autism (see above). Most autistic behaviour can be understood in terms of anxiety. Someone with a diagnosis of autism and of anxiety disorder probably has one diagnosis too many.	disorder separately but your over-arching categories (or similar) may be helpful in summarising the evidence.
59	SH	Autistic Rights Movement UK	3.1.2c	There ought to be explicit reference here to the criminal justice system; the police, the prison system, the probation service, court officials, etc. Most particularly, there ought to be reference to the prison medical service. There is emerging and compelling evidence that there are a disproportionate number of autistic people in the prison system, many of whom are undiagnosed. There need to be clear procedures for assessment and diagnosis for prisoners. There need to be reasonable adjustments for diagnosed individuals entering the criminal justice system. More importantly those who enter the system undiagnosed should stand a reasonable chance of being diagnosed as a result. The probation service needs the diagnosis to be able to work with the individual.	Thank you for your comment. The recommendations made by this guideline will be applicable to prison healthcare settings, as outlined in 3.2 a)
60	SH	British Dietetic Association	General	This stakeholder responded with no comments to make	
61	SH	British Psychological Society	General	We welcome the proposed development of this guidance. A significant issue is the need for clarity or directive on which services hold responsibility for accepting people with ASD without a learning disability. They receive a service based on need from children and families	Thank you.

				services, then get to 18 and find that we assess on different criteria and they are not eligible for a service from anyone – they frequently end up coming to LD Teams as ‘vulnerable adults’ but theoretically do not qualify for health input therefore.	
62	SH	British Psychological Society	2.1a	Reasonably robust epidemiological data exists for the prevalence of ASC in people who also have a learning disability. We would like to see specific reference to this group of people as they form a reasonably distinct sub group of people with ASC.	We agree this is an important issue and have included those with a learning disability with the “low functioning” group.
63	SH	British Psychological Society	2.1f	There is an increased risk of people with ASC who also have a learning disability showing increased levels of challenging behaviours (often self injury or aggression towards others). This is likely to lead to exclusion from services including placement in expensive out of area placements.	Thank you for your comment.
64	SH	British Psychological Society	2.2b	In the penultimate sentence, we would like to see the role of carers being acknowledged. The sentence could be amended: “……However, many adults ***or their carers*** who suspect……”.	Thank you we have amended the scope in light of your comments.
65	SH	British Psychological Society	2.2b	We would like to see an additional statement added here: **“Variations in access to diagnostic services exist dependent on whether or not someone has a concomitant learning disability. It is likely that this group of people will currently access specialist Learning Disability health services for a diagnosis”**	Thank you for this comment – we accept that what you suggest will be the case for some people with a learning disability but unfortunately not all and therefore although we have amended the text we have not taken up your specific suggestion.
66	SH	British Psychological Society	2.2e	The second sentence refers to people being *‘wrongly’* diagnosed. This implies a failing in the process. It is often the case that it is difficult to differentiate between the ASD and a mental illness. At times it may be more important to carry out a functional assessment of the person’s behaviour rather than a diagnosis alone.	Thank you for this comment – the process does indeed fail for some people. We accept your comment that differential diagnosis may be difficult – it is our intention in this guideline to provide recommendations which will improve diagnostic accuracy
67	SH	British Psychological Society	2.2h	We would like to make an addition to this paragraph: **“Many adults who have a learning disability do not**	Thank you for this comment – we agree it raises an important point but feel that it is too detailed to be included in the scope. However we will draw this

				have a formal diagnosis of ASC despite showing the characteristics described in 2.1 b). This is largely the result of historical service models that did not advocate diagnostic approaches. The necessary developmental histories for many of these people is often no longer available."	comment to the attention of the guideline development group.
68	SH	British Psychological Society	2.2i	Assessment and diagnosis of adults with higher functioning ASD (or Aspergers) usually do not get a diagnosis as they are not considered to have a severe and enduring mental health problem or a learning disability. They therefore do not have access to any services to get an assessment in the first place. Expertise is also limited/lacking in adult mental health services around AS. We would like to make an addition to the end of this sentence: **"…… or other purposeful/ meaningful activity, especially if the person has a learning disability."**	Thank you for this comment we have amended the text in light of your comment
69	SH	British Psychological Society	2.2k	We would like to add a sentence here to acknowledge that people with ASC who also have a learning disability are at even greater risk of exclusion and that they are disproportionally likely to be placed in Out of Area placements many miles from their homes. People with AS or High functioning ASD - main reason for this is that they do not meet criteria for services for LD or MH. They fall between services and cannot get support from either unless they have an LD or MH problem.	We agree that the issues you raise are important but the points you make apply to a very significant number of people with ASC – this point of 2.2k is to identify subgroups who are particularly vulnerable to exclusion – albeit within a group already suffering considerably from exclusion.
70	SH	British Psychological Society	2.2m	It is unclear what if any guidance there will be for N. Ireland.	NICE guidance is available for use in Northern Ireland.
71	SH	British Psychological Society	3.1.1c	We would like to see the guidance make specific reference to the needs of: • people with significant cognitive impairments • people whose ASC contributes to them displaying challenging behaviours such as self injury and	Thank you for this comment – we recognise the problem you set out and will consider the problems of arriving at a diagnosis of ASC in the absence of any corroborating developmental history.

				aggression that places them at additional risk of exclusion At present developmental history is a key component of ASC diagnosis. However, for many of the most 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. This means these groups are less likely to receive an ASC diagnosis and are therefore more likely to be excluded from appropriate services. Consideration should therefore also be given to the specific needs of people for whom a detailed developmental history is not available; specifically, how at least some of this group might be able to be given a 'likely' or 'probable' diagnosis based on current behaviour and what is known of their history, so as to ensure they are not unfairly excluded from appropriate services. An optimal assessment usually includes a history of the person's particular behaviours aged 4-5 years to pin down early developmental delay and 'autistic' behaviours. Any diagnostic tools to be considered need to take into account that with adults, often there is no reliable parent or adult available to give that information. If there is – its reliability may be questionable if the time gap is too great (30 -40 years).	
72	SH	British Psychological Society	3.3.1c	We would like to see Positive Behavioural Support (PBS) specifically included as one of the potential interventions. This paragraph needs to clarify what the intervention is for. Presumably it is not to 'treat' the autism but to address some of the resultant handicapping conditions that arise from the disability (e.g. reduction of the	Thank you for your comment. All relevant interventions will be looked at – the list in 3.3.1 c) is not exhaustive and it is not possible to list all interventions here.

				person’s self injury; reduction of aggression to others etc)	
73	SH	British Psychological Society	3.4	We would like to see an additional outcome along the lines of: **Reduction in the reliance on Out of Area placements** or **Increased ability of the person to remain living in their community of choice.** Furthermore, this section needs to say something about the fact that frequently a big difference can be made with just a few hours practical support a week. This would likely come under the remit of Social Services rather than health – but is an important part of a holistic approach. Often that is all the ‘intervention’ that is needed, rather than jumping in and assuming a therapeutic intervention is needed.	Thank you but we consider this issue to be outside of the scope and a matter to be determined by health and social care services. We cannot comment on this at this stage – we have not yet reviewed the relevant evidence.
74	SH	British Psychological Society	3.4e	Additional coexisting conditions that could be cited include challenging behaviours such as aggression and self injury.	Thank you for your comment, this is an illustrative rather than an exhaustive list.
75	SH	British Psychological Society	3.5	One of the economic aspects that should be included is the costs associated with the reliance on Out of Area placements.	Thank you – this issue is going to be considered, depending also on availability of relevant data; such costs are captured in the scope (“costs considered will usually be only from an NHS and personal social services perspective”). Moreover, the scope has been broadened to capture wider social costs associated with autism in adults.
76	SH	Department of Health	General	This stakeholder responded with no comments to make	
77	SH	Hertfordshire Partnership NHS Foundation Trust	2.2h 2.2l	We endorse this area as being one of concern and would be glad for guidance about how to effect a smooth transition between child and adult services	Thank you for your comment.
78	SH	Hertfordshire Partnership NHS Foundation Trust	General	Although we recognise that these are NHS guidelines, we would like them to address, if possible, how best to support people with an ASC who have forensic issues.	Thank you for your comment. NICE guidelines are applicable to all NHS services, including those provided in prisons.
79	SH	Hertfordshire Partnership NHS Foundation Trust	2.2l & 3.3.1g	Many service for adults are currently configured as being for adults with learning disabilities or those with	Thank you for your comment. We hope the development of this guideline will ensure better NHS

				mental health problems and it is not always clear where the needs of more able people with an ASC should be addressed – or if a third stream of provision is needed. Some guidance in this area would be helpful.	services for all.
80	SH	Hertfordshire Partnership NHS Foundation Trust	General	A lot of families with Autistic family members often get into as much as rigid/ stuck patterns around the individual, having lived for so long in these patterns. This makes it incredibly hard for the individual to separate from the family, etc, and vice versa. Family members find it hard to let go and to trust others to work with their son/daughter, or to accept room for mistakes, learning, etc. There is often a lot of blaming of staff for lack of understanding (some of which is very true and justified) but there is no space for curiosity and learning. I think it will be extremely helpful for the guidance to include helping both staff and families to understand what is going on. It will reduce the ongoing battles and heartache the families face	Thank you for your comment, we will consider this when developing the guideline.
81	SH	Hertfordshire Partnership NHS Foundation Trust	General	Why not have one clinical guideline to cover children as well as adults, rather than separate them out	The Department of Health refer topics to NICE and we are unable to alter these. Also, the scope of a guideline covering both children and adults is unlikely to be manageable.
82	SH	Institute of Psychiatry	2.1	There are no data indicating that the “prevalence” of ASD’s has increased-the rise in numbers is due to the increase in numbers of cases diagnosed Asperger syndrome is not a “recent subgroup” The condition was described in the 1940’s. This diagnostic category may, of course also be removed from DSM-V	Thank for these comments – we will amend the text regarding Asperger Syndrome. We are aware of possible changes in DSM-V.
83	SH	Institute of Psychiatry	2.2b	The point about difficulty in getting a diagnosis needs to be made more strongly. The individuals who are most likely to be missed in childhood are those of normal IQ/more subtle deficits (e.g. Asperger group). If they seek a diagnosis there is often no service t hey can turn to. They fall outside the remit of LD services, and if they do not have a mental health disorder Adult Mental Health Services cannot accept them. There	Thank you for this comment - we have amended the text in light of your comment.

				are so few NHS services offering diagnostic assessments for adults that many people have to resort to private assessments. This excludes those of lower incomes, and often do not improve access to local services.	
84	SH	Institute of Psychiatry	2.2h	Even for individuals who have been well supported by CAMHS services, successful transition to adult services frequently fails One of the major problems is that many adults with ASD are not intellectually impaired (i.e. IQ is >70) and they may not have mental health problems that are severe enough to access adult MH services, or the support systems (especially social services support) that these services can provide. They are often left to cope alone and unsupported with the result that , as time goes on they may well develop mental health problems that could have been avoided. The provision of relatively low- intensity support in early adulthood, or at the transitional stage between child and adulthood could avoid the need for later, more intensive & expensive support	Thank you for your comment. We shall be addressing the transition between children's and adults' services in this guideline.
85	SH	Institute of Psychiatry	3.1.1c	OCD could be added to the list of coexisting conditions. Another group that needs particular help is that of *parents* with ASD. Many only realise that they, too, have the condition when their own child is diagnosed, and usually do not have a formal diagnosis themselves. They have many issues with regard to coping with family life but almost no specialised help is available to help them deal with their very special problems	Thank you we have added OCD. We agree the needs of families and carers should be included and we have included them in the scope in 3.3.1.f.
86	SH	Liverpool University Dental Hospital	General	The scope does not include the impact of poor oral health in this group of people. This is a missed opportunity. Dental diseases are preventable, but this requires regular educational input and the application of preventative strategies tailored to an individual. It is essential that oral health care is built into the care pathway.	Thank you for your comment, the scope does include physical interventions, see 3.3.1 e).

				Dental disease causes pain/discomfort, which can not always be appropriately expressed by the individual with ASD and this can impacts negatively on behaviour. This in turn can have a negative impact on well being and general care. People with ASD often present to numerous medical specialities in an attempt to diagnose the problem. People with ASD find dental treatment traumatic and many are unsuitable for management within the general dental services. Extra time, skills and interdisciplinary team work is required. Alternative methods of pain and anxiety control are often required which necessitates accessing specialist dental services. The time taken from recognising a problem to delivery of dental treatment can be time consuming and expensive. Poor oral health has an impact on social acceptability and a persons quality of life.	
87	SH	London Autistic Rights Movement	1	The term “management” could be misinterpreted as suggesting that autism is an illness that needs to be controlled or reduced. A more appropriate word would be “support” or “medical support” (as this relates to clinical guidelines rather than social or care services). This is a better way of expressing that emphasis should be on accepting that autism is part of who people are and the priority is to help them be the best that they can be, and to adhere to the Social Model of Disability.	As this comment is a duplicate please see comment 1 for the response.
88	SH	London Autistic Rights Movement	1.2	Please see above. Suggested improved wording: “To produce a clinical guideline on the support of adults with autistic spectrum conditions.”	As this comment is a duplicate please see comment 2 for the response.
89	SH	London Autistic Rights Movement	2.1c	The current wording is quite derogatory and fails to differentiate between being able to do something but finding it significantly more difficult than neuro-typicals, and not being able to do it at all. It also does not reflect the fact that there can be	As this comment is a duplicate please see comment 3 for the response.

				positive elements to autism Suggested improved wording: “Other features commonly found are difficulty with cognitive and behavioural flexibility, altered sensory sensitivity (which can have both advantages and disadvantages), sensory processing difficulties, stereotyped mannerisms, emotional regulation difficulties, and a narrow yet highly focused range of interests and activities.”	
90	SH	London Autistic Rights Movement	2.1d	Reference to medical professionals taking into account the Social Model of disability when considering impairments and impact on person’s functioning is **necessary** as while someone may be able to function so well in certain situations as to not be considered eligible for diagnosis, the reality of the way society operates and discriminates may well represent a substantial impact upon the individual’s functioning.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
91	SH	London Autistic Rights Movement	2.1f	More specific reference should be made to the fact that people on the autistic spectrum with an IQ above 70 fall in the ‘gap’ between mental health and learning disability services, often being considered ineligible for neither. Reference should also be made to the fact that many people are misdiagnosed and the fact that most medical professionals still have poor and inadequate knowledge of autistic spectrum conditions. Please also include reference to the fact that autism is a misunderstood, misrepresented and ‘hidden’ disability means that people on the spectrum are far more likely to experience bullying, ridicule, humiliation and discrimination.	As this comment is a duplicate please see comment 5 for the response.
92	SH	London Autistic Rights Movement	2.2a	Please could you elaborate on what specifically you are referring to when you say ‘genetic counselling’?	As this comment is a duplicate please see comment 6 for the response.
93	SH	London Autistic Rights	2.2b	In outlining the ‘ideal’ scenario, there is no reference to	As this comment is a duplicate please see comment 7

		Movement		the autistic individual having a say in the support and care they receive. This is not acceptable! All autistic individuals should have a say in any plan for future support or interventions for them. They should also be made aware of the positive elements of autism and of the autistic rights and pride movements for the sake of their own self-esteem, sense of identity and to give them true choice over their future. We recommend the use of the 'discovery' process advocated by Tony Attwood which includes looking at positive aspects. There also need to be a taking into account of autism-like symptoms being caused by such things as brain injuries, infections, strokes, traumatic births. There should be screening for these things, particularly as research by Headway suggests up to 70% of brain injuries are never diagnosed. Autism should be seen as including all those who have autism-like symptoms whatever the cause, and not as a specific genetic condition. Please see http://everist.org/archives/asp/Discovering_Asper.htm http://www.timesonline.co.uk/tol/comment/columnists/magnus_linklater/article5496799.ece http://www.newscientist.com/article/dn16941-savant-skills-may-be-widespread-in-people-with-autism.html http://www.newscientist.com/article/mg20627581.500-the-advantages-of-autism.html?DCMP=OTC-rss&nsref=online-news http://www.autreat.com/History_of_ANI.html	for the response.

				http://www.taaproject.com/about-us/mission-statement/ http://www.autisticadvocacy.org/modules/smartsection/category.php?categoryid=8 http://greg.quuxuum.org/journal/o_neill.html http://autisticsavant.blogspot.com/	
94	SH	London Autistic Rights Movement	2.2c	We would suggest adding the recommendation that further research needs to be done into the value of biomedical interventions and genetic counselling to ascertain how helpful this is in facilitating autistic individuals to fulfil their potential. There are numerous theories and supposed 'cures' and 'treatments' with little or no scientific basis and these should not be used until it can be proven that they are of genuine benefit and are safe.	As this comment is a duplicate please see comment 8 for the response.
95	SH	London Autistic Rights Movement	2.2f	It should also be added that current 'information-sharing' rarely, if ever, includes information on positive elements of autism, autistic self-advocacy and the rights/pride movement.	As this comment is a duplicate please see comment 9 for the response.
96	SH	London Autistic Rights Movement	2.2g	Change "leaves room for improvement" to "is extremely and unacceptably poor". The current wording is simply not strong enough to convey the reality of the situation.	Thank you but we feel that the language used is appropriate for this document.
97	SH	London Autistic Rights Movement	2.2i	You MUST add here that discrimination, misunderstanding, misrepresentation, refusal by employers to fulfil their legal obligations to make 'reasonable adjustments', and supported employment schemes that are ineffectual and have poor understanding, are a reason why people on the spectrum struggle to sustain long-term employment. Currently, what you have written does not reflect the truth of the situation as it seems you are blaming autistic individuals and not acknowledging the discrimination we face. It is also necessary to acknowledge that not all people	Thank you for your comment. This is a clinical guideline and NICE are unable to make recommendations to non-NHS organisations.

				on the autistic spectrum will be able to sustain employment and that ensuring that the person is happy and healthy is of greater importance than viewing them purely in terms of their economic productivity. http://www.tuda.org.uk/works.htm	
98	SH	London Autistic Rights Movement	2.2k	We would recommend that you contact an appropriate user-led organisation to check that ‘gender identity problems’ is the correct and non-offensive wording. It should also be added that people who identify as asexual often find that this is disrespected and unfairly pathologised by medical professionals. http://www.asexuality.org/home/overview.html	As this comment is a duplicate please see comment 11 for the response.
99	SH	London Autistic Rights Movement	3.1.1c	We would recommend that you contact an appropriate user-led organisation to check that ‘gender identity disorders’ is the correct and non-offensive wording.	As this comment is a duplicate please see comment 11 for the response.
100	SH	London Autistic Rights Movement	3.2c	Would be useful to discuss how this can be applied to the private sector where many organisations and individuals tout questionable ‘therapies’ and ‘cures’ and where assessments are offered by people who may well not have appropriate qualifications or experience. While we appreciate that this would not usually be in the remit of NICE, it is well known that out of desperation many parents send their children (including their adult children) to such people which could be risking their child’s safety. http://www.dailymail.co.uk/health/article-1023351/The-great-autism-rip---How-huge-industry-feeds-parents-desperate-cure-children.html	Thank you for your comment. NICE are unable to make recommendations to non-NHS organisations.
101	SH	London Autistic Rights Movement	3.3.1b	Please elaborate on what you are referring to when you say ‘genetic and biomedical techniques’? How well proven are these? How will strengths and skills be identified and how will it be ensured that these are preserved and valued (but	As this comment is a duplicate please see comment 14 for the response.

				not used as an excuse to refuse or reduce support)? Identifying strengths and skills is important but it must be made clear that the purpose of this is to tailor support to enable the individual to fulfil their potential and not used to force or push them into inappropriate employment or training or to manipulate, them.	
102	SH	London Autistic Rights Movement	3.3.1c	Please note that ABA is highly controversial and people on the spectrum may well not want this therapy and should have the right to refuse this without being penalised or discharged. http://www.springerlink.com/content/vnx08r94v2p3n703/ http://www.sentex.net/~nexus23/naa_vic.html http://www.sentex.net/~nexus23/naa_fac.html Please also note that CBT must be tailored and adapted to suit people on the spectrum. Dr. Tony Attwood has stated that ‘conventional’ psychological therapies can be useless or even damaging for people on the spectrum. Other psychological therapies should also be available as CBT is not appropriate for everyone and the bias that has been shown towards CBT is concerning. http://bjp.rcpsych.org/cgi/content/abstract/196/3/173 http://books.google.co.uk/books?id=qJZmsp3ZVG8C&pg=PA160&lpg=PA160&dq=attwood+asperger+therapy+damaging&source=bl&ots=lDtuiMwGxq&sig=wmzNM87Q_Q2e5GqdlgDbQ2xsWmA&hl=en&ei=W5PwS4XVKJHy0gSm6NjfBw&sa=X&oi=book_result&ct=result&resnum=3&ved=0CCEQ6AEwAg#v=onepage&q=therapy&f=false **WE OPPOSE ANY THERAPY THAT SEEKS TO MAKE AN AUTISTIC INDIVIDUAL ACT OR FAKE ‘NEURO-TYPICAL’ OR THAT MEASURES THEIR**	As this comment is a duplicate please see comment 15 for the response.

				PROGRESS BY HOW ‘NT’ THEY SEEM OR THAT SEEKS TO SUPPRESS, DISCOURAGE OR PUNISH ANY NON-HARMFUL AUTISTIC BEHAVIOURS, OR REMOVE OR DISREGARD AUTISTIC SKILLS, STRENGTHS AND TALENTS. It should be noted that while mentoring, befriending and social groups can be useful, some people on the spectrum prefer not to socialise, and this should be respected. Enforced socialisation can be very stressful to people on the spectrum and can even be akin to abuse. Dr Attwood writes about the importance of solitude for people on the spectrum http://books.google.co.uk/books?id=qJZmsp3ZVG8C&pg=PA160&lpg=PA160&dq=attwood+asperger+therapy+damaging&source=bl&ots=lDtuiMwGxq&sig=wmzNM87Q_Q2e5GqdlgDbQ2xsWmA&hl=en&ei=W5PwS4XVKJHy0gSm6NjfBw&sa=X&oi=book_result&ct=result&resnum=3&ved=0CCEQ6AEwAg#v=onepage&q=therapy&f=false Please note that appropriate mentoring / befriending / social groups may well be those that involve other people on the spectrum, e.g. an autistic individual mentoring another autistic person, online fora for people on the spectrum etc. It should also be noted firstly that employment may not be possible for all people on the spectrum and secondly that any supported employment scheme must be tailored to suit the unique needs of people on the spectrum and must have as a priority finding the right career for the autistic individuals and advocating for their rights and equality within the workplace. Support should be available for all types and levels of	

				job, from entry level to senior level. This support should also exist for people who are only able to work part time and people who want to work on a freelance / self-employed basis.	
103	SH	London Autistic Rights Movement	3.3.1d	Only as long as these do not cause side effects that the individual on the spectrum cannot cope with or suppress any non-harmful autistic behaviours or autistic strengths / talents The scope must also cover how this will be monitored to ensure that people on the spectrum are not made to endure side effects that are detrimental to their quality of life. Autistic individuals must have the right to refuse or be taken off medication they are not happy with without being (or threat of being) penalised or discharged. The unusual pharmacokinetic effects experienced by people on the spectrum must also be acknowledged and taken into consideration when prescribing medication. ***Please also see comment 23 regarding 3.5***	As this comment is a duplicate please see comment 16 for the response
104	SH	London Autistic Rights Movement	3.3.1e	Yes, but only if there is substantial research to show that these help the autistic individual and as long as they are not used to try to make someone more 'NT' or 'less autistic' or to stop or reduce non-harmful autistic behaviours. The autistic individual should have the final decision. In the case of dietary interventions that involve more expensive foods, these should be available on prescription (in the same way as for Coeliac disease) in order to ensure autistic individuals are not financially penalised. Discussion about this should form part of the "key issues". http://www.coeliac.org.uk/healthcare-	The purpose of this guideline is to assess the efficacy of interventions using the available evidence base. Thank you for this comment. This is outside of the scope and matter for the NHS to consider.

				professionals/prescriptions	
105	SH	London Autistic Rights Movement	3.3.1f	This should include support from autistic advocates and sources that give positive information about autistic traits such as http://everist.org/archives/asp/Discovering_Asper.htm and http://www.newscientist.com/article/mg20627581.500-the-advantages-of-autism.html?DCMP=OTC-rss&nsref=online-news All information must be provided in formats accessible to the individual on (or suspected to be on) the autistic spectrum e.g. Easy Read format, alternative colours, sans serif text, audio etc.	As this comment is a duplicate please see comment 18 for the response
106	SH	London Autistic Rights Movement	3.3.1g	Suggested change to wording: "The organisation and delivery of care, and care pathways for the effective components of support and treatment of co-existing conditions (including transition planning), based on an ethos of multi-professional working and with the wishes, skills and realization of potential of the autistic individual being paramount at all times." We would also recommend that user-led (in particular autistic-led) organizations are have ongoing involvement at all levels to provide information, support, 'expert patient' input etc. to medical and care professionals as we strongly believe that support co-designed by autistics for autistics will lead to the best possible outcomes for all individuals on the spectrum. It is important to consider how this can be implemented as one of the "key issues".	As this comment is a duplicate please see comment 19 for the response.
107	SH	London Autistic Rights Movement	3.4a & 3.4b	This must include identifying, recognising, preserving and encouraging the positive elements of autism, including any special skills, talents or abilities (including savantism where applicable).	As this comment is a duplicate please see comment 20 for the response.
108	SH	London Autistic Rights	3.4d	This MUST be within the context of the social model	As this comment is a duplicate please see comment 21

		Movement		and inclusive/accessible design. Difficulties in functioning in social/occupational/educational settings are often exacerbated (or even solely caused) by sensorily inaccessible environments, discrimination, bullying, misunderstanding, inaccessible information etc. Only when these are changed and society is truly inclusive can people on the spectrum have a chance to function at their best. Viewing difficulties in functioning as a problem within the individual is inaccurate, insulting and discriminatory, as well as extremely damaging to the rights of autistics as well as our self esteem. Please also note the enforced socialisation, making someone suppress non-harmful autistic behaviours and seeking to make an autistic person as NT as possible are discriminatory, offensive and damaging. It is essential that a main outcome is for NICE guidelines to contribute as far as possible to improved access, and recommendations for 'autism friendly' environments, communication and information in accessible formats. (e.g. in medical, care, educational and employment settings as well as tailoring Care Plans, Person Centred Plans, Special Educational Needs Assessments etc. to contain such recommendations)	for the response.
109	SH	London Autistic Rights Movement	3.5	The difficulty here is that issues that are well recognised and acknowledged by both professionals and individuals on the spectrum may not be represented in research. For example, many people on the spectrum experience unusual pharmacokinetic effects such as unexpected or severe side effects, responding to	As this comment is a duplicate please see comment 22 for the response.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

				unusually high or low dosage levels, paradoxical reactions etc. This has implications in prescribing and monitoring recommendations. This could also mean that medications that are blacklisted, because ‘cheaper medications that work just as well are available,’ could actually be necessary for people on the spectrum due to their unusual reactions – so perhaps it is necessary to consider removing certain medications from blacklists for people on the spectrum. There is, as far as we are aware, no research to back this up, but researching such a thing would be difficult. Which medication would you choose? How would you pick a control group etc.? While research and evidence are important, if something is widely anecdotally recognised by both professionals and autistics, this must be accepted by economists. Evidence must, primarily, be from autistics themselves regarding what does and doesn’t help them and whether or not the positives of a particular therapy outweigh the negatives. Relying on testimony from the medical world and/or carers only may lead to these people recommending or endorsing things that they see as making autistics ‘easier to control’ or ‘less difficult’ which are not the same as identifying and recognising those therapies that actually benefit autistics themselves.	
110	SH	London Autistic Rights Movement	5	Please make sure all of your documents are available in accessible formats such as Easy Read, alternative colours, Word (not just .pdf), audio, Braille etc.	As this comment is a duplicate please see comment 23 for the response.
111	SH	London Autistic Rights Movement	General	The scope should also include recommendations for future research and a set review date for the guidelines currently in development, e.g. 2015. The word	Thank you for your comment. It is not the purpose of the scope to make recommendations. The development of clinical guidelines often highlights the

				“disorder” should be replaced throughout with the word “difference” in respect of autism spectrum differences, as the use of the term “disorder” is at odds with the need to create awareness of the positive aspects of autism. This comments pro forma also represents the views of organisations the London Autistic Rights Movement is affiliated to, namely Neurodiversity International and Autistic Rights Movement UK	need for further research and we make research recommendations accordingly within the guideline.
112	SH	National Autistic Society	General	The National Autistic Society very much welcomes the development of new guidelines of the diagnosis and management of autism in adults.	Thank you.
113	SH	National Autistic Society	1.2	The remit talks about autistic spectrum disorders, while the rest of the scope uses the term “conditions”. The scope also switches between autism spectrum and autistic spectrum. There is already much confusion about terminology and diagnostic labels in relation to the whole autism spectrum and so it would be useful to clarify at as early an opportunity as possible, which term is being used and a (non-exhaustive) list of the diagnoses that this includes. In particular, it is our experience that adults with Asperger syndrome have been prevented from accessing services and so it is particularly important to highlight that the scope will include adults with Asperger syndrome, as well as those identified with other conditions on the spectrum (including for example Kanner autism, classic autism, atypical autism and pervasive developmental disorder). For your information, The National Autistic Society uses autism spectrum disorder (ASD) or autism by itself (with an explanation that when using “autism” we mean all diagnoses of autism on the spectrum).	We have adopted the term condition to be in line with the recent DH strategy paper on autism. We will however, clarify precisely what will be included in the guideline including the relevant diagnoses. Thank you for pointing out this inconsistency - we will adopt the term autistic spectrum conditions and we will use this throughout the guideline. Thank you for pointing this out to us, we shall add Asperger syndrome to 3.1.1 b).
114	SH	National Autistic Society	2.1b 2.1c	The scope refers to both the American Diagnostic and Statistical Manual of Mental Disorder (DSM IV) and to	Thank you for your comment. We will certainly be mindful of the proposed changes to DSM and ICD

			2.1d 2.1e	the World Health Organisation's International Classification of Diseases (ICD 10), but makes no reference to the proposed changes to the DSM classification (expected to be published 2013) or to the expected changes to the ICD (expected by 2015). The draft version of DSM V proposes quite a new and different approach to diagnosing autism and this could have a significant impact on the rate of diagnosis and the way a diagnosis is reached. It is therefore important that the scope recognises these changes and that the NICE guidelines are sufficiently flexible to ensure that when changes are made to diagnostic classifications, this does not affect the way that the guidelines work and are implemented. Moreover, given that the draft version of DSM V proposes getting rid of Asperger syndrome as a diagnosis, as part of these guidelines NICE should look at the implications of this and offer guidance on what it means.	however we are unable to comment on something that is yet to be published.
115	SH	National Autistic Society	2.1b 2.1c 2.1d 2.1e	This section is also slightly confusing in its current form as it starts by setting out what DSM IV says about the triad and then switches to ICD 10, to explain the conditions needed for a diagnosis. It would be clearer if the two classification systems were set out at the outset.	Thank you we have amended the scope to make this issue clearer
116	SH	National Autistic Society	2.1f	'Diagnostic overshadowing' can also mean that medical problems experienced by people on the spectrum are not identified because symptoms are attributed to a person's autism and not investigated further. This is particularly true for people who have no verbal communication and may communicate pain through what is seen to be "challenging behaviour".	Thank you for this comment we have amended this section to take account of your comment.
117	SH	National Autistic Society	2.2a	The reference to children in (a) is a little confusing. This section should perhaps start with the wording from (b).	Thank you we have re-worded section 2.2a
118	SH	National Autistic Society	2.2b	It should also be recognised that often where a	Thank you for your comment. We hope the

				diagnosis is not available locally through the NHS, individuals commonly self-refer to the private sector. This can be costly and not available to all. Moreover, it is even less likely that a diagnosis and assessment gained privately will be linked into local care pathways to support, meaning once an individual has a diagnosis they are still unable to access the support they need. Furthermore, a private diagnosis is sometimes not recognised by other health and social care professionals. Diagnosis is most useful when it is part of a needs and skills based assessment, which leads to personalised package of care.	development of this guideline will ensure better NHS services for all.
119	SH	National Autistic Society	2.2f	It should be noted that the adult autism strategy and first year delivery plan set out that the statutory guidance on autism services (to be published by the end of 2010) will set out details of what information adults with autism and their family or carers are likely to need after diagnosis. It would also be useful to think about what information someone might need if an assessment has been inconclusive and a diagnosis is not reached.	Thank you for your comment. We will take this into account when developing the guideline.
120	SH	National Autistic Society	2.2h	On the management of autism in children, we urge NICE to develop the proposed guidance on this.	Thank you for your comment. This topic is currently under consideration by NICE and the DH - we will draw your comment to the attention of NICE.
121	SH	National Autistic Society	2.2i	It would be useful to acknowledge here that there are some adults with autism who will need significant support to engage in employment and that some adults with autism may never work.	Thank you we agree with this comment and we will examine evidence for interventions that support people in gaining and sustaining employment (see 3.3.1.c).
122	SH	National Autistic Society	2.2k	It would be useful to acknowledge in this section the differences in accessing services and the different types of services that might be needed due to ageing.	Thank you for your comment. We will add the issues surrounding older people to our scope.
123	SH	National Autistic Society	2.2l	The adult autism strategy for England is about more than designing services to improve support for adults with autism. It is also about supporting adults with autism into work, educating employers, encouraging a	Thank you for your comment, we agree that the autism strategy is about all of these things and we have amended the text in light of your comment.

				cultural shift in the way autism is understood, so that services are provided across the public sector make appropriate adjustments for adults with autism.	
124	SH	National Autistic Society	2.2m	We would welcome clarification on the application of the NICE guidelines, as we were under the impression that clinical guidelines developed by NICE applied to England, Wales and Northern Ireland.	NICE guidance is available for use in Northern Ireland.
125	SH	National Autistic Society	3.1.1a	We believe that it is unhelpful to separate autism into two distinct categories (high functioning and low functioning autism) as has been done here. As already highlighted in the scope autism is a complex spectrum condition and cannot be easily divided into these groups. To do so would misrepresent the spectrum and would inadvertently exclude those who cannot be described as either high or low functioning.	Thank you for this comment – we appreciate that the terms are open to misunderstanding by some but as they are in widespread use within the NHS we think it is important that they are represented in the guideline. We can assure you that we intend to cover the full spectrum and we will consider in the GDG the utility of the terms when we develop our recommendations.
126	SH	National Autistic Society	3.1.1b	Adults with Asperger syndrome have consistently missed out on services because of their diagnosis. It must be explicit here that the scope includes Asperger syndrome as well as all of the other diagnoses on the spectrum.	Thank you for pointing this out to us, we shall add Asperger syndrome to 3.1.1 b).
127	SH	National Autistic Society	3.1.1c	As already highlighted, the specific needs of older adults with autism should also be looked at as a separate group.	Thank you for your comment. We will add the issues surrounding older people to our scope.
128	SH	National Autistic Society	3.1.2	While we understand that NICE must respond to the remit given by the Department of Health, which refers specifically to adults with autism, we urge NICE to look at transition into adult services as part of this guidance. 2.2 h highlights key problems in relation to transition, making it clear that first access to adult services is a key challenge that needs addressing. Recent research by the NAS has found that there are no transition plans for 70% of children with autism who are accessing CAMHS services. Moreover, most of the CAMHS teams we spoke to as part of our research do not routinely plan for transition to adult services. For those services that did plan for transition, they found co-operation with adult services difficult, making it even	Thank you for your comment. We will be looking at the transition from children’s to adults’ services in this guideline.

				more important that transition is included as part of the adult guideline. Any future guidelines for managing autism in children should also look at this to ensure a smooth transition is standard. Transition is mentioned in 3.3.1 g but we believe it should be clearer that the scope covers transition.	
129	SH	National Autistic Society	3.3.1a	It would be useful to give some guidance to NHS bodies around the level of training that professionals would need to make sure that they recognise the signs of autism so that they can refer on for diagnosis.	Thank you for your comment. We will consider this issue as part of 3.3g.
130	SH	National Autistic Society	3.3.1a	An indication of the types of training needed in order for individuals, as part of a multi-disciplinary team to be in a position to diagnose autism would also be useful	Thank you for your comment. We will consider this issue as part of 3.3g.
131	SH	National Autistic Society	3.3.1c 3.3.1d 3.3.1e 3.3.1f 3.3.1g	There are some significant concerns about the quality and usefulness of some of the interventions currently available – some of which, with no evidence base, claim to “cure”. A useful outcome of the guideline would be to develop some means for people with autism and parents/carers to check the validity of these claims. Research autism has a database of interventions and the evidence for them, which could assist in this.	The purpose of this guideline is to assess the efficacy of interventions using the available evidence base.
132	SH	National Autistic Society	3.3.1f	Consideration should also be paid to what information and support is given when an assessment has not been able to conclusively confirm or rule out a diagnosis of autism	Thank you for this comment – this issue will be part of the discussion when the GDG consider the evidence on assessment.
133	SH	National Autistic Society	3.3.2	While we understand that the diagnosis and management of co-existing conditions may be beyond the scope of this guideline, it is absolutely essential that the interaction of co-existing conditions with autism is considered in recommendations around diagnosis and assessment of autism and around the interventions used.	Thank you for your comment. Co-occurring conditions will be addressed as outlined in 3.1.1 c).
134	SH	National Autistic Society	4.1	We urge NICE to also take forward the proposal to develop a guideline on “managing autism in children”, which should include guidance on support that children with autism need, as well as guidance on adapting	This topic is currently under consideration by NICE and the DH - we will draw your comment to the attention of NICE.

				interventions for those children with autism who also have a mental health problem.	
135	SH	National Public Health Service for Wales	General	This stakeholder responded with no comments to make	
136	SH	Neurodiversity International	1	The term "management" could be misinterpreted as suggesting that autism is an illness that needs to be controlled or reduced. A more appropriate word would be "support" or "medical support" (as this relates to clinical guidelines rather than social or care services). This is a better way of expressing that emphasis should be on accepting that autism is part of who people are and the priority is to help them be the best that they can be, and to adhere to the Social Model of Disability.	As this comment is a duplicate please see comment 1 for the response.
137	SH	Neurodiversity International	1.2	Please see above. Suggested improved wording: "To produce a discovery including clinical guideline on the support of adults with autistic spectrum differences as a type of neurodiversity often overlapping with other types, whether developmental (e.g. "developmental coordination disorder" (dcd) or acquired (through brain injury) or degenerative or as a consequence of mental health differences including conditions." Note that it is the policy of the neurodiverse (including autistic) rights movement to use the word difference rather than condition as this is scientifically more accurate – recognizing both positive and negative aspects of autism. "Discovery comes from the widely acknowledged and acclaimed clinical expert on Asperger's Syndrome, Tony Attwood's "Discovering Aspie: The Positive Aspects of Asperger's Syndrome" "Discovery criteria" (which include the likelihood, for example, that the person with Asperger's Syndrome will be more honest on average than the general population)". There must be specific recognition that up to 90% of autistic people are also dyspraxic, 50+% are dyslexic and up to 99% have some form of black on white scotopic sensitivity, 20+% have ADHD, up to 80% have casein and/or gluten processing differences	We have adopted the term condition to be in line with the recent DH strategy paper on autism. We will however, clarify precisely what will be included in the guideline including the relevant diagnoses. We note your comments on Asperger Syndrome and we will amend the scope to make clear that Asperger Syndrome will be included. We will also undertake a comprehensive review of the diagnosis and assessment of ASC and consider such problems as dyspraxia. The purpose of the consultation is to seek the views of all stakeholders and it can not be the case that any one stakeholder organisation can have the "final say" on any matter covered in the scope.

				which effectively amount to intolerances requiring a different diet, the majority have OCD, bowel problems, etc. Discovery and diagnostic procedures must be comprehensive, not the current mess of people having to go to lots of different over-narrow and unconnected specialists for each diagnosis. The issue of abuse and hidden brain injury must also be explored. Ultimately all definitions must be agreed in detail by representative autistic organisations themselves which are to have the final say. Likewise, mutatis mutandis (with the necessary changes) for other types of neurodiversity.	
138	SH	Neurodiversity International	2.1c	The current wording is quite derogatory and fails to differentiate between being able to do something but finding it significantly more difficult than neuro-typicals, and not being able to do it at all. It also does not reflect the fact that there can be positive elements to autism Suggested improved wording: "Other features commonly found are difficulty with cognitive and behavioural flexibility, altered sensory sensitivity (which can have both advantages and disadvantages), sensory processing difficulties, stereotyped mannerisms, emotional regulation difficulties, and a narrow yet highly focused range of interests and activities."	As this comment is a duplicate please see comment 3 for the response.
139	SH	Neurodiversity International	2.1d	Reference to medical professionals taking into account the Social Model of disability when considering impairments and impact on person's functioning is **necessary** as while someone may be able to function so well in certain situations as to not be considered eligible for diagnosis, the reality of the way society operates and discriminates may well represent a substantial impact upon the individual's functioning.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
140	SH	Neurodiversity International	2.1f	More specific reference should be made to the fact that	As this comment is a duplicate please see comment 5

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				people on the autistic spectrum with an IQ above 70 fall in the ‘gap’ between mental health and learning disability services, and also quite often other services (physical disability, long-term conditions, brain injury and memory services, etc) often being considered ineligible for neither mental health nor learning disability or any other service. Reference should also be made to the fact that many people are misdiagnosed and the fact that most medical professionals still have poor and inadequate knowledge of autistic spectrum differences including conditions. Let alone wider neurodiversity. A comprehensive neurological and metabolic diagnosis, treatment and development service needs to be created with numbers and training of professionals to match the best Please also include reference to the fact that autism is a misunderstood, misrepresented and ‘hidden’ disability means that people on the spectrum are far more likely to experience bullying, ridicule, humiliation and discrimination.	for the response.
141	SH	Neurodiversity International	2.2a	Please could you elaborate on what specifically you are referring to when you say ‘genetic counselling’?	As this comment is a duplicate please see comment 6 for the response.
142	SH	Neurodiversity International	2.2b	In outlining the ‘ideal’ scenario, there is no reference to the autistic individual having a say in the support and care they receive. This is not acceptable! All autistic individuals should have a say in any plan for future support or interventions for them. They should also be made aware of the positive elements of all forms of neurodiversity including autism and of the neurodiverse (including dyslexic, dyspraxic, adhd and autistic rights and pride movements) for the sake of their own self-esteem, sense of identity and to give them true choice over their future. We recommend the use of the ‘discovery’ process advocated by Tony	As this comment is a duplicate please see comment 7 for the response.

				Attwood which includes looking at positive aspects. There also need to be a taking into account of autism-like symptoms being caused by such things as brain injuries, infections, strokes, traumatic births. There should be screening for these things, particularly as research by Headway suggests up to 70% of brain injuries are never diagnosed. Autism should be seen as including all those who have autism-like symptoms whatever the cause, and not as a specific genetic condition. It needs to be recognised that traumas and abuse of all sorts as well as brain injuries can trigger autism, and people who have had an infant or early childhood brain injury are being diagnosed as autistic. The criteria needs to be whether or not someone with a brain injury can remember what they were like before the brain injury. If they can, then they are likely to “mourn the loss of their previous self” and should be classified as people with acquired neurodiversity with some autistic like characteristics. Headway has held conferences on brain injury which have included such things as autistic type behaviours (including in adults) after brain injury as the main theme. According to the Childhood Brain Injury Trust (CBIT) in over half of cases of brain injuries in infants under the age of two, parents and/or carers are at least partly responsible. These are often covered up, with additional problems for the victim. Every discovery and diagnosis must screen for this as part of the discovery and diagnostic procedure itself. There must be no statute of limitations on damages (using the analogy of abuse cases). Please see http://everist.org/archives/asp/Discovering_Asper.htm http://www.timesonline.co.uk/tol/comment/columnists/magnus_linklater/article5496799.ece	

				http://www.newscientist.com/article/dn16941-savant-skills-may-be-widespread-in-people-with-autism.html http://www.newscientist.com/article/mg20627581.500-the-advantages-of-autism.html?DCMP=OTC-rss&nsref=online-news http://www.autreat.com/History_of_ANI.html http://www.taaproject.com/about-us/mission-statement/ http://www.autisticadvocacy.org/modules/smartsection/category.php?categoryid=8 http://greg.quuxuum.org/journal/o_neill.html http://autisticsavant.blogspot.com/	
143	SH	Neurodiversity International	2.2c	We would suggest adding the recommendation that further research needs to be done into the value of biomedical interventions and genetic counselling to ascertain how helpful this is in facilitating autistic individuals to fulfil their potential. There are numerous theories and supposed ‘cures’ and ‘treatments’ with little or no scientific basis and these should not be used until it can be proven that they are of genuine benefit and are safe. There needs to be a full and integrated range of medical including neurological, metabolic, dietary, sensory integration, homeopathic and traditional services involved. Intellectual property laws must be revised to enable the profitable evaluation and marketing of traditional medicines and natural remedies which are found to be effective. These must be made available on prescription.	Thank you for your comment. It is not the purpose of the scope to make recommendations. The development of clinical guidelines often highlights the need for further research and we make research recommendations accordingly within the guideline. The purpose of this guideline is to assess the efficacy of interventions using the available evidence base. We are unable to make recommendations to changes in the law.
144	SH	Neurodiversity International	2.2f	It should also be added that current ‘information-sharing’ rarely, if ever, includes information on positive elements of autism, autistic self-advocacy and the rights/pride movement.	As this comment is a duplicate please see comment 9 for the response.
145	SH	Neurodiversity International	2.2g	Change “leaves room for improvement” to “is	As this comment is a duplicate please see comment 96

				extremely and unacceptably poor". The current wording is simply not strong enough to convey the reality of the situation.	for the response.
146	SH	Neurodiversity International	2.2i	You MUST add here that discrimination, misunderstanding, misrepresentation, refusal by employers to fulfil their legal obligations to make 'reasonable adjustments', and supported employment schemes that are ineffectual and have poor understanding, are a reason why people on the spectrum struggle to sustain long-term employment. Currently, what you have written does not reflect the truth of the situation as it seems you are blaming autistic individuals and not acknowledging the discrimination we face. It is essential that access standards are revised to meet our needs, including through supporting the British Standards Institute (BSI) Task Group on Neurodiversity, Cognitive Impairment and Access to the Built Environment. It is worth reinforcing that Autism is a form of neurodiversity and that a number of autism-specific organisations are represented on this Task Group including the London Autistic Rights Movement (LARM) and the National Autistic Society (NAS). It is also necessary to acknowledge that not all people on the autistic spectrum will be able to sustain employment and that ensuring that the person is happy and healthy is of greater importance than viewing them purely in terms of their economic productivity. They can instead become supported employers, as has been shown by such examples as a very severely autistic non-verbal person employing over 10 people in his not-for-profit recycling organisation which also funds his salary and 9 full time carers. http://www.tuda.org.uk/works.htm	Thank you for your comment. This is a clinical guideline and NICE are unable to make recommendations on the employment practices of non-NHS organisations.
147	SH	Neurodiversity International	2.2k	We would recommend that you contact an appropriate user-led organisation to check that 'gender identity problems' is the correct and non-offensive wording.	As this comment is a duplicate please see comment 11 for the response.

				Some intersex and hermaphroditic conditions also cause a greater propensity for neurodiversity including autism (e.g. Kleinfelt Syndrome and Marfan Syndrome). Varying shades of intersex and hermaphroditic conditions need to be recognised as more common than people think and changing of people's gender (e.g. through surgery to sex organs) without informed consent should be banned. The person needs to be old enough, except in the case of a threat to their life or very severe injury, to give their consent. It should also be added that people who identify as asexual often find that this is disrespected and unfairly pathologised by medical professionals. http://www.asexuality.org/home/overview.html	
148	SH	Neurodiversity International	3.1.1c	We would recommend that you contact an appropriate user-led organisation to check that 'gender identity disorders' is the correct and non-offensive wording. Again, difference is better than disorder as the person is not necessarily "disordered" or "dysfunctional". They are certainly and often very positively "different".	As this comment is a duplicate please see comment 11 for the response.
149	SH	Neurodiversity International	3.2c	Would be useful to discuss how this can be applied to the private sector where many organisations and individuals tout questionable 'therapies' and 'cures' and where assessments are offered by people who may well not have appropriate qualifications or experience. While we appreciate that this would not usually be in the remit of NICE, it is well known that out of desperation many parents send their children (including their adult children) to such people which could be risking their child's safety. http://www.dailymail.co.uk/health/article-1023351/The-great-autism-rip---How-huge-industry-feeds-parents-desperate-cure-children.html	As this comment is a duplicate please see comment 100 for the response.
150	SH	Neurodiversity International	3.3.1b	Please elaborate on what you are referring to when	As this comment is a duplicate please see comment 14

				you say ‘genetic and biomedical techniques’? How well proven are these? How will strengths and skills be identified and how will it be ensured that these are preserved and valued (but not used as an excuse to refuse or reduce support)? Identifying strengths and skills is important but it must be made clear that the purpose of this is to tailor support to enable the individual to fulfil their potential and not used to force or push them into inappropriate employment or training or to manipulate, them.	for the response.
151	SH	Neurodiversity International	3.3.1c	Please note that ABA is highly controversial and people on the spectrum may well not want this therapy and should have the right to refuse this without being penalised or discharged. http://www.springerlink.com/content/vnx08r94v2p3n703/ http://www.sentex.net/~nexus23/naa_vic.html http://www.sentex.net/~nexus23/naa_fac.html Please also note that CBT must be tailored and adapted to suit people on the spectrum. Dr. Tony Attwood has stated that ‘conventional’ psychological therapies can be useless or even damaging for people on the spectrum. Other psychological therapies should also be available as CBT is not appropriate for everyone and the bias that has been shown towards CBT is concerning. Dr Amita Shaw has done authoritative research which shows that non-Asperger specific (and non-specific CBT for other types of autism) can be extremely damaging. She also points out that sessions should sometimes be as short as 15 minutes at a time. http://bjp.rcpsych.org/cgi/content/abstract/196/3/173 http://books.google.co.uk/books?id=qJZmsp3ZVG8C&	As this comment is a duplicate please see comment 15 for the response.

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				pg=PA160&lpg=PA160&dq=attwood+asperger+therapy+damaging&source=bl&ots=lDtuiMwGxq&sig=wmzNM87Q_Q2e5GqdlgDbQ2xsWmA&hl=en&ei=W5PwS4XVKJHy0gSm6NjfBw&sa=X&oi=book_result&ct=result&resnum=3&ved=0CCEQ6AEwAg#v=onepage&q=therapy&f=false **WE OPPOSE ANY THERAPY THAT SEEKS TO MAKE AN AUTISTIC INDIVIDUAL ACT OR FAKE ‘NEURO-TYPICAL’ OR THAT MEASURES THEIR PROGRESS BY HOW ‘NT’ THEY SEEM OR THAT SEEKS TO SUPPRESS, DISCOURAGE OR PUNISH ANY NON-HARMFUL AUTISTIC BEHAVIOURS, OR REMOVE OR DISREGARD AUTISTIC SKILLS, STRENGTHS AND TALENTS, except where the autistic person gives their informed consent to this after also being informed of any potentially negative consequences.** It should be noted that while mentoring, befriending and social groups can be useful, some people on the spectrum prefer not to socialise, and this should be respected. Enforced socialisation can be very stressful to people on the spectrum and can even be akin to abuse, if not torture. Dr Attwood writes about the importance of solitude for people on the spectrum http://books.google.co.uk/books?id=qJZmsp3ZVG8C&pg=PA160&lpg=PA160&dq=attwood+asperger+therapy+damaging&source=bl&ots=lDtuiMwGxq&sig=wmzNM87Q_Q2e5GqdlgDbQ2xsWmA&hl=en&ei=W5PwS4XVKJHy0gSm6NjfBw&sa=X&oi=book_result&ct=result&resnum=3&ved=0CCEQ6AEwAg#v=onepage&q=therapy&f=false Please note that appropriate mentoring / befriending / social groups may well be those that involve other	

				people on the spectrum, e.g. an autistic individual mentoring another autistic person, online fora for people on the spectrum etc. It should also be noted firstly that employment may not be possible for all people on the spectrum and secondly that any supported employment scheme must be tailored to suit the unique needs of people on the spectrum and must have as a priority finding the right career for the autistic individuals and advocating for their rights and equality within the workplace. Those with very high support needs and some others should be encouraged to become employers of their own support staff (with the full administrative backup which they need) and also self-employment. Support should be available for all types and levels of job, from entry level to senior level. This support should also exist for people who are only able to work part time and people who want to work on a freelance / self-employed basis.	
152	SH	Neurodiversity International	3.3.1d	Only as long as these do not cause side effects that the individual on the spectrum cannot cope with or suppress any non-harmful autistic behaviours or autistic strengths / talents The scope must also cover how this will be monitored to ensure that people on the spectrum are not made to endure side effects that are detrimental to their quality of life. Autistic individuals must have the right to refuse or be taken off medication they are not happy with without being (or threat of being) penalised or discharged. The unusual pharmacokinetic effects experienced by people on the spectrum must also be acknowledged and taken into consideration when prescribing medication. As Professor Patricia Howlin emphasises	As this comment is a duplicate please see comment 16 for the response

				microtitration (or building up from microscopic and far less than normal doses up to full dosage and sometimes, if the person under reacts, to much higher than normal recommended doses is an essential part of any treatment process for neurodiverse including autistic people and others with known sensitivities ***Please also see comment 23 regarding 3.5***	
153	SH	Neurodiversity International	3.3.1e	Yes, but only if there is substantial research to show that these help the autistic individual and as long as they are not used to try to make someone more 'NT' or 'less autistic' or to stop or reduce non-harmful autistic behaviours. Likewise for other types of neurodiverse behaviours. The autistic individual should have the final decision. In the case of dietary interventions that involve more expensive foods, these should be available on prescription (in the same way as for Coeliac disease) in order to ensure autistic individuals are not financially penalised. Discussion about this should form part of the "key issues". http://www.coeliac.org.uk/healthcare-professionals/prescriptions	The purpose of this guideline is to assess the efficacy of interventions using the available evidence base. Thank you for this comment this outside of the scope and matter for the NHS to consider.
154	SH	Neurodiversity International	3.3.1f	This should include support from neurodiverse including autistic advocates and sources that give positive information about neurodiverse including autistic traits such as http://everist.org/archives/asp/Discovering_Asper.htm and http://www.newscientist.com/article/mg20627581.500-the-advantages-of-autism.html?DCMP=OTC-rss&nsref=online-news All information must be provided in formats accessible to the individual on (or suspected to be on) the autistic spectrum e.g. Easy Read format, alternative colours, sans serif text, audio etc.	Thank you for this comment – this issue will be part of the discussion when the GDG consider the evidence on assessment.

155	SH	Neurodiversity International	3.3.1g	Suggested change to wording: "The organisation and delivery of care, and care pathways for the effective components of support and treatment of co-existing conditions (including transition planning), based on an ethos of multi-professional working and with the wishes, skills and realization of potential of the autistic individual being paramount at all times." We would also recommend that user-led (in particular autistic-led) organizations are have ongoing involvement at all levels to provide information, support, 'expert patient' input etc. to medical and care professionals as we strongly believe that support co-designed by autistics for autistics will lead to the best possible outcomes for all individuals on the spectrum. It is important to consider how this can be implemented as one of the "key issues".	As this comment is a duplicate please see comment 19 for the response.
156	SH	Neurodiversity International	3.4a & 3.4b	This must include identifying, recognising, preserving and encouraging the positive elements of autism, including any special skills, talents or abilities (including savantism where applicable).	As this comment is a duplicate please see comment 20 for the response.
157	SH	Neurodiversity International	3.4d	This MUST be within the context of the social model and sustainable including inclusive/accessible design. See also previous comments on the BSI. It is also essential to tackle the hierarchy of impairments and the hierarchy of equalities which tend to place neurodiverse including autistic people at the bottom of the pile. Difficulties in functioning in social/occupational/educational settings are often exacerbated (or even solely caused) by sensorily inaccessible environments, discrimination, bullying, misunderstanding, inaccessible information etc. Only when these are changed and society is truly inclusive can people on the spectrum have a chance to function	Thank you for this comment –the issues that you raise will be considered by the GDG when considering the relevant evidence.

				at their best. Viewing difficulties in functioning as a problem within the individual is inaccurate, insulting and discriminatory, as well as extremely damaging to the rights of neurodiverse people (nds) including autistics as well as our self esteem. It is essential to look at the positive first, then at the social model of disability and the way in which society disables us through inaccessible environments and negative and discriminatory attitudes. Please also note the enforced socialisation, making someone suppress non-harmful autistic behaviours and seeking to make an autistic person as NT as possible are discriminatory, offensive and damaging. It is essential that a main outcome is for NICE guidelines to contribute as far as possible to improved access, and recommendations for 'autism friendly' environments, communication and information in accessible formats. (e.g. in medical, care, educational and employment settings as well as tailoring Care Plans, Person Centred Plans, Special Educational Needs Assessments etc. to contain such recommendations)	
158	SH	Neurodiversity International	3.5	The difficulty here is that issues that are well recognised and acknowledged by both professionals and individuals on the spectrum may not be represented in research. For example, many people on the spectrum experience unusual pharmacokinetic effects such as unexpected or severe side effects, responding to unusually high or low dosage levels, paradoxical reactions etc. This has implications in prescribing and monitoring	As this comment is a duplicate please see comment 22 for the response.

				recommendations. This could also mean that medications that are blacklisted, because ‘cheaper medications that work just as well are available,’ could actually be necessary for people on the spectrum due to their unusual reactions – so perhaps it is necessary to consider removing certain medications from blacklists for people on the spectrum. There is, as far as we are aware, no research to back this up, but researching such a thing would be difficult. Which medication would you choose? How would you pick a control group etc.? While research and evidence are important, if something is widely anecdotally recognised by both professionals and autistics, this must be accepted by economists. Evidence must, primarily, be from autistics themselves regarding what does and doesn’t help them and whether or not the positives of a particular therapy outweigh the negatives. Relying on testimony from the medical world and/or carers only may lead to these people recommending or endorsing things that they see as making autistics ‘easier to control’ or ‘less difficult’ which are not the same as identifying and recognising those therapies that actually benefit autistics themselves.	
159	SH	Neurodiversity International	5	Please make sure all of your documents are available in accessible formats such as Easy Read, alternative colours, Word (not just .pdf), audio, Braille etc.	As this comment is a duplicate please see comment 23 for the response.
160	SH	Neurodiversity International	General	The scope should also include recommendations for future research and a set review date for the guidelines currently in development, e.g. 2015. The word “disorder” should be replaced throughout with the word “difference” in respect of autism spectrum differences, as the use of the term “disorder” is at odds with the need to create awareness of the positive aspects of	Thank you for your comment. It is not the purpose of the scope to make recommendations. The development of clinical guidelines often highlights the need for further research and we make research recommendations accordingly within the guideline.

				autism. This comments pro forma also represents the views of organisations the London Autistic Rights Movement is affiliated to, namely Neurodiversity International and Autistic Rights Movement UK, with additional comments added in red by Neurodiversity International which expand on a number of points for greater clarity. Hence the NDI submission is being sent under separate cover. NDI would like to thank LARM Steering Group member Anya Ustaszewska for the initial draft, the LARM membership and the Politics of Autism yahoo group for suggestions for the final LARM draft completed by LARM Chair Roderick Cobley.	
161	SH	NHS Direct	General	NHS Direct welcome the guideline and have no specific comment on the content.	Thank you.
162	SH	NHS Nottinghamshire County	General	Very pleased to see that this guidance is being developed.	Thank you.
163	SH	NHS Nottinghamshire County	General	Need to ensure that the different issues and needs associated with some conditions on the Autistic Spectrum are not overshadowed by general features which apply to all ASCs. For example, we would wish some of the specific issues associated with Aspergers Syndrome to be highlighted. Adults with Aspergers are often subject to even greater marginalisation and exclusion, experiencing difficulties in accessing services and support – and in particular accessing diagnosis. Aspergers is often misunderstood or not recognised by professionals both due to its relative ‘newness’ as a category and because those with Aspergers often have higher levels of functioning not generally associated with autism.	Thank you for your comment. Asperger Syndrome will be covered in this guideline and we have amended 3.1.1. b) to reflect this.
164	SH	NHS Nottinghamshire County	2.1f	Agree that health, education and social care professionals often overlook ASCs, but they also lack knowledge and understanding about ASCs which compounds this and increases barriers to accessing appropriate services. Essential that the guidance makes reference to the need for training for frontline	Thank you for your comment. We will consider this issue as part of 3.3g.

				staff.	
165	SH	NHS Nottinghamshire County	2.2j	Agree. Would like to see 2nd sentence read: *Adults at the higher end of the autistic spectrum* (*such as those with suspected Aspergers Syndrome*). This would add give added emphasis to the fact that the guidance includes those with Aspergers.	Thank you for pointing this out to us, we shall add Asperger syndrome to 3.1.1 b).
166	SH	NHS Nottinghamshire County	3.1.1b	Aspergers Syndrome should be included as one of the examples given – gives added emphasis and also puts the content in line with that in para 2.1.e	Thank you for pointing this out to us, we shall add Asperger syndrome to 3.1.1 b).
167	SH	NHS Nottinghamshire County	3.1.1c	Pleased to see that consideration will be given to co-existing conditions such as those listed.	Thank you for your comment. Co-occurring conditions are an important consideration in this group.
168	SH	Pathological Demand Avoidance Contact Group	3.1.1b	Could the tern Pathological Demand Avoidance Syndrome be included in this group as more and more children are being diagnosed with this autism spectrum condition and therefore they will become adults with the condition too!	Pathological Demand Avoidance Syndrome is not part of the formal diagnostic systems (DSM-IV or ICD-10) and will therefore not be considered but aspects of the behaviour associated with PDAS will be considered
169	SH	Royal College of General Practitioners Wales	3.3.1g	RCGP Wales welcomes the opportunity to respond to this document. This is the area that requires most work – as early diagnosis in Primary care setting is dependant upon initial presentation and history taking, but the time required and skills necessary for full use of diagnostic toolkits is best done by the provision of specialist centres of excellence to whom Primary care can refer .	Thank you for your comment. We hope the development of this guideline will ensure better NHS services for all.
170	SH	Royal College of Nursing	General	The Royal College of Nursing welcomes proposals to develop this guideline. It is timely. The draft scope seems comprehensive.	Thank you.
171	SH	Royal College of Nursing	3.1.1a	Include Asperger's syndrome in the list for clarity.	Thank you for pointing this out to us, we shall add Asperger syndrome to 3.1.1 b).
172	SH	Royal College of Psychiatrists	2.1b	DSM-IV – I assume the 'c' is a typo?	Thank you for pointing this out to us, we have amended this in the text.
173	SH	Royal College of Psychiatrists	2.1f	Diagnostic overshadowing is a two-way process – may I suggest: "Diagnostic overshadowing' means there may be a tendency to overlook symptoms of autism spectrum conditions in these groups and attribute them to being part of an intellectual disability *or to any of the above coexisting condition as well as to attributing the*	Thank you for this comment we have amended this section to take account of your comment.

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

				conditions to autism”	
174	SH	Royal College of Psychiatrists	3.1.1a	The use of ‘low-functioning’ implies that this includes adults with a substantial coexistant, generalised, learning disability. It would be helpful to be explicit whether this group is to be included or excluded.	Thank you – this is not the case but may include, as we have by way of example, those without a learning disability but who have profound communication difficulties that significantly impair functioning.
175	SH	Royal College of Psychiatrists	3.1.1c	While minority ethnic groups probably includes the group, I wonder if special mention should be made of visitors, immigrants and asylum seekers who come from different cultural backgrounds and with limited English ?	Thank you for your comment. This will be covered by BME groups.
176	SH	Royal College of Psychiatrists	3.3.1b	Should this recognise that the nature of a diagnostic assessment will be tailored to the needs of the individual, should this list also include the assessment of mental capacity (including, for example, the capacity to offend, be a witness in a legal case etc.)	We consider this to be outside of the scope
177	SH	Royal College of Psychiatrists	3.3.2	“the primary diagnosis” is ambiguous” as it implies a hierarchy. Might it be better phrased “a primary diagnosis”?	Thank for this comment we have amended the text as you suggested
178	SH	Royal College of Speech and Language Therapists	2.2c	“Healthcare Professionals” – while diagnosis by be undertaken by different individuals (paediatrician, ed psych, SLT etc), diagnosis, treatment and monitoring of the communication aspects should be undertaken by a speech and language therapist with experience and expertise in autistic spectrum disorders	Thank you for your comment. Speech and language therapists would be included under the term ‘healthcare professionals’.
179	SH	Royal College of Speech and Language Therapists	2.2d	This issue may support the screening for communication issues and autism in these disorder groups.	Thank you for this comment – we will consider communication issues when developing our recommendations.
180	SH	Royal College of Speech and Language Therapists	2.2g	Shortages in SLT ALD services make lack of diagnosis and treatment worse	Thank you for this comment – our intention in the guideline is to recommend what constitutes a good assessment, it will be for the NHS to determine how such services are staffed.
181	SH	Royal College of Speech and Language Therapists	2.2l	The RCSLT’s response to the government’s strategy is available for information	Thank you for pointing this out to us.
182	SH	Royal College of Speech and Language Therapists	3.2	Omits adult education settings with health input	Thank you but this would be included under the general health heading.
183	SH	Royal College of Speech and Language Therapists	3.2a	RCSLT has much supporting evidence on screening and support for prisoners in secure settings	Please send us any studies you feel will be relevant to this guideline.
184	SH	Royal College of Speech	3.3.1	Needs to include communication support in b, c, and f	Thank you for this comment - this is covered under the

		and Language Therapists		including working with and through others, and supporting families	provision of information in 3.3.1.f
185	SH	Royal College of Surgeons of England	General	The scope does not include the impact of poor oral health in this group of people. I know that this was raised and agreed as a really important issue at two of the tables (at least) at the scope event which took place at NICE HQ. Poor oral health is preventable and it is essential that oral health care is built into the care pathway. Poor oral health causes pain/discomfort, can not always be appropriately expressed by the individual with autism spectrum disorders and often impacts negatively on behaviour. This in turn can have a negative impact on well being and general care. Many people with autism spectrum disorders find it very difficult to accept dental treatment. Getting to a point where treatment can be delivered (not always achieved) can be lengthy and costly. Poor oral health has an impact on social acceptability in the population as a whole this can be exaggerated for people with autism spectrum disorders who may already be experiencing some form of stigmatism/discrimination whether it be intentional or not. For example, It is evidenced that people with poor dental appearance (missing, bad, broken front teeth) are less likely to gain employment. I reiterate that poor oral health is preventable and it is essential that oral health care is built into the care pathway to ensure that this is one less barrier that people with autism spectrum disorders have to deal with.	Thank you for your comment, the scope does include physical interventions, see 3.3.1 e).
186	SH	Royal College of Surgeons of England	General	Can there be a reassurance that although the childrens' and young peoples' guideline is ahead of the	We understand your concerns and will be working jointly with the children's guideline to ensure a sensible

				adult guideline that a balance can be struck so that: a. it will be considered in defining the adult guidance, and b. it will not lead the defining of the adult guidance	and appropriate balance is struck.
187	SH	Scottish Intercollegiate Guidelines Network (SIGN)	General	Thank you for the invitation to comment on this proposed guideline. Our comments are as follows... We welcome this proposed guideline. It will directly complement the scope of SIGN 98 on ASD in children and young people, ie it will consider assessment and clinical intervention. Its publication will assist in further raising the profile of ASD and the need to ensure seamless care pathways across the entire age range. We respectfully suggest that specific mention be made of the need to consider issues connected to ASD pathology in the over 65 adult population. It is entirely possible, for example, for adults over 65 to be presenting as undiagnosed cases of ASD in this age range. Also, we respectfully suggest that consideration be given to the development of a user's version of the guideline to assist in dissemination of information, and also a version for carers of adults with ASD. These could be developed within a users and carers scoping forum as occurred in SIGN 98. We have found the parent/carer and young persons' version of SIGN 98 to be very helpful in raising awareness of the issues connected to clinical care within ASD.	Thank you for your comments. We will add the issues surrounding older people to our scope.
188	SH	Sheffield Bullying Observatory	General	It is excellent that NIHCE is undertaking these guidelines: I proposed something similar to Dr. Wing and others about 7 years ago, but did not take the initiative myself and I don't remember if I added it to the NICE website as a proposal at the time. I am pleased that someone did. The document is, as one might expect, well ordered and systematic but very much based on a medical	Thank you for your comments. We intend to adopt a broad focus in the guideline but our focus is on the NHS and inevitably this leads to a focus on medical issues.

				model which is, in my view, only partly applicable to adults with an ASD, and then usually to adults with autism rather than more able adults. My comments mostly reflect this.	
189	SH	Sheffield Bullying Observatory	General	There is no evidence that ASDs are always lifelong conditions, and good evidence that they are not, at least in a proportion of people	Thank you for your comment, as you have not supplied any references for this we are unable to comment further.
190	SH	Sheffield Bullying Observatory	General	My own clinical experience is that the figure of 1% for prevalence in adults is an over-estimate. Although I was an advisor to the Leicester study, I have not been given access to the data analysis and so do not know how this figure was arrived at.	Thank you but we have relied on published data in developing this scope and the figured quote reflect this data.
191	SH	Sheffield Bullying Observatory	General	There is insufficient consideration of the emotional consequences of ASD, but these are likely, in my clinical experience, to be at least as important in quality of life and social exclusion, including exclusion from employment, as the primary impairment	Thank you this issue along with others will be considered in the review of the evidence.
192	SH	Sheffield Bullying Observatory	General	The ‘management’ of ASD already presupposes that society has no obligation to enable people with an ASD to lead a more fulfilling life. It is taken from the medical model, and to a now out of date view of disability. People with an ASD are exposed to bullying and stigmatization that is a consequence of neurotypicality and its association with tribalism and this perspective needs to be included as well as the medical one. There is mention of exclusion but not in the context of a reflection on neurotypical social structures. The approach here and elsewhere is overwhelmingly medical	Thank you we intended to adopt a broad focus in the guideline but our focus is on the NHS and inevitably this leads to a focus on medical issues.
193	SH	Sheffield Bullying Observatory	General	Exploitation and bullying needs to be given much more emphasis. For example, the long-term impact of bullying, its frequency in the workplace and in the neighbourhood needs to be considered.	Thank you for your comment, we will consider this when developing the guideline.
194	SH	Sheffield Bullying Observatory	General	The possible underdiagnosis of women with an ASD, or their misdiagnosis as having a ‘personality disorder’ is to be applauded as it are the consideration of underdiagnosis in people of different cultures. However, this cannot be effectively dealt with without a	Thank you for your comment, we will consider this when developing the guideline.

				consideration of whether other cultural groups perceive an ASD as a disability in the same way that white Westerners do. Looking at these issues in ADHD suggests important differences in attitudes to medication.	
195	SH	Sheffield Bullying Observatory	General	There is considerable overlap with ADHD. This guideline therefore needs to be articulated with NIHCE guidelines for ADHD, particularly the guideline for ADHD in adults, now in preparation.	Thank you for your comment, we will consider this when developing the guideline.
196	SH	Sheffield Bullying Observatory	General	The biomedical emphasis is brought out strongly by the discussion of investigations. Whilst this does need to be covered, a more important area of systematic assessment is family and social functioning.	Thank you we will consider both interventions help families and also support them – this is already covered in the scope.
197	SH	Sheffield Bullying Observatory	General	There is no discussion of forensic issues, including offending, false confessions, the use of compulsory treatments	Thank you but we consider this issue to be outside the current scope
198	SH	Sheffield Bullying Observatory	3.4	Psychosis and bipolar disorder are omitted here	Thank you for your comment, this is an illustrative rather than an exhaustive list.
199	SH	Sheffield Bullying Observatory	General	Cognitive-behavioural therapy is specifically mentioned although there is no evidence of its superiority over other approaches. My own clinical experience is that it is a less successful approach than person-centered counselling.	Thank you for your comment, this is an illustrative rather than an exhaustive list.
200	SH	Sheffield Bullying Observatory	General	The specific topics mentioned in the document do not reflect the balance of difficulties encountered in psychiatric practice. For example, joint working between learning disability and adult mental health services is not considered. Nor is the impact of old age. Nor catatonia, nor paedophilia. ABA is mentioned but must only be applicable to a tiny proportion of adults with an ASD. It is to be hoped that the topics themselves are open to considerable change and improvement	Thank you for your comment, we will consider this when developing the guideline.
201	SH	Sheffield Bullying Observatory	Economic analysis	Although it is understandable why QuALYs are being used, the economic issue will be how quality of life is calculated in order to make the adjustments. Pain and disability are not readily applied to ASD. Loss of income, the most commonly used cost measure, may	The preferred measure of benefit is the QALY, but its use depends on availability of appropriate data. Estimation of QALYs is possible to take into account other quality of life issues that are relevant to adults with ASC. However, we are aware that available data

				be a misleading measure of cost unless the effect on parental income is also considered. Burden in terms of life restriction for carers needs also be factored in, but needs better estimators of soft costs like life satisfaction.	may not allow estimation of QALYs in this guideline. In this case, an alternative measure of benefit will be chosen. The scope has been extended to cover this issue. Loss of income is a measure beyond the scope of NICE economic analyses and will not be considered in the reference-case or any extra analyses (see NICE ‘guide to the methods of technology appraisal’, 2008). The burden to carers may not be possible to factor in formally, but will be taken into account indirectly, if the HRQoL of adults with ASC is improved.
202	SH	Sheffield Health and Social Care Foundation Trust	1 & 1.1	The title ASC does not make clear that those conditions are disorders – the language/terminology used may have huge implications for gateways/access to care and support	We have adopted the term condition to be in line with the recent DH strategy paper on autism. We will however, clarify precisely what will be included in the guideline including the relevant diagnoses.
203	SH	Sheffield Health and Social Care Foundation Trust	2.1e	DSM V will be out by the time of NICE Guidelines. The draft DSM V does not include Asperger Syndrome, and it is intended to re classify as mild PDD/ASD	Thank you for your comment. We are aware of the revised DSM classification and will be mindful of this during development.
204	SH	Sheffield Health and Social Care Foundation Trust	2.1c	There needs to be more acknowledgement of the *multi-layered* needs of adults with Asperger Syndrome – as well as having clear pathways for obtaining the ‘primary’ ASC diagnosis, these need to be in place for related learning difficulties and associated conditions e.g. Dyspraxia, Dyslexia, Sensory Impairment, Speech and language Difficulties etc. For individuals who are not in employment or education having these related difficulties assessed appears to be particularly problematic.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
205	SH	Sheffield Health and Social Care Foundation Trust	2.1f 2.2d	Re. “diagnosis overshadowing” – there needs to be explicit guidance on the ‘pitfalls’ around *misdiagnosis* and the overlap between/comorbidity with other conditions (e.g. Aspergers being misdiagnosed as OCD, personality disorder, psychosis etc). Psychosis is not mentioned in the scope. Many patients receive antipsychotic medication un-necessarily.	Thank you for this comment we have amended this section to take account of your comment.

206	SH	Sheffield Health and Social Care Foundation Trust	2.1f	The issue of accessing *social support* must be addressed – it seems to be a barrier for *many* and too often people only receive support following crisis – there is not enough access to *ongoing preventative / proactive / practical support.* Another issue: too many people misconstrue the true ability / coping of people with Asperger Syndrome because of terms like “high functioning” or “mild Autism”, or because they see certain ‘pockets’ of skills without appreciating these often go hand in hand with significant areas of need / impairment.	Thank you for your comment, we will consider this when developing the guideline.
207	SH	Sheffield Health and Social Care Foundation Trust	2.1f	There needs to be far more support targeting individuals with ASCs into work *and* supporting them (and employers) once they’re there - to prevent/manage problems in the workplace and to enable progression. In addition, access to DLA and ESA financial support does not currently seem equitable and many are assessed by individuals who do not seem to understand the ‘invisible’ disabilities ASCs involve. The term “High Functioning” in relation to ASCs too often seems to mask and prevent the recognition of massive areas of need/difficulty.	Thank you for your comment. This is a clinical guideline and NICE are unable to make recommendations to non-NHS organisations.
208	SH	Sheffield Health and Social Care Foundation Trust	2.1e	Re. the diagnostic classification systems (DSM IV and ICD10) – there needs to be clear acknowledgement of how Asperger Syndrome can present slightly differently among *females* (versus males). There also needs to be more formal acknowledgment of *unusual sensory experience* and *clarification around exclusion criterion* that seem questionable e.g. early language delay ruling out Asperger Syndrome.	Thank you for your comment. The information you provide will be useful for guideline development, but is probably more detail than is required for the scope.
209	SH	Sheffield Health and Social Care Foundation Trust	2.2b 3.3.1f	The absence of *follow-up support* for adults with Asperger Syndrome is often a huge issue and ‘gap’ in services. ‘Time-limited’ approaches are not always appropriate for this condition given that it’s life-long and the difficulties caused by evolving/ongoing life transitions (big and ‘small’!) e.g. school>higher edu/work, leaving school, marrying, break-ups, children, job changes/progression, children,	Thank – we agree and this is recognised in the final sentence of section 2.2b

				retirement…etc etc	
210	SH	Sheffield Health and Social Care Foundation Trust	2.2g	Training must improve and be integrated *within* the training of all health and social care professionals – as any of these could be required to work with individuals with ASCs: doctors, nurses, social workers, support workers, psychologists, psychiatrists, OTs, SLTs…etc. Training should *not* be tokenistic or ad hoc and when questions or problems arise individuals or teams should be identified who can provide specialist knowledge, advice and consultation.	Thank you for your comment. We will consider this issue as part of 3.3g.
211	SH	Sheffield Health and Social Care Foundation Trust	2.2h 2.2l 3.1.1c	Too many *young adults* with ASCs are falling between services – there are no clear pathways or protocols for this particularly vulnerable group (17-25yrs). There needs to be acknowledgement that young people with ASCs do not necessarily come though CAMHS – some come via schools/units and some come from a situation where they have never had any special input (the latter group being at particular risk of falling between services).	Thank you for your comment. We shall be addressing the transition between children's and adults' services in this guideline.
212	SH	Sheffield Health and Social Care Foundation Trust	2.2j	Training must tackle the issue of harmful *stereotypes* around ASCs, as well as highlight the huge *diversity* among different individuals with ASCs.	Thank you for your comment. We will consider this issue as part of 3.3g.
213	SH	Sheffield Health and Social Care Foundation Trust	2.2k 3.1.1c	What about *older people* with ASCs / diagnosis in later life?	Thank you for your comment. We will add the issues surrounding older people to our scope.
214	SH	Sheffield Health and Social Care Foundation Trust	3.2	There is no mention of the Mental Health Act assessment of people with ASC (Code of Practice of the MHA chapter 34), or the occasional need for inpatient treatment in general psychiatric wards, PICUs or specialist units.	Thank you for your comment. As set out in 3.2 all NHS services will be considered.
215	SH	Sheffield Health and Social Care Foundation Trust	3.1.1a	There needs to be acknowledgement that some people who are very intelligent can have considerable need because they are "very Autistic", whilst other individuals with a learning disability might have ASC impairments which are comparatively "mild" – the diversity in individual profiles of need is huge!	Thank you – we agree that this can be the case hence our use of the example, that is some with a learning disability but who has profound communication difficulties that significantly impair functioning.
216	SH	Sheffield Health and Social Care Foundation Trust	3.3.1b	There is a lot of inconsistency in practice around *diagnostic tools* and whether or not assessment is *multi-disciplinary* – explicit guidance around this would	Thank you for your comment. The purpose of this guideline is to assess the efficacy of interventions using the available evidence base.

				be helpful, as well WHO should or should not be conducting diagnostic assessment.	
217	SH	Sheffield Health and Social Care Foundation Trust	3.3.1c	What about more systemic support to *families / partners*? What about *speech and language* and *occupational therapy* interventions (e.g. sensory integration / executive functioning difficulty support)? The evidence base for these things may involve a wide search – looking at existing literature within various professions.	Thank you for your comment, the needs of carers will also be addressed in this guideline, as outlined in 3.3.1 f). The purpose of this guideline is to assess the efficacy of interventions using the available evidence base.
218	SH	Sheffield Health and Social Care Foundation Trust	3.3.1g	*Which* professions should be involved and how?	Thank you for your comment, this is something we shall explore during development.
219	SH	Sheffield Health and Social Care Foundation Trust	3.4	To include: More support for families; more adults living independently (away from the parental home); job progression and satisfaction; social skills development and confidence and reduced isolation in education (not just 'academic achievement')	Thank you for your comment, the issues you raise here will be considered during development.
220	SH	Welsh Assembly Government	General	Our comments are as follows: The Autistic Spectrum Disorder Strategic Action Plan for Wales (2008) is mentioned on Pg 5 at paragraph M. You may not be aware but we are sure it would be helpful to include the recent Welsh assembly Government document on ASD adults with Autism Report published (22 January): http://wales.gov.uk/topics/health/publications/socialcare/reports/asd/?lang=en	Thank you for bringing this to our attention, we will add a reference to this document to the scope

These stakeholder organisations were approached but did not respond

Abertawe Bro Morgannwg University (ABMU) Local Health Board
Association of Dance Movement Therapy UK
Autism North East
Bangor University
Bradford District Care Trust
British Association for Behavioural & Cognitive Psychotherapies (BABCP)
British Association for Counselling and Psychotherapy
British National Formulary (BNF)
Calderstones Partnerships NHS Foundation Trust
Care Quality Commission (CQC)
CIS'ters
Citizens Commission on Human Rights
Coeliac UK
College of Mental Health Pharmacy
College of Occupational Therapists
Commission for Social Care Inspection
COMMUNITY INTEGRATED CARE
Connecting for Health
Craegmoor Healthcare
DANDA: Developmental Adult Neurodiversity Association
Department for Children, Schools and Families
Department of Health Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI)
East and North Herts NHS Trust
Faculty of Dental Surgery
Faculty of Occupational Medicine
Gloucestershire Hospitals NHS Trust
Humber Mental Health Teaching NHS Trust
Leeds PCT
Leicestershire Partnership NHS Trust & Managed Clinical Network for PD
Medicines and Healthcare Products Regulatory Agency (MHRA)
Mersey Care NHS Trust
Mersey Care NHS Trust
Ministry of Defence (MoD)
Mother and Child Foundation
National Patient Safety Agency (NPSA)
National Treatment Agency for Substance Misuse

NETSCC, Health Technology Assessment
NHS Knowsley
NHS Plus
NHS Quality Improvement Scotland
NHS Sheffield
NICE TLOC GDG
North Staffordshire Combined Healthcare NHS Trust
Northumberland Tyne & Wear Trust
Nottinghamshire Healthcare NHS Trust
Oxfordshire & Buckinghamshire Mental Health Partnership NHS Trust
Oxleas NHS FoundationTrust
PERIGON Healthcare Ltd
Poole and Bournemouth PCT
Research Autism
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians London
Royal Society of Medicine
Ruskin Mill Educational Trust
Sheffield Teaching Hospitals NHS Foundation Trust
Social Care Institute for Excellence (SCIE)
Social Exclusion Task Force
South Essex Partnership NHS Foundation Trust
South West Autistic Rights Movement
St Andrew's Healthcare
Sussex Partnership NHS Foundation Trust
Talking Mats research and development center
Tees Esk & Wear Valleys NHS Trust
The Princess Royal Trust for Carers
Turning Point
Welsh Scientific Advisory Committee (WSAC)
Western Health and Social Care Trust
York NHS Foundation Trust