

National Institute for Health and Clinical Excellence

**Autism Management in Children
Scope Consultation Table
2 September – 30 September 2011**

Type (NB this is for internal purposes – remove before posting on web)

SH = Registered Stakeholders. These comments and responses will be posted on the NICE website after guideline development begins.

GRP = Guidelines Review Panel member. These are added to this table for convenience but will not be posted on the web.

NICE = Comments from NICE. These are added to this table for convenience but will not be posted on the web.

Non Reg = Comments from organisations and people who have not registered as stakeholder. These are added for convenience but will not be posted on the web.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	SH	Autism Rights Group Highland (ARGH)	1	general	We wish to thank you for using the more appropriate and less offensive term ASC throughout this guideline, we consider this to be the correct terminology.	Thank you for your comment, however, since the scope consultation NICE has decided to standardise the terminology used in all three of the guidelines on autism that it is developing. Therefore, we will now use the term 'autism' instead of 'ASC'.
2	SH	British Association for Adoption and Fostering (BAAF)	1	General	<p>This response is being submitted on behalf of the BAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for looked after children and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence.</p> <p>Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people.</p>	Thank you for your comment. We share your concern that looked after and adopted children constitute a vulnerable group, and section 4.1.1. (b) of the scope states that looked after children will be given special consideration. However, this guideline will not specifically address children on the autistic spectrum who have been adopted, although it will be relevant to them.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
3	SH	Cerebra	1	General	There are one or two concerns I have that are not fully addressed by the guidelines as they are. I am particularly heartened by what the guidelines say about children with complex conditions that include ASD characteristics, and those who have characteristics of ASD which nevertheless fall below the thresholds for receiving the diagnosis. It is good that these children and their circumstances are recognised as possibly needing similar help to those who have the diagnosis, because in my experience they tend to be cut off from such help, and their difficulties are sometimes minimised by local professionals, contributing to a worse build-up of problems. While this sometimes leads to diagnosis and better access to services later, it would be desirable for children and their families not to have to experience a worsening of their circumstances before the help they seek is finally put in place. To be more flexible than some services currently are, so that ASD-oriented services could be open to children children with threshold-borderline and/or complex neurodevelopmental/mental/organic situations, may help.	Thank you. We agree that these issues are important, however we would refer you to NICE clinical guideline 128 on diagnosis of autism in children and young people. We will discuss these issues in the introduction to this guideline, however we have not discussed diagnosis in the guideline scope.
4	SH	Department of Health	1	General	The Department of Health has no substantive comments to make regarding this consultation	Thank you for your comment.
5	SH	NHS Direct	1	General	NHS Direct welcome the guideline and have no comments on the contents of the scope.	Thank you for your comment.
6	NICE	NICE Technical Adviser	1	General	This is a well thought out and comprehensive scope , clearly aiming to identify issues important to children and young people who experience autism as well as their families, carers and others involved in offering support or direct care.	Thank you for your comment.
7	SH	Royal College of Nursing	1	general	The Royal College of Nursing welcomes proposals to develop this guideline. It is timely.	Thank you for your comment.
8	SH	Royal College of Paediatrics and Child Health	1	General	Clear, easy to read and very comprehensive.	Thank you for your comment.
9	SH	Royal College of Psychiatrists in Wales	1	General	We agree by and large with the scope of the guideline regarding the management and support of children and young people on the autism spectrum.	Thank you for 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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
10	SH	Royal College of Speech and Language Therapists	1	general	<p>We note that an independent economic evaluation of speech and language therapy (SLT) commissioned by The Royal College of Speech and Language Therapists (RCSLT) and published by Matrix Evidence in December 2010 has evaluated the provision of SLT for children with autism.¹ The report estimates that every £1 invested in enhanced SLT for children with autism generates £1.46 through lifetime savings and productivity gains.² It says: "In comparison to routine SLT, an enhanced SLT program targeting parent-child interaction results in improved communication which increases future independence. Increased independence results in a greater number of individuals living in private and supported accommodation in adulthood, relative to residential and hospital settings."³ The benefit of providing enhanced SLT for the 8,763 children in the UK aged 2-4 with core autism requiring SLT is estimated as £31m, the annual cost as £21m per year and the annual net benefit as £10m.⁴</p> <p>¹ Marsh, K., Bertranou, E., Suominen, S. and Venkatachalam, M. (2010) <i>An economic evaluation of speech and language therapy</i>, Matrix Evidence, p. 6. http://www.rcslt.org/giving_voice/matrix_report</p> <p>² Matrix report, p. 8. ³ Matrix report, p. 8. ⁴ Matrix report, p. 87.</p>	Thank you for drawing our attention to this piece of work, however this consultation is about the content of the scope of the guideline and not the evidence that may be considered during development. There will be a systematic search for economic evidence. Studies identified through this search that meet our set inclusion criteria will be considered during guideline development.
11	SH	The National Autistic Society	1	General	<p>The National Autistic Society (NAS) warmly welcomes the work that NICE are currently undertaking in relation to autism.</p> <p>These guidelines have the potential to substantially improve clinical knowledge, individual experience and the nature of support offered to people with autism and the NAS would be happy to do all it can to help support their development.</p> <p>We would like to also underline the importance of these guidelines looking at how to adapt treatment for mental</p>	Thank you for your comment. We understand that the number of treatments available makes things difficult for parents, and we agree that it is important to ensure that parents and carers are well-informed about available interventions. In developing this guideline we will consider all interventions for which there is evidence.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					<p>health issues for those children with autism who also have a mental health problem and believe it would be particularly beneficial if this is clearly part of the scope.</p> <p>The 'management' of autism in children can be a contentious issue. Parents whose child has just received a diagnosis are particularly susceptible to trying anything.</p> <p>There are large number of treatments and therapies available; indeed on the Research Autism website they list 877 such interventions. This makes it extremely difficult for people with autism, parents and professionals to find an approach that is best-suited to their individual circumstance/need.</p> <p>A guideline on the use of different interventions is therefore particularly welcome.</p> <p>Autism is a lifelong condition and although certain approaches may help control and manage characteristics behaviours and/or enhance particular skills that make life for the individual much easier and more enjoyable, people with autism are likely to continue to require some level of support and assistance throughout their life.</p>	
12	SH	Cerebra	2	General	<p>An associated matter that also concerns me is the approach to "parenting" interventions in local settings, because parents of children in these two categories sometimes say that the parenting techniques they are taught seem inappropriate for these particular children, and could even be making their condition worse. I think they are often given these classes because the child is perceived as having attachment and/or behavioural difficulties. I am sure you will already be aware of the stigma that is attached to these classes, which in itself can lead to a negative cycle of relationships locally. I know they are very useful for those they are suitable for, but if a child's ASD is not recognised and it does not help them, the</p>	<p>Thank you for your comment, and for highlighting this issue. NICE has developed a guideline on the diagnosis of children and young people with autism (CG 128), which covers the care pathway up until diagnosis. This guideline will look at psychosocial interventions, including parenting interventions if there is evidence in this area.</p>

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					onus in everyone's mind locally tends to veer towards parents doing something wrong and the child needing to "pull their socks up", which they may well not be able to do based on the punitive approach that then creeps in, for example at school. The problem is compounded by the fact that nurseries, schools and other settings sometimes say they perceive no problems with the young child and the problems only surface at home (leading other local professionals to think that it is "only" an attachment disorder) but on occasions when I have investigated a bit more deeply, I have found that they actually do have them, coming out slightly differently perhaps in the different setting, but still there.	
13	SH	Royal College of Paediatrics and Child Health	2	General	Overall, the scope seems very apposite.	Thank you for your comment.
14	SH	Royal College of Speech and Language Therapists	2	general	We would emphasise the need to have regard to the relevant national strategies for each country.	Thank you for your comment, which we agree with. NICE guidelines make recommendations for services in England and Wales, although recommendations may also be relevant for Scotland and Northern Ireland.
15	SH	The National Autistic Society	2	General	In our view, the most common interventions can be categorised into 10 broad areas. Namely: <ul style="list-style-type: none"> 1. Behavioural interventions 2. Complementary therapies 3. Diet and supplements 4. Medical interventions 5. Physiological interventions 6. Relationship-based interventions 7. Service-based interventions 8. Skills-based interventions 9. Standard therapies 10. Technology <p>Clearly, however, many interventions use a combination of many of these approaches and it is very difficult to define</p>	Thank you for 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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					<p>exactly which category an intervention should be classed as.</p> <p>Using a combination of factors is often very important and we do warn against any one intervention or therapy that claims to be the 'cure' for autism.</p> <p>As such, the NAS does not offer an opinion on which interventions 'work best' and instead focus on becoming an expert advisor to people with autism and parents/carers.</p>	
16	SH	Cerebra	3	General	<p>I also encounter parents who say that non-clinical local professionals have told them that their child does not really have a condition, even when the child has a diagnosis - it is even more difficult when there is no diagnosis. (This makes me a bit concerned about the training that these professionals receive before they reach the local setting - I have tried to get to the bottom of it and am not yet certain, but my instinct says that this is the point where some misconceptions about brain-related problems have crept in. This also raises the question of awareness of professional boundaries. I wonder whether there is scope for clinical specialists in this area to provide some input into the training of other professionals before they start in the field.) It seems to me that it would be helpful for clinicians to realise the difficulties that are sometimes presented to families in the wider social context, especially where there are ASD characteristics and possibly the child has other diagnoses but not that one on the list. I know you will already be aware of the many cases where ASD is not picked up at all until the child is much older, or even adult, and these guidelines do seem to hold out the promise that this will happen to fewer people once they are in place.</p>	<p>Thank you for your comment. The recently published NICE guideline on the diagnosis of autism in children and young people aims to help improve diagnosis. This guideline will be concerned with the post-diagnosis part of the care pathway, and as stated in the scope, it will take account of the wider social context of the management of children and young people with autism, and the support of them and their families.</p>
17	SH	Royal College of Paediatrics and Child Health	3	General	<p>Chelation therapy, hyperbaric oxygen, swimming with dolphins, stem cell injections are unproven potentially dangerous treatments that have and are being used for children with autism.</p>	<p>Thank you for your comment. We agree that there are a number of misconceptions in this area, and a major purpose of this guideline will be to identify interventions for which there is evidence.</p>
18	SH	Royal College of	3	general	<p>We note that recent changes to statementing have led to a</p>	<p>Thank you. In developing this guideline the GDG</p>

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Speech and Language Therapists			broad range of different interpretations which is confusing to families.	will have regard to the recent green paper from DfE on joint assessments.
19	SH	The National Autistic Society	3	General	<p>The NAS agrees with the findings of the 'National Autism Plan for Children' (2003), which states that the interventions that are most effective are those that:</p> <ol style="list-style-type: none"> 1) Use predictability, routine and consistency as important elements in the teaching of news skills and reducing problem behaviours 2) Use visual strategies to emphasise meaning 3) Offer social opportunities 4) Teach understanding of the problems associated with autism 5) Employ a functional approach to problem behaviours 6) Build on basic behavioural strategies and break down complex tasks into their constituent parts to enhance learning 7) Use naturally occurring reinforcers <p>Also, it is worth emphasising that the early the intervention the better and we are pleased that the scope makes explicit reference to this.</p>	Thank you for your comment, however this consultation is about the content of the scope of the guideline and not the evidence that may be considered during development.
20	SH	College of Occupational Therapists	5	General	A significant number of children with ASD require input from Social Care occupational therapy or Social Services for safety issues around the home, as the children show decreased personal safety awareness or exhibit challenging behaviour which puts their family at risk. This service, often referred to as 'Safe Environment Provision' needs to be reflected as it potentially has far reaching financial implications.	Thank you – this issue is going to be considered, depending on the availability of relevant clinical and cost data. Costs relating to provision of the service are within the perspective of main economic analyses, although, as stated in the scope, economic analyses will adopt a wider perspective, relevant to the financial implications of the management of children with autism, depending on availability of relevant data.
21	SH	Royal College of Paediatrics and Child Health	5	General	This seems to be a comprehensive scope that complements the diagnostic guidelines soon to be released. The selective eating disorders and lack of exercise that many children with ASD have seem to be major issues as far as long term health is concerned.	Thank you for your comment, however this consultation is about the content of the scope of the guideline and not the evidence that may be considered during development.
22	SH	College of	6	General	We note that the anticipated publication date of this NICE	Thank you for your comment, however this issue is

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Occupational Therapists			guideline is November 2013. Is consideration therefore being given to the forthcoming American Psychiatric Association's <i>Diagnostic and Statistical Manual of Mental Disorders (DSM-5)</i> due to be published in May 2013? http://www.dsm5.org/Pages/Default.aspx	covered in the recent NICE clinical guideline (CG 128) on the diagnosis of autism in children and young people.
23a	SH	Royal College of Paediatrics and Child Health	6	General	This is an important guideline that will hopefully streamline the management of autism in children and young people.	Thank you for your comment.
23b	SH	Royal College of Paediatrics and Child Health	7	General	<p>The scope has managed to capture important questions that physicians and allied health professional ask when dealing with children and young people with autism and their families. Currently, there is a huge market advertising all sorts of treatment options that parents are drawn into without any evidence to back them up. Hopefully the guideline should be able to address those different treatment modalities.</p> <p>The scope seems quite comprehensive. We are delighted to see that the term "autism" is used to cover the wider range of the spectrum rather than using different titles (autism spectrum, atypical autism, etc) that add little value and create confusion different understanding among clinicians and families.</p>	Thank you for your comment. A major purpose of this guideline will be to seek to identify interventions for which there is evidence.
24	SH	Royal College of Paediatrics and Child Health	8	General	It will be helpful that when the guideline is written it is not limited or restricted and takes into consideration (as much as possible) the common practices among paediatricians outside the UK.	Thank you for your comment, which we have noted.
25	SH	Royal College of Nursing	9	General	As diagnosis is primarily in Community Health settings there is a key role for Community Paediatricians and for forging better links between them and school nurses. NICE's acknowledgment of this should lead to better partnership arrangements and properly funded, as per the suggested title change.	Thank you for your comment. We agree that the role played by community paediatricians and school nurses is important.
26	SH	Royal College of Paediatrics and Child Health	9	General	We think this is an excellent proposal but will involve many disciplines and may be difficult to find an evidence basis or adequate way of measuring outcome and assessing cost effectiveness.	Thank you for your comment. The purpose of this guideline is to assess the efficacy and cost effectiveness of interventions using the available evidence base. The collaboration between the

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					There should be some representation for adult mental health services to help evaluate the long term benefits or effects of recognition and management of autism in childhood.	National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence, and the members of the GDG, will ensure that this evidence is reviewed by professionals from different disciplines. We also have comprehensive search strategies in order to find the evidence base. We shall be addressing the transition between children's and adults' services in this guideline, and where there is available evidence we will look at long-term effects of childhood interventions. In addition, we will attempt to capture long-term outcomes and associated financial implications in our economic analyses, from childhood through adulthood, depending on availability of clinical and cost data. The scope ('Economic aspects') has been amended to reflect this issue.
27	SH	Autism Rights Group Highland (ARGH)	10	general	The different way that women and girls will present must be covered, the current diagnostic schedules and some preconceived ideas of health professionals and others lean heavily towards the male presentation. The stereotype that four times as many males are autistic is misleading; it is only correct to say that four times as many males are diagnosed / identified. Cultural differences should also be considered in terms of assessment and diagnosis, for example eye contact and social differences.	Thank you for your comment – this guideline will not be dealing with the diagnosis and assessment of children and young people with autism as this is covered by existing NICE guidance: "Autism: recognition, referral and diagnosis of children and young people on the autism spectrum". However, consideration will be given to the particular management and support needs of girls and young women.
28	SH	Royal College of Paediatrics and Child Health	10	General	The scope of this guideline seems appropriate and covers the relevant issues.	Thank you for your comment.
29	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	11	General	The British Association for Music Therapy is happy to work with NICE in any evaluation of the evidence base for music therapy.	Thank you for your comment, which we have noted.
30	SH	Royal College of	11	General	It is not clear whether the guideline is exclusively for people	Thank you for your comment. This guideline will

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Paediatrics and Child Health			<p>with a formal diagnosis of autism or also for other individuals without a formal diagnosis but who display sufficient features for the diagnosis to be considered a possibility.</p> <p>Whilst it might be intended that this guideline should apply to those with a formal diagnosis of autism, some of the interventions recommended may be relevant for those with social communication difficulties but who do not have a formal diagnosis of autism and it would be helpful for this to be mentioned in the guideline.</p>	address the post-diagnosis section of the care pathway, and so will not discuss diagnosis. The population covered by this guideline will be children and young people with a diagnosis of autism.
31	SH	Royal College of Paediatrics and Child Health	12	General	The guideline should specifically consider parent programmes, particularly with regard to SLT provision (such as the Hanen parent programmes).	Thank you for your comment - the list of possible interventions is offered as examples – if we find evidence of sufficient quality we will consider parent programmes in the guideline.
32	SH	Royal College of Paediatrics and Child Health	13	General	The scope has a strong “health” intervention emphasis and would be improved by strengthening the explicit need for education interventions and flexibility of education provision. For example: Education should be included in the first all encompassing bullet point 4.2a, not as a separate point (4.2b) which sounds less important.	Thank you for your comment. We agree that education is very important, however NICE and SCIE are only able to make recommendations about health and social care. For this reason, we are not able to include educational interventions in section 4.2 a.
33	SH	Association of Child Psychotherapists	1	1	<p>We feel that the word 'management' implies a one-sided intervention - something imposed rather than negotiated. While management may be an important element at some point(s) in the care of a child with autism, it is but one aspect of what the guidelines cover. This is confirmed in section 3.2.h: "... this will provide guidance to the NHS on the full range of care for children and young people with autism: case identification, assessment and diagnosis; management; and support for children and young people, their families and other carers".</p> <p>As this defines a care pathway, could the term 'management' be replaced with the term 'care', as in Autism: the care and support of children and young people on the autism spectrum?</p>	Thank you for your comment. This guideline is being developed jointly by NICE and SCIE, and we agree that the care of children and young people is of vital importance. However, we think that 'management' is an appropriate term, because the guideline will address matters that are not covered by the term 'care', for example, alterations to routine and acute healthcare, and the interface with other services. We think that your points are covered by the term 'support'.
34	SH	Royal College of	8	1	Guideline Title Suggest Change:	Thank you for your comment. Since the scope

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Nursing			Autism – management of autism in children and young people To Autism – care and partnership working between health services and families who have a child or young person with autism.	consultation NICE has decided to standardise the titles of the three guidelines on autism being developed.
35	SH	Association of Child Psychotherapists	2	1.1	For the reasons stated at point 1, could the short titled read: Autism: care of autism in children and young people?	Thank you. As stated above, NICE have standardised the long and short tiles to all autism guidelines.
36	SH	Royal College of Paediatrics and Child Health	28	3	Quality of Life in autistic children will be difficult/possibly meaningless. Firstly many of these children have other learning disabilities. Secondly, they are unable to understand facial expressions/body language. So written scales of happy/sad faces are unlikely to help non-verbal children to reply. Thirdly, autistic children take pleasure in unusual interests eg spinning objects or watching movies repeatedly. This adds to their Quality of Life, but is this a useful measure? Possibly the level of satisfaction/QOL improvement of parents/carer/families would be a more useful indicator.	Thank you for your comment – where there is available data we will examine quality of life outcomes for both children and young people and their parents/carers/families. However, we will be limited to the outcome measures available in the evidence base.
37	SH	College of Occupational Therapists	1	3.1 b	The College would suggest the inclusion that many children with ASD frequently present with sensory processing disorder and developmental coordination disorder, in particular poor motor planning abilities/dyspraxia.	Thank you for your comment. This is an illustrative rather than an exhaustive list.
38	SH	ESPA Research	1	3.1 a)	Inclusion of the word 'currently' to read '.. currently diagnosed on the basis of a triad of impairments..'. If one is to believe the draft versions of schedules such as DSM-V specifically with autism in mind, the triad will be replaced by a dyad of impairments where communication and social interaction domains will be merged into a domain titled 'social affect'. Given the lifetime of the guideline in development, implementation of the final draft may coincide with the proposed diagnostic changes.	The triad does not refer to the current three axes of diagnosis, but rather to a profile from Dr Lorna Wing. In the guideline we will make clear that we are using current DSM or ICD diagnostic criteria.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
39	SH	The British Psychological Society (BPS)	1	3.1 e	With reference to the statement that “recent studies have reported prevalence rates of at least 1% of the child population”. The BPS recommends that this statistic is explained more clearly, i.e., whether it includes observational and interview methods or just one of these (which would likely give a higher rate).	Thank you for your comment. The statistic you are referring to is based on combined observational and interview methods (Baird <i>et al.</i> , 2006) however we are not able to explain this in the scope as to do so would not fit in with NICE’s house style.
40	SH	Autism Rights Group Highland (ARGH)	2	3.1 e	It cannot reliably be said that ASC is four times more common in boys than girls, this is incorrect. It would be accurately to say that Autism is four times more commonly diagnosed in boys, as it often manifests less obviously or differently in girls.	Thank you for your comment, this has been changed as you suggest.
41	SH	ESPA Research	2	3.1 e)	Some amendment is proposed for the sentence regarding the gender ratio in autism. The 4:1 figure has historically been the figure given; although several more contemporary estimates place the ratio substantially higher depending on the ‘type’ of autism examined. Although outside the scope of the current guideline, some mention of the possibility of a differing presentation in females vs. males may be helpful also influencing the gender ratio figures.	Thank you for your comment. We have removed reference to this figure.
42	NICE	NICE Technical Adviser	2	3.1 b	Although I appreciate the need for precision, I think the current phrasing in this paragraph presents detail that is perhaps at best unnecessary and at worst alienating our stakeholders. The clinical description is of course understandable and appreciated, but such detailed precision in para B is probably not needed and more likely to confuse. I have suggested some changes that might be helpful to consider. Obviously feel free to ignore, but please be aware that some of the jargon and phrases should be amended. 'In addition to these core features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, mental and behavioural problems. including a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances;	Thank you. We have made this change as you suggest.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. Some or all of these features substantially impact on the quality of life of the individual and lead to a social vulnerability especially in the most able group.	
43	SH	The British Psychological Society (BPS)	2	3.1e	It would be helpful if a reference for the studies could be added to this section.	Thank you for your comment. However, this is an issue for NICE, as we are following their house style by not including references.
44	SH	Association of Child Psychotherapists	3	3.1	<p>The definition set out here will serve as the basis upon which the efficacy of all interventions will be judged. While it is acknowledged that there is generally a congenital component, privation and extreme adversity have also been shown to impact profoundly on early developing systems, leading to the manifestation of autistic and autistic-like symptoms (see for example Hobson & Lee, 2010; Reid, 1999; Rutter, et al, 1999 – references below).</p> <p>Would the authors consider: 'Autism is generally considered as a spectrum of lifelong neurodevelopmental, biologically-based and genetically heritable conditions, diagnosed on the basis of a triad of behavioural impairments: impaired social interaction, impaired communication, and restricted and repetitive interests and activities'?</p> <p>Our point here is that the nature of autism excludes ordinary experiences that typically promotes psychological development. From a developmental perspective, if autism is not identified early there is a high likelihood of cumulative disability (i.e. a deterioration in function due to a development based on cumulative deficiency/deficit). Such reactive developmental responses are amenable to psychological interventions. This is commensurate with section 3.2.b: "There is currently no cure for autism. However, there is general agreement that early diagnosis followed by appropriate therapeutic intervention can improve outcomes in</p>	Thank you. We will be acknowledging that adverse environments can have profound effects.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					<p>later life for most people".</p> <p><i>Hobson, R.P. and Lee, A. (2010). Reversible autism among congenitally blind children? A controlled follow-up study. Journal of Child Psychology and Psychiatry, 51, 1235-1241.</i></p> <p><i>Reid, S. (1999). Autism and trauma. Autistic Post-Traumatic Developmental Disorder. In A. Alvarez and S. Reid (eds) Autism and personality: Findings from the Tavistock Autism Workshop (p 93-112). Routledge, London</i></p> <p><i>Rutter, M., Andersen-Wood, L., Beckett, C. et al. (1999). Quasi-autistic patterns following severe early global privation. English and Romanian Adoptees (ERA) Study Team. Journal of Child Psychology and Psychiatry and Allied Disciplines, 40, 537-549</i></p>	
45	SH	Autism Rights Group Highland (ARGH)	3	3.1 h	Intellectual disability co-occurs in approximately 50% of children... We would be interested to know where this figure comes from. In Highland, more than 90% of autistic children follow the mainstream curriculum; a large number of them are highly gifted.	This prevalence estimate comes from a recent study in press (Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T., Baird, G., IQ in children with autism spectrum disorders: Population data from the SNAP Project. Psychological Medicine) and this corroborates other estimates of the prevalence of intellectual disability in autism (see Matson & Shoemaker, 2009, for a review).
46	SH	ESPA Research	3	3.1 f)	Under current diagnostic guidelines, the sentence suggestive of symptoms manifesting at "the transition to secondary school" is counter-intuitive. Diagnosis at present stipulates presentation before 36 months of age. Even the revisions proposed to DSM-V highlight presentation in early infancy (though removing the precise timing). Presentation at transition to secondary school denotes presentation at 11-12 years of age. This age bracket could also denote late recognition rather than late onset.	Diagnostic criteria do stipulate presence in early childhood but diagnosis may be delayed and manifestations can be 'exposed' later, for example, in particular situations including adverse experiences.
47	NICE	NICE Technical Adviser	3	3.1 c	Suggest delete – 'an uneven cognitive profile with' this is jargon and unnecessary – meaning of sentence can survive	This is a commonly used phrase used in autism, and an uneven profile is relevant to behavioural

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					without it.	manifestations and learning problems.
48	SH	Association of Child Psychotherapists	4	3.1 b	Amend to mental, emotional and behavioural problems.	Thank you, we have made this change as you suggest.
49	SH	ESPA Research	4	3.1 f)	There are various different types of regression suggested for some cases of autism. Regression and stasis are the main descriptions although research has also hinted at other combination regressive phenotypes including the 'delay+regression' presentation. Furthermore there is wide variation in the current data on the rates of regression dependent on the criteria used to describe this issue.	Thank you for your comment, however this issue is too detailed for the scope.
50	NICE	NICE Technical Adviser	4	3.1 f	Insert 'some' – for clinical precision please. although 'some' features may not manifest until a change of situation,	Thank you, we have made this change as you suggest.
51	SH	Royal College of Speech and Language Therapists	4	3.1 a	In order for the guideline to be up to date it is important to bear in mind that DSM v is collapsing the triad into two core features reasoning that impaired communication automatically implies social interaction difficulties and vice versa.	Thank you for your comment. This is covered by the previous guideline on diagnosis in children and young people (CG 128).
52	NICE	NICE Technical Adviser	5	3.1 f	Rephrase 'stasis of language' unnecessary jargon	Thank you, however we have not made this change as this is a commonly used phrase in this area of research.
53	SH	Royal College of Speech and Language Therapists	5	3.1 f and g)	It would be helpful to have information in this section about the presentation of ASD in girls and how this may differ from the presentation in boys.	Thank you, however this is outside the remit of this guideline. Please refer to NICE clinical guideline 128 on the diagnosis of autism in children and young people.
54	NICE	NICE Technical Adviser	6	3.1 g	Rephrase – para is lengthy and obtuse, quick fix would just be to stop at 'mature' lose rest of the sentence.	Thank you for your comment, however we do not agree with this suggestion. The scoping group discussed this issue and through that it was important to note the impact of various factors on the expression of autism.
55	SH	Royal College of Speech and Language Therapists	6	3.1 h)	It may be helpful to add information about which co-morbid mental health / psychiatric disorders are most common with ASD.	Thank you, however this falls outside of the remit of the current guideline. Please refer to NICE clinical guideline 128 on the diagnosis of autism in children and young people.
56	SH	British Association for	1	3.2	The scope outlines a period of 20 years, some of the	Thank you for your comment. There will be a

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Music Therapy (formerly Association of Professional Music Therapists)		d	interventions listed have been in existence for longer than this and many since or previously in development are not listed. Does the scope intend to review an exhaustive list of therapeutic interventions in relation to time span they have been in existence or in relation to their development and association with their research/evidence base?	systematic search for evidence published, and it will be for the GDG to decide what an appropriate start date for the review will be.
57	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	2	3.2e	This section could read more accurately to reflect current provision – “In routine practice, <u>where available</u> , specialist behavioural and educational interventions...”	Thank you, however we do not agree that this change is necessary because we believe the meaning of this sentence is clear as it is.
58	SH	College of Occupational Therapists	2	3.2	Current practice – There is no mention of the involvement of children’s occupational therapy in the initial assessment process. Occupational therapists can and do provide a holistic plan of the child, providing the parents with functional information to support their child.	Thank you for your comment. The scope of this guideline is restricted to the post-diagnosis section of the care pathway, and so any mention here of initial assessment is intended as background information only. Although we acknowledge the importance of occupational therapy, it would not be possible to list every profession involved in this important work, as practices may vary region.
59	SH	College of Occupational Therapists	2	3.2	Current practice – There is no mention of the involvement of children’s occupational therapy in the initial assessment process. Occupational therapists can and do provide a holistic plan of the child, providing the parents with functional information to support their child.	Duplicate comment
60	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	3	3.2g	The term “paucity” is unclear in how it is used within this scope. It is potentially unhelpful used at this point in the scope given the message it conveys when previously in the scope different but not a full extensive list of therapeutic interventions are outlined. It would be more helpful to contextualise this important area of evidence base <i>availability</i> further at this point in the scope in relation to outlining the following – What parameters will be deemed appropriately to quantify an evidence base as well as thresholds for possible contra-	Thank you for your comment. We do not feel that this is a contentious point to make, as the lack of evidence in this area is widely acknowledged. The therapeutic interventions listed in this scope are indicative of what is widely available; we are not pre-empting the evidence by indicating which interventions are preferable. We agree that it is important parents and carers have access to information about which interventions are evidence-based. Details of the grading of evidence which will be followed in the

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					<p>indication of any interventions included or excluded?</p> <p>We note for example that the well respected high profile charity www.researchautism.net has engaged actively and robustly in addressing the subject of available evidence of the scope and significant work has been done to provide an overview of the evidence base for music therapy intervention.</p> <p>Parents and carers of children with ASD need helpful ways to articulate the dilemma's when faced with the difficult task of delineating how they might support their child/young person's needs. This includes guidance for accessing appropriate therapeutic provision which are evidence based and consideration of associated costs. Will NICE take into account the work and approach used by eg www.researchautism.net or other voluntary agencies who have developed suitable skilled ways to support families?</p>	<p>development of this guideline can be found in the NICE guidelines manual: http://www.nice.org.uk/guidelinesmanual</p>
61	SH	The British Psychological Society (BPS)	3	3.2 a	<p>With reference to: "young children will be referred to paediatricians". It is possible for children to also be referred to other professionals, e.g., team managers, clinical psychologists etc., and we recommend that this is made clear within this section.</p>	<p>Thank you. This is a point about common practice, however we make it clear elsewhere in this sentence that there are variations in practice. This section of the scope is intended as background to the issues that will be covered by this guideline, and as such it would not be appropriate or possible to attempt to give an exhaustive list here.</p>
62	SH	Autism Rights Group Highland (ARGH)	4	3.2 d	<p>Autism is accepted to be a neurological difference present from birth; the word 'onset' implies that autism is acquired. Perhaps a change to manifestation of observable differences, or just substitute onset for observed manifestation.</p>	<p>Thank you for your comment, however we do not agree. There are neurodevelopmental disorders which have a point of onset, and we do not think that the wording used here implies causation.</p>
63	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	4	3.2 h	<p>Clarifying the skill mix and competency issues for provision of interventions beyond simply the identity of professionals (eg SALT, OT, Clinical Psychologist, Paediatrician as included in the guidance for recognition, referral and diagnosis) will be crucial to consider within this guidance.</p> <p>We feel this will be needed in relation to responding to the different levels of intervention in relation to stages of ASD</p>	<p>Thank you for your comment, however this issue will be addressed during development.</p>

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					needs across childhood and in conjunction with associated cost projections. Identifying competencies which might exist to deliver individual and collaborative interventions across historically thought of professional boundaries and multi-disciplinary skill mixes needs to be held in mind by NICE - simply listing professions does not reflect accurately what may be offered as an assessment or intervention.	
64	SH	Association of Child Psychotherapists	5	3.2 a	A multi-disciplinary team (including mental health and medical professionals as well as SALT, OT and educational professionals) is considered best suited to assess and diagnose autism spectrum disorders.	Thank you for your comment, with which we agree.
65	SH	ESPA Research	5	3.2 b)	Although there is some evidence for the effect of early intervention on later life outcome in autism, the research so far in this area is scant. Follow-up studies continue although the picture is not a uniform one following intervention. The area of outcome is also complicated by determining exactly what outcome means (reduction of symptoms, improvement in quality of life, reduction of risk of other conditions) and the various socio-economic factors which influence 'good outcome'.	Thank you for your comment. The issue you raise will be important for guideline development and should be reflected in the evidence review for the guideline. However, it is probably more detail than is required for the scope
66	SH	Association of Child Psychotherapists	6	3.2 d	Include psychoanalytic psychotherapy. The list should include non-directive play-based/talking therapy.	Thank you for your comment, however this list is intended to be illustrative rather than exhaustive.
67	SH	Association of Child Psychotherapists	6	3.2 d	Include psychoanalytic psychotherapy. The list should include non-directive play-based/talking therapy.	Duplicate comment
68	SH	ESPA Research	6	3.2 d)	Some of the interventions listed were suggested much earlier than 20 years ago e.g. vitamins and other nutraceuticals. The addition of 'dietary intervention' should also be added to this list.	Thank you, we have made this change as you suggest.
69	SH	ESPA Research	7	3.2 g)	It perhaps should also be noted that several therapies, particularly the pharmaceutical interventions can also carry variable side-effects impacting on core and peripheral symptoms and also general health.	Thank you. We will not recommend pharmaceutical interventions without considering their side-effect profile.
70	NICE	NICE Technical Adviser	7	3.2 c	Suggest replace 'heterogeneity' with 'complexity' – it is a complex condition as you've pointed out in previous sections.	Thank you. We agree that autism is a complex condition, however this section is making a point

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						about the heterogeneous presentation of autism in children and young people.
71	SH	Royal College of Speech and Language Therapists	7	3.2 a)	On initial recognition we suggest making clear that this is not diagnosis but a recognition that autistic features are present. We suggest including SLT as local speech and language therapists (SLTs) frequently identify the autism in young children as part of their assessment. Nursery teachers should be added as they have different qualifications from primary or secondary teachers and can identify children with suspected features of autism. It might be helpful if the document could make clear who is permitted to give the diagnosis to the client/parent/carer.	Thank you for your comment, however this issue is covered by a separate NICE guideline on children and young people with autism (CG 128).
72	NICE	NICE Technical Adviser	8	3.2 h	Suggest add the word 'management' on the end of the sentence – little bit unclear what the second bit of the pathway actually is.	Thank you, however we think it is clear that the second part of the care pathway is post-diagnosis.
73	SH	Royal College of Speech and Language Therapists	8	3.2 d)	Clarification of what is meant by facilitated communication might be useful. The specific technique was not supported by NICE guidelines. However, alternative communication strategies, for example PECS and TEACCH, are widely used.	Thank you for your comment. The interventions listed here are not being recommended, they are intended to illustrate the different types of interventions that have been proposed. For this reason, we do not think it is relevant to elaborate.
74	SH	Royal College of Speech and Language Therapists	9	3.2 d)	The National Autistic Society EarlyBird course could be considered.	Thank you for your comment, which we have noted.
75	SH	Association of Child Psychotherapists	10	3.2 b	We welcome this statement, and believe that diagnosis and intervention as early as possible are beneficial. Child psychotherapists address the emotional repercussions of the condition for the child and the family; a salient concern of many families is the current frequent difficulty in accessing mental health services (source: Office of the Children's Commissioner).	Thank you for your comment. We agree that access to mental health services can be difficult, and in the scope we have stated that early diagnosis and intervention can be beneficial for children and young people with autism.
76	SH	Royal College of Speech and Language Therapists	10	3.2 g)	Effective therapies include the EarlyBird parent training programme and efficacy studies are available. PECS is also effective and research is available.	Thank you for your comment, which we have noted.
77	SH	Royal College of Paediatrics and Child Health	14	3.2 c	We question the use of the phrase "AGE OF ONSET" regarding what we would consider is a condition that is present from birth, if we believe the hardwiring of the brain	Thank you for your comment, however we do not agree. There are neurodevelopmental disorders which have a point of onset, and we do not think

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					is different from neurotypical people, so whilst in infancy there may not be a clear indication of the condition because of the very fact that a child is emotionally and socially immature, over time there will come a point when there is enough variation from the neurotypical developmental norm to confirm a diagnosis. This point is however not the point of onset but rather the point at which that variation becomes recognised as significantly different by parents and professionals against the background of their peer group. So the age of presentation will depend on the severity of the condition, whether or not the condition is already diagnosed within the family and the impact that the condition is having on the individual child's academic, emotional and social well being.	that the wording used here implies causation.
78	NICE	NICE Technical Adviser	9	4.1	The groups included and excluded are entirely appropriate. Good to see age up to 19.	Thank you for your comment.
79	SH	British Association for Adoption and Fostering (BAAF)	2	4.1.1 b	We welcome the recognition that both looked after children, and children and young people from black or minority ethnic groups have particular needs which must be specifically addressed by the guidance. There is a higher prevalence of autism in looked after children than the general population. Placement instability and the difficulties associated with corporate parenting introduce additional complexity to the management of autism in looked after children, which must be addressed to improve outcomes.	Thank you for your comment.
80	SH	Royal Society of Medicine	2	4.1.1 b	The phrase advising the inclusion of associated problems only "insofar as these affect the management of autism" could be omitted if the suggestion above concerning 4.3.2 (c) is accepted and accompanying psychological difficulties are viewed as "non-core features" rather than "co-existent conditions"	Thank you, however we think that the current wording of the scope is clearer and so we have not made this change.
81	SH	Association of Child Psychotherapists	7	4.1.1 b	Replace word 'management' with ' care '. Amend to coexisting mental, emotional and behavioural problems.	Thank you for your comment. This guideline is being developed jointly by NICE and SCIE, and we agree that the care of children and young people is of vital important. However, we think that 'management' is an appropriate term, because the

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						<p>guideline will address matters that are not covered by the term 'care', for example, alterations to routine and acute healthcare, and the interface with other services.</p> <p>We agree with your suggestion to make reference to emotional problems, and we have made this change.</p>
82	SH	Royal College of Speech and Language Therapists	11	4.1.1 b)	The impact of having a severe learning disability on therapy outcome should be specified. The importance of highlighting this in managing carer expectations should be recognised, as often families focus on autism rather than learning disability.	Thank you, we agree with your comment and think it highlights the importance of the 'profile' in other guidelines. This will be considered as part of the guideline, however we do not think it is necessary to change the scope.
83	SH	Royal College of Speech and Language Therapists	12	4.1.1 b)	In relation to children and young people from black or minority ethnic groups the impact of being bilingual should be specified, for example on effectiveness of training for carers, on home environment and on effectiveness of language therapy.	Thank you. We agree with your comment, however we have not amended the scope as this issue is covered by NICE's equalities policy, which we will comply with in developing this guideline.
84	SH	Royal College of Paediatrics and Child Health	15	4.1.1	<p>Although the diagnosis of autism is not part of this document, we think that it does need to be taken into consideration in this section.</p> <p>Looked-after children are a very different and difficult group to study. Profound maltreatment/neglect/trauma at an early age may have lasting effects on the developing brain. Professor Rutter (Maudsley) described quasi-autism in groups of adopted Rumanian children. Also, avoidant attachment disorder (which is part of a differential diagnosis for autism) is frequently seen in looked-after children. Some may slowly recover, even if they have fulfilled the criteria for autism. Thus it is important to know who and when such a diagnosis was made in looked-after children (ie before or after entry to care), particularly if interventions are to be assessed.</p> <p>With sensory impairments, the diagnosis of autism is also</p>	Thank you, we agree that cases of looked after children and those who have been profoundly neglected are very different. We also agree that diagnosis in VI is difficult, and we would refer you to the recently published NICE clinical guideline 128 for details of the specialist expertise required.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					different, children with visual impairment particularly. Dr Alison Salt, Wolfson Centre, London is a leading expert on diagnosing autism in VI children and should be involved in such children.	
85	SH	Royal College of Paediatrics and Child Health	16	4.1.1	Will the guideline also include children with a specific genetic diagnosis who display features of autism (e.g. Fragile-X, tuberous sclerosis)?	Thank you. This guideline will include all children and young people with a diagnosis of autism, up to their 19 th birthday. The guideline will give special consideration to children and young people with co-existing conditions, only insofar as these affect the management of autism.
86	SH	Royal College of Paediatrics and Child Health	17	4.1.1 a	We are particularly pleased to see that the age range has been extended above the 18 th birthday to the 19 th birthday, as transition issues can be so problematic in this group of young people.	Thank you for your comment.
87	SH	Royal College of Paediatrics and Child Health	18	4.1.1 b	We are not clear why management of girls and young women needs particular consideration. Another group whose management should be given special consideration is the children with one or both parents with ASD (diagnosed or not) or mental health problems. These children are at a disadvantage because of their parents' own difficulties. In this group there may be less engagement with services both pre and post diagnosis and less ability to understand and implement behavioural strategies. In these situations it is often extremely difficult to manage the children without appropriate interventions for parents as well.	Thank you for your comment. Girls and young women were added to this section because of issues related to diagnosis of autism in females, however we agree with your point and so we have removed this point. However, we have not added children and young people with a parent with autism – although we agree that this is an important issue, it would not be possible for us to consider it in the time we have available for guideline development.
88	SH	Royal College of Paediatrics and Child Health	19	4.1.1 b	'Consideration will be given to.....' within the list group the following are not included: 1. Boys. It is stated earlier that autism is diagnosed four times more commonly in boys. 2. 'Able children' however you want to define this. It is stated in 1(b) There is a substantial overall impact....leading to social vulnerability especially in the most able group'. Are these two groups considered because of the volume of cases (1) and the quality statement made in 3.2b 'therapeutic	Thank you, however we do not feel it is necessary to be as specific as you suggest, as evidence relating to these groups will be looked at during development. We have removed girls and young women from this list.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					intervention can improve outcomes in later life for most people'. If you have already identified two risk groups it seems anomalous that they are not specifically given 'consideration'.	
89	SH	Royal College of Paediatrics and Child Health	20	4.1.1 b	'children and young people from black or minority ethnic groups' We do not understand why, in the context of the draft document, this group is singled out. Is the incidence higher in this group?	This group is mentioned as minority groups may face additional problems in accessing services and thus consideration may be needed as to particular support needs
90	SH	Ambitious about Autism	1	4.1.2	Whilst the guidelines do not apply to people who are aged 19 and over, it is essential that it stresses the importance of supporting young people transitioning to adulthood and the need for all professionals, involved in the management of autism in a young person, to plan effectively with young people and their families.	Thank you for your comment, which we have noted. We agree this is a very important point, and make specific reference to effective transition in 4.4 (e)
91	SH	Royal College of Paediatrics and Child Health	21	4.2 a	We are pleased that this guideline will apply to both health and social care, but it is expected to be relevant also to other services such as <u>as forensic services and youth justice settings</u> . Raising awareness of children and young people with ASD in these settings is extremely important and in terms of management, implementing appropriate ASD intervention may turn around these children's lives.	Thank you for your comment. This guideline will not specifically address these groups, however it will make recommendations relevant to their care.
92	NICE	NICE Technical Adviser	10	4.2	The settings, also appropriate, but I have some concern as to how the GDG would be helped to develop recommendations covering forensic settings and youth justice services. Interested to hear what colleagues propose.	Thank you for your comment. This guideline will make recommendations that will be relevant to settings including forensic services and youth justice settings, however these will not be covered explicitly.
93	SH	Royal College of Nursing	2	4.3	Particular attention should be paid to 'inclusion' in both mainstream health care services in particular maintaining regular contact and developing an ongoing relationship with the family GP and wider primary health care services.	Thank you for your comment, we agree this is an important issue.
94	SH	Royal College of Nursing	3	4.3	In addition healthcare professionals should be careful to give unbiased information that then impacts adversely on educational opportunities resulting in a bias towards 'special education' that often results in isolation from non-disabled peers and complex difficulties on transition and in adult life.	Thank you for 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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
95	SH	Royal College of Nursing	4	4.3	Healthcare professional also need to be aware of the risk of misdiagnosis especially where fetal alcohol spectrum disorder is a potential problem.	Thank you for your comment. FAS is an aetiological disorder, ASD and other behavioural phenotypes are just that – behavioural – and may occur in FAS.
96	SH	Royal College of Nursing	5	4.3	Importance of communication and the potential role of interventions such as facilitated communication, intensive interaction and the role that technology and use of multi-media can play in the life of young people with Autism.	Thank you for your comment.
97	NICE	NICE Technical Adviser	11	4.3	Key clinical issues Although I am impressed at the range and number of topics listed here, I have concerns about the amount of work needed to cover all these issues within the time and resources available. I also have concerns about availability of effectiveness and cost effectiveness evidence in some of the sections listed, particularly those that cover service interface and multi-agency working. These are notoriously difficult areas to cover, so I would be interested to know what methods colleagues propose to use to firstly identify evidence that helps the development of national guidance that is implementable and secondly how they will bridge existing gaps and missing information.	Thank you for your comment. We are aware that certain the search strategies for review questions based on the scope will require careful thought, and this will be discussed when the search strategy is agreed at the start of the development process. In keeping with the NICE guidelines process, where there are gaps in the evidence, the GDG may engage in consensus work in order to make recommendations, or may make recommendations for further research.
98	SH	Royal College of Paediatrics and Child Health	22	4.3 c) and d)	We are pleased that the guideline will cover less orthodox forms of intervention such as those listed in these two paragraphs. It is vital to clarify as much as possible what works and what doesn't and for which interventions there is clear evidence of positive outcome or not. Savings can be made both by families and agencies through adopting intervention programs for which there is evidence of positive outcome rather than embark on expensive and time consuming programs without much evidence to support them.	Thank you for your comment.
99	SH	Royal College of Paediatrics and Child Health	23	4.3 h	When thinking about how to inform children, it might be useful for parents and professionals, some mention of <u>when</u> children should be told of their diagnosis. This issue cannot be the object of a strict guideline but some broad advice might be possible.	Thank you for your comment, however this issue falls outside of the remit of this guideline, which is concerned with the management of children and young people with autism.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
100	SH	Royal College of Paediatrics and Child Health	27	4.3	As this guidance is of crucial importance to education services, it is important that it is acceptable to those services. Putting "educational interventions" under a "clinical management" heading may not be seen as appropriate. Change of title to "Interventions" might help.	Thank you, we have changed this heading to 'management' and the sub-heading to 'key issues...'
101	SH	Association for Family Therapy and Systemic Practice (AFT)	1	4.3.1 a	Because of the impact on parents and siblings, it would be helpful to use a systemic approach with behavioural therapies, as well as individual psychological / psychotherapeutic treatments. Whilst there is not an evidence base for autism, some services use methods such as the Solution Focused Approach, so that families find ways to manage the issues. Whilst there is not research on this, an example of how this can be used is: Simon, G. (2003): Systemic Family Therapy with a child who has a diagnosis of Asperger syndrome. Human Systems. 15.4.257-274.	Thank you for your comment and for drawing this reference to our attention.
102	SH	Coeliac UK	1	4.3.1	Coeliac UK welcomes the inclusion of 'nutritional interventions' under clinical issues to be covered. Dietary treatments can be self-prescribed for autism spectrum disorders, including the use of a gluten-free and casein-free diet. We suggest that the gluten-free (and casein-free) diet is included in the scope of the nutritional interventions covered by the evidence review. It is important to clarify the status of the evidence-base in this area, so that patients and carers are not misled by anecdotal stories or inappropriate extrapolation of results from small studies. In the absence of an evidence-based approach, we are concerned that children with autism may be limiting dietary intake and that the implementation of a gluten-free casein-free diet will impact upon food choice and nutrition.	Thank you for your comment. The interventions listed in this section are not intended to form an exhaustive list, and so if there is evidence for specific diets as an effective intervention for autism, this evidence will be reviewed. All evidence for interventions will be reviewed according to the NICE guidelines manual 2009.
103	SH	Northumberland Tyne and Wear NHS Foundation Trust	1	4.3.1	This bullet point refers to interventions that address communication and social interaction. It would be helpful if the domain of restricted, stereotyped and repetitive	Thank you, however this list is intended to be illustrative and so any interventions for autism will be considered here.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					behaviours was also included in this section	
104	SH	Nottinghamshire Healthcare NHS Trust	1	4.3.1	The guidelines should also include the modification of psychological interventions for the management and treatment of emotional and mental health disorders, as these often need significant adaptation for young people with ASD. In particular, the guidelines should make reference to existing guidelines, such as Management of Depression in CYP, and explore what issues may be different in the ASD population.	Thank you for your comment. It will not be possible within the time available for the developers to look at the management of all coexisting conditions, and so where appropriate the guideline will refer to other NICE guidelines.
105	SH	Step by Step School	1	4.3.1 b	"Sympatholytics" needs to be added to list	Thank you, however this list of interventions is not intended to be exhaustive and so we have not made this change.
106	SH	The British Association of Dramatherapists	1	4.3.1 a	We are pleased to see that Dramatherapy has been included as a psychosocial intervention along with the other Art therapies however we would like to point out that Dramatherapy in the UK is one word.	Thank you for your comment, we have made this change.
107	SH	Ambitious about Autism	2	4.3.1	<p>Ambitious about Autism is pleased that the development group will review a range of interventions, including Applied Behaviour Analysis (ABA), which is widely used and recommended for young people with autism...</p> <p>In creating these guidelines, we believe it is essential that the development group:</p> <ul style="list-style-type: none"> - Clearly identifies what long-term outcomes are being sought for people with autism. Although outcomes will be diverse, themes, such as achieving relative independence, will be consistent across groups. - Evaluates each intervention based on how it contributes towards achieving these outcomes. - Considers evidence from a range of stakeholders including people with autism, their families, providers and academics,. - Considers evidence from outside the UK.. <p>Ambitious about Autism would be pleased to have the opportunity to provide evidence to the group.</p>	<p>Thank you for your comment – where there is available data we will examine long-term outcomes. However, we will be limited to the outcome measures available in the evidence base.</p> <p>There will be parent/carer representatives on this guideline development group, and academic evidence will be searched for systematically.</p> <p>Evidence from outside the UK may be considered, however, questions about whether and how this will be done will be dealt with once development starts and in conjunction with the guideline development group.</p>

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
108	SH	Royal College of Psychiatrists in Wales	2	4.3.1	We suggest including arrangements for transition from child to adult services.	Thank you for your comment. Transition to adult services will be covered in this guideline, as stated in section 4.4 (e) of the consultation draft.
109	SH	Step by Step School	2	4.3.1 b and 4.3.1 (c)	Chelation is a pharmacological intervention rather than a physical intervention and would be better grouped in section 4.3.1 (b) than 4.3.1 (c)	Thank you for your comment, chelation will be moved to the pharmacological intervention section as suggested
110	SH	Ambitious about Autism	3	4.3.1	Ambitious about Autism recognises that NICE guidelines do not have the same level of influence on education providers as on health providers. However, we are pleased that education is included given that children need an integrated approach from health, social care and education and that the proposed changes in the SEND Green Paper should result in closer joint-working between professionals and bodies. Ambitious about Autism believes it is essential that educational interventions remain part of the scope of these guidelines.	Thank you for your comment. NICE and SCIE cannot make recommendations directly to educational, however we agree that they are very important in this area.
111	SH	British Association for Adoption and Fostering (BAAF)	3	4.3.1 g	Recognition that alterations to routine and acute healthcare may be needed is particularly relevant for looked after children and young people. Often their unique needs are not well served by standard health care services offered to the general population.	Thank you for your comment.
112	SH	College of Occupational Therapists	3	4.3.1	There is no mention of functional approach to the child, working in conjunction with the families and with the education system, ensuring access to the curriculum.	Thank you for your comment, however the interventions listed in this section are intended to be illustrative rather than exhaustive.
113	SH	Royal College of Psychiatrists in Wales	3	4.3.1 e	It is currently difficult, in the clinical setting, for children and young people with co-ordination problems (for example dyspraxia) to access specialist physiotherapy and occupational. We suggest adding "co-ordination problems – i.e., Dyspraxia" to the existing list.	Thank you for your comment, however the interventions listed in this section are intended to be illustrative rather than exhaustive.
114	SH	Step by Step School	3	4.3.1 d	Suggest "dietary enzymes" is added to list	Thank you for your comment, however the interventions listed in this section are intended to be illustrative rather than exhaustive.
115	SH	British Association for Adoption and Fostering (BAAF)	4	4.3.1 i	Because of their circumstances in care, looked after children and young people and their carers often have different support needs. This recognition, and addressing their unique needs throughout the care pathway is essential to	Thank you for your comment, which we have noted.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					effective guidance.	
116	SH	Step by Step School	4	4.3.1 g	Needs to be broadened to include “dentistry and eye sight testing”	Thank you for your comment, and for drawing our attention to these two areas. However, the alterations to healthcare listed here are intended to be illustrative rather than exhaustive, and so we have not added them to the scope.
117	SH	The British Psychological Society (BPS)	4	4.3.1 a	With reference to “interventions that address communication and social interaction”. Examples are provided for all the other types of psychosocial interventions listed, but none for this one. To address this, we recommend that music interaction therapy (different from music therapy), interactive intervention and PACT could be added.	Thank you, however we have only listed examples of interventions where we feel it is helpful to do so. The interventions listed in this scope are intended to be illustrative rather exhaustive.
118	SH	Autism Rights Group Highland (ARGH)	5	4.3.1 e	Changes to environment should be mentioned here, for example, low stimulatory environments or other changes to accommodate individual's differences: lighting, temperature, colours and so on, hyposensitivity should be considered along with hypersensitivity. Environment and affect on people with sensory differences is often overlooked. ‘Down time’ should be recognised as necessary for some autistic people, breaks and time without demands from others or environmental stressors. Language and communication is key to a persons behaviour; in many circumstances ‘challenging behaviour’ could be termed ‘extreme communication’, when someone has no method of communicating that is respected or attended to, they can be left in a situation which is frustrating and leaves them no means of interacting with others at all. It should be stressed that communication is a two way thing, communication strategies and styles vary greatly, and this has to be recognised. Assistive technology to improve communication (and often therefore reduce the need for more extreme communication) should be offered more readily. Quote from Outreach IT: “To be included, empowered, and	Thank you for your comment. We will be paying particular attention to environments that promote good function and those that are aversive. We agree that communication is important, and the guideline will look at evidence for interventions that address communication.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					able to take a real part in decisions about their own lives, autistic people need effective ways to communicate. Legislation supports their right of access to Information and Communication Technology (ICT)".	
119	SH	British Association for Adoption and Fostering (BAAF)	5	4.3.1 j	Looked after children are typically involved with multiple services and it has been repeatedly shown that less than optimal outcomes result from poor partnership working. Specific and detailed guidance to address effective inter-agency working is critical to improved outcomes.	Thank you for your comment. We agree that looked after children face particular challenges, and this is why they are listed as a group that will be given particular consideration.
120	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	5	4.3.1 a	<p>How has this list been compiled?</p> <p>Will there be further delineation between these sub-categories of psychosocial intervention including the full range of interventions currently available for children with ASD?</p> <p>Art-based therapies (Art, music and dramatherapy) should be termed <u>Arts</u> therapies to reflect current UK HPC governed practice.</p> <p>This review within NICE is welcomed by the British Association for Music therapy.</p> <p>Inclusion of dance movement psychotherapy as one of the four current UK Arts therapies modalities is required in the scope inline with the point above regarding the need for consideration of all psychosocial interventions.</p> <p>Will dynamic therapies be including in the review e.g. the role of child and adolescent psychotherapy?</p> <p>Will the review include family/therapy based interventions given the huge impact ASD can have on family functioning and needs of parents and carers?</p>	<p>Thank you for your comment. This list has been compiled by looking at common psychosocial interventions for autism, and is intended to be illustrative rather than exhaustive. All interventions for autism for which there is evidence will be considered in the development of this guideline.</p> <p>We have amended the wording of this bullet point, so that it reads 'arts-based therapies', as you suggest.</p>
121	SH	Step by Step School	5	4.3.1	Need a new category "genetic counselling following diagnosis of first child with autism diagnosis"	Thank you for your comment. We agree this is a very important issue, however we would refer you

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						to the NICE guideline on the diagnosis of children which autism (CG 128).
122	SH	The British Psychological Society (BPS)	5	4.3.1 a	We recommend that Early Start Denver Model is added to the examples of behavioural therapies.	Thank you for your comment. We have noted this intervention, but we have not amended the scope as you suggest, as the list included is not intended to be exhaustive.
123	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	6	4.3.1 i & j	Will the review make recommendations on the context where by interventions are best delivered i.e. linking the clinical management of ASD to recommendation on the most appropriate setting for such interventions to take place effectively and be supported appropriately? If this is what these points in the scope address we welcome the opportunity for guidance to be developed on this issue given the variety of interventions and related resources available in different parts of the country.	Thank you for your comment. The guideline will make recommendations on the basis of a systematic search for evidence. If there is good evidence for delivering recommendations in specific settings then the guideline will reflect this fact.
124	SH	Royal College of Nursing	6	4.3.1 e	Inclusion of pain and distress recognition in individuals who are unable to communicate in traditional ways.	Thank you, however this will be covered by looking at interventions that address communication and social interaction (see 4.3.1a).
125	SH	Step by Step School	6	4.3.1	Need a new category "guidance on national criteria when families are eligible for respite care"	Thank you. Respite care is covered by section 4.3.1.(i) of the scope, which addresses the support needs of children and young people, their families and carers.
126	SH	Royal College of Nursing	7	4.3.1 f - j	This section is especially relevant to the School Nursing Services - nurses should be aware that autism affects around 1% of the UK population. School nurses therefore, should contribute to support of children and young people with this condition in the same way as they do for physical long term conditions such as asthma, diabetes, epilepsy.	Thank you. We agree that school nurses have an important part to play in the support of children and young people with a range of conditions.
127	SH	Step by Step School	7	4.3.1	Need a new category "guidance on location and frequency of NHS care following diagnosis – guidance on appropriate balance between GP, community paediatric and tertiary centre provision"	Thank you. We have included information giving for children and young people and their families throughout the care pathway (see 4.3.1 f of the consultation draft) as we agree that guidance on care is very important. However it would be outside

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						of the scope of this guideline to comment on service provision, as this is an implementation issue for local services to decide on.
128	SH	Association of Child Psychotherapists	8	4.3.1 a	Psychoanalytic psychotherapy is a form of psychosocial intervention and should be included in this list of such interventions. We wonder if it might be stressed that this form of intervention is available on the NHS.	Thank you for your comment. The list of interventions here is illustrative rather than exhaustive, and so we have not added psychoanalytic psychotherapy as you suggest. It is not the place of a NICE guideline to inform people which services are available on the NHS.
129	SH	ESPA Research	8	4.3.1 c)	Addition of 'HBOT' acronym after hyperbaric oxygen therapy.	Thank you, however we have not made this change as it does not follow our house style.
130	SH	Association of Child Psychotherapists	9	4.3.1	The last in the list should read interventions that address feelings , communication and social interaction.	Thank you, however we feel that feelings are addressed by other interventions listed here.
131	SH	Royal College of Speech and Language Therapists	13	4.3.1	Speech and language therapy should be added to the list.	Thank you, however we feel that this is covered by 'interventions that address communication'. This list is only intended to be illustrative and general, and we will be more specific about particular interventions in the guideline.
132	SH	Royal College of Speech and Language Therapists	14	4.3.1	Augmentative and Alternative Communication should be added to the list.	Thank you for your comment, however the list of interventions here is illustrative rather than exhaustive and so we have not made this change.
133	SH	Royal College of Speech and Language Therapists	15	4.3.1	Environmental intervention should be included – adaptations made to the environment (visual structures etc).	Thank you for your comment, however this is covered under 4.3.1f which addresses modifications to manage challenging behaviour.
134	SH	Royal College of Speech and Language Therapists	16	4.3.1	Play-based intervention should be included, for example the Hanen approach.	Thank you for your comment, however the list of interventions here is illustrative rather than exhaustive and so we have not made this change.
135	SH	Royal College of Speech and Language Therapists	17	4.3.1	Information about managing puberty and sexual development is vital in this section.	Thank you for your comment. We agree this is an important issue however it will be covered under supplying information (section 4.3.1 h of the scope).
136	SH	Royal College of Speech and Language Therapists	18	4.3.1 a)	We would draw attention to the 'Social Communication Intervention Packages' established in Kingston with outcome data for children with/without a diagnosis of ASD. There is a standard process of selection of the children annually. The aims of the packages are early intervention and management of a child's problems without the need to resort to statutory	Thank you for your comment, and for bringing this to our attention.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					assessment. Schools receive funding for teaching assistant time and regular support is offered by a team of SLTs and teachers working in provision for children with autism. It is a good example of joint commissioning of services for children of school age.	
137	SH	Royal College of Speech and Language Therapists	19	4.3.1 a)	Interventions addressing communication and social interaction should include parent training interventions.	Thank you. If there is evidence for parent training interventions then this will be reviewed in the guideline.
138	SH	Royal College of Speech and Language Therapists	20	4.3.1 i)	The value of family therapy to support families in managing the impact of having a family member with ASD should be explored.	Thank you. The support needs of children and young people and their families will be considered in the development of this guideline.
139	SH	Royal College of Speech and Language Therapists	21	4.3.1 j)	We would stress the importance of collaboration between health, social care and education services and guidance to improve this.	Thank you. We agree that collaboration between health, social care and education services is vitally important, and this guideline will help facilitate cooperation by making recommendations that are relevant to all services.
140	SH	Royal College of Paediatrics and Child Health	24	4.3.1 a	The physical environment in which health and educational interventions are provided is of major importance. This should be either added to 4.3.1a or put as a separate heading. For example: However good an educational intervention may be, it will be useless if a child is overwhelmed by the busy, noisy class environment. There may need to be modification of classroom / learning physical / sensory environment for each individual.	Thank you. We agree that physical environment can be very important, and alternations to health and social care due to autism will be covered in this guideline. We have a specific section underling aversive environments that may promote challenging behaviour (see 4.3.1 (f) and (g)).
141	SH	Royal College of Paediatrics and Child Health	25	4.3.1	Could an extra subheading be added? k) Family and systemic interventions, including: <ul style="list-style-type: none"> • Work with parents alone • Work with the whole family • Family therapy • Work with the professional network involved with the child, including for instance the school and other 	Thank you. We would consider family and systemic interventions to be covered under psychosocial interventions, and so we do not feel that this addition is required.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					support services.	
142	SH	Royal Society of Medicine	1	4.3.2 c	This section excludes "Management of coexisting conditions, unless these affect interventions, management or support for autism". We appreciate that this represents the usual policy of NICE and that the scope should not be unduly extended; but in this case we think the policy should be modified. The management of autism is very largely the management of "coexisting conditions" such as aggression, hyperactivity and phobias and it is often incorrect to think of them as separate conditions that happen to coexist. They will sometimes require a different treatment approach from that recommended in the absence of autism. We would therefore advise that problems such as these should be included in a broad concept of "non-core features" of autism, to be considered in the guideline	Thank you. We agree that the management of autism and coexisting conditions is a very important issue. It would not be possible for us to consider the treatment of all coexisting conditions within the time available for the development of this guideline. However we will refer to NICE guidance for the management of coexisting conditions where appropriate.
143	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	7	4.3.2 b	Does NICE have a plan to address the needs of children with Rett syndrome in future guideline development? The British Association for Music therapy would welcome input into any such guidance given our extensive involvement with this vulnerable client group.	The National Collaborating Centres are unable to comment on future guideline topics
144	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	8	4.3.2 c	Will conduct disorder be considered within this category? If so what arrangements will be made within the guidance to support those young people with ASD who have Conduct Disorder which is identified as their primary need for needs for support and management?	Thank you. Where appropriate, this guideline will refer to the NICE guideline on conduct disorders, which is currently being developed.
145	SH	Royal College of Paediatrics and Child Health	26	4.3.2 j	The support of parents should be given much more prominence. The outcome for children will depend on the families' ability to deal with everyday life and handle behaviours appropriately, (in conjunction with the service led interventions). It is important that interventions to support parents eg with the daily management of challenging behaviours, is considered either in this section or in 4.3.2a.	Thank you, we agree this is an important issue and the support needs of children and young people, and their families are carers are stated in 4.3.1 (i).
146	SH	Autism Rights Group Highland (ARGH)	6	4.4	A main outcome should be added: health related quality of life is not enough, quality of life as measured by a person's	Thank you, quality of life is listed as a main outcome.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					contentment or happiness should be considered. An Autistic persons perspective on their own overall quality of life. Ensuring that loss of autistic - ness or normalisation are not taken as success.	
147	SH	Royal College of Speech and Language Therapists	22	4.4	This might cover the benefit/cost of accessing social situations, for example youth clubs, sports facilities and other groups in which children would participate.	Thank you for your suggestion, not for scope, will consider during development.
148	SH	Royal College of Speech and Language Therapists	23	4.4 b)	On the psychosocial aspect of interaction and participation communication is a major feature. Augmentative and Alternative Communication is increasingly used to facilitate communication and education in children. The issue of who assesses individuals for aided communication and who funds powered AAC devices (computers / VOCAs / Symbol grid designed AAC device) should be covered in the study as this varies across the country and by commissioning and funding.	Thank you, however it is for individual services to make arrangements for implementation.
149	SH	Step by Step School	8	4.4 d	Suggest to broaden to be "families including siblings"	Thank you, we have made this change as you suggest.
150	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	9	4.4 d & f	This guidance offers scope to comprehensively review the impact of ASD on families and siblings and bring to further recognition their needs. We welcome this opportunity.	Thank you for your comment.
151	SH	Autism Rights Group Highland (ARGH)	7	4.4 c	These outcomes should not be measured in terms of normalisation, success criteria need to be carefully considered from an ethics points of view to allow autistic people the right to be autistic whilst ensuring they have the highest quality of life and life choices possible (as chosen by them).	Thank you for your comment, which we have noted.
152	SH	Royal College of Speech and Language Therapists	25	4.4 e)	We welcome the inclusion of effective transition to adult services as one of the main outcomes. We suggest that information is required about effective transition at all key stages, including from early years to school, infants to juniors and primary to secondary, and the most effective methods for managing these.	Thank you for your comment. We agree that effective transition at all key stages is important, and we will consider this during guideline development.
153	SH	Royal College of Speech and	24	4.4 d)	Information about the effects on siblings in particular should be included.	Thank you, we have made this change as you suggest.

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Language Therapists				
154	SH	Autism Rights Group Highland (ARGH)	8	4.4f	Experience of care: should be specifically measured from an autistic perspective.	Thank you for your comment, which we have noted.
155	SH	Step by Step School	9	4.4f	Suggest to broaden: A key outcome of implementation of this guideline will be "satisfaction with NHS healthcare, including routine care, acute setting, dentistry, eye care, etc)	Thank you, however it is not for this guideline to comment on implementation. The outcomes listed here are the main outcomes that will be considered when reviewing the evidence in this area.
156	SH	Autism Rights Group Highland (ARGH)	9	4.5	Economic Aspects: This passage does not explicitly state the interplay between investment into children and young people and significant savings in their adulthood by promoting mental health, independent living and employability. Since children's and adult services are paid out of different budgets, it is easy to lose the long-term view.	Thank you. We have amended the scope and state that economic analyses will attempt to consider outcomes and financial implications of interventions for the management and support of children and young people with autism through adulthood. Although the perspective of main economic analyses in NICE guidelines is that of the NHS and personal social services, we have stated that additional analyses with a wider perspective may be conducted to consider other costs associated with autism such as costs of education and housing services.
157	SH	British Association for Music Therapy (formerly Association of Professional Music Therapists)	10	4.5	Costs for interventions should be considered beyond professional identity boundaries and related to levels of skill mix/competency needed to work with ASD within the wide range of services from supportive early years intervention through to specialist educational provision/specialist CAMHS interventions.	Thank you, we will consider your suggestion depending also on available resource use and unit cost data.
158	SH	Royal College of Paediatrics and Child Health	29	4.5	<u>Economic aspects</u> This guidance is a great opportunity to raise awareness of the huge savings to be had by all agencies, through the adequate and timely treatment and management of ASD and its associated problems early on. At present it is very likely that thousands of undiagnosed and untreated adults with ASDs are not only suffering a great deal in their personal lives but, in many cases, draining vast resources from almost all public services.	Thank you. We have amended the scope to clarify that economic analyses will attempt to consider outcomes and financial implications of interventions for the management and support of children and young people with autism through adulthood. Although the perspective of main economic analyses in NICE guideline economic is that of the NHS and personal social services, we have stated that additional analyses with a wider perspective may be conducted to consider other costs associated with autism such as costs of education

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.

	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Timely diagnosis and management may lead in the future to reduced need of involvement by services such as: special education and training, social care, housing services, lack of productivity as an adult, marital problems, family break-up, NHS and mental health services, court fees, police, jails, unemployment in adulthood.	and housing services.
159	NICE	NICE Technical Adviser	12	5	Entirely appropriate, however as you mention looked after children and young people as a particular group, please include the reference to NICE/SCIE PH28 guidance on this scope and any additional documentation as appropriate. As you have pointed out in the scope, there are a substantial number of LACYP in the care of the local authority with a range of complex needs including ASD.	Thank you, we have made this change as you suggest.

These organisations were approached but did not respond:

Action for ADHD - Northants
 Action for Aspergers
 Airedale NHS Trust
 Alder Hey Children's NHS Foundation Trust
 Associate Development Solutions Ltd
 Association for Psychoanalytic Psychotherapy in the NHS
 Association of Directors of Childrens Services
 Association of Optometrists
 Association of Paediatric Chartered Physiotherapists
 Association of Professional Music Therapists
 Autism Alliance UK
 Autism Diagnostic Research Centre
 Autism Education Trust

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.

Autism NI - Northern Ireland's Autism Charity
Autism Outreach
Autism West Midlands
Barnsley Hospital NHS Foundation Trust
Belfast Health and Social Care Trust
Betsi Cadwaladr University Health Board
Birmingham Community Healthcare Trust
Bradford and Airedale Primary Care Trust
Bradford District Care Trust
Breakspear Medical Group Ltd
Bridgewater CHC
Bright Futures Autism Limited
British Academy of Childhood Disability
British Association for Counselling and Psychotherapy
British Association of Art Therapists
British Association of Behavioural and Cognitive Psychotherapies
British Association of Drama Therapists
British Association of Play Therapists
British Association of Psychodrama and Sociodrama
British Association of Social Workers
British Confederation of Psychotherapists / Psychoanalytic Council
British Dietetic Association
British Medical Association
British Medical Journal
British National Formulary
British Paediatric Mental Health Group
British Psychological Society
British Society of Neuroradiologists
British Society of Paediatric Gastroenterology Hepatology and Nutrition

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.

Calderdale and Huddersfield NHS Trust
Camden Link
Camden Provider Services
Care Quality Commission (CQC)
Central & North West London NHS Foundation Trust
Central Lancashire Primary Care Trust
Central London Community Healthcare
Challenging Behaviour Foundation
City and Hackney Teaching Primary Care Trust
Cochrane Developmental, Psychosocial and Learning Problems
College of Mental Health Pharmacists
College of Mental Health Pharmacy
Contact
Critical Psychiatry Network
Department for Communities and Local Government
Department for Education
Department of Health
Department of Health, Social Services and Public Safety - Northern Ireland
Dimensions
Disabilities Trust, The
Dorset Primary Care Trust
Ealing Hospital NHS Trust
Energy Therapy World-Wide Net
Epilepsy Action
Equalities National Council
European Association for Behaviour Analysis
Federation of Ophthalmic and Dispensing Opticians
Five Boroughs Partnership NHS Trust

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.

Foundation for People with Learning Disabilities
Gender Identity Research and Education Society
George Eliot Hospital NHS Trust
George Still Forum
Glencare
Great Western Hospitals NHS Foundation Trust
Greater Manchester West Mental Health NHS Foundation Trust
Halton & St. Helens Primary Care Trust
Hartlepool Borough Council
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Healthcare Inspectorate Wales
Hertfordshire Partnership NHS Trust
Hindu Council UK
Humber NHS Foundation Trust
Information Centre for Health and Social Care
Kent and Medway NHS and Social Care Partnership Trust
Lancashire Care NHS Foundation Trust
Leeds Community Healthcare NHS Trust
Leicestershire Partnership NHS Trust
Liverpool Primary Care Trust
Luton and Dunstable Hospital NHS Trust
Medicines and Healthcare products Regulatory Agency
Mild Professional Home Ltd
Mind Wise New Vision
Ministry of Defence
National Association for Gifted Children
National Attention Deficit Disorder Information and Support Service

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.

National Autistic Society
National CAMHS Support Service
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Commissioning Group
National Deaf Child and Adolescent Unit
National Institute for Health Research Health Technology Assessment Programme
National Patient Safety Agency
National Public Health Service for Wales
National Treatment Agency for Substance Misuse
NCC Women & Childrens Health
Neonatal & Paediatric Pharmacists Group
NHS Clinical Knowledge Summaries
NHS Confederation
NHS Connecting for Health
NHS Plus
NHS Warwickshire Primary Care Trust
NHS West Essex
North Essex Mental Health Partnership Trust
North Tees and Hartlepool NHS Foundation Trust
Office of the Children's Commissioner
Optical Confederation, The
Oxford Health NHS Foundation Trust
Parents' Education as Autism Therapists
Parents for the Early intervention of Autism
Patient Assembly
Pfizer

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.

Play Therapy UK
Positively Pregnant
PromoCon
Public Health Wales NHS Trust
Qbtech Ltd
Queen's University Belfast
RAF Families Federation
Rainbows Childrens Hospice
RASDN - HSC.Board/Public Health Agency
Research Autism
Ridgeway Partnership
Rotherham Primary Care Trust
Royal Berkshire NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Psychiatrists in Scotland
Royal College of Psychiatrists in Wales
Royal College of Radiologists
Royal College of Surgeons of England
Royal National Institute of Blind People
Royal Pharmaceutical Society
Royal Society of Medicine
Ruskin Mill Educational Trust

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.

Safeguarding the Rights of Children with Autism
School And Public Health Nurses Association
Scottish Intercollegiate Guidelines Network
Sensory Integration Network
Shire Pharmaceuticals Ltd
Social Care Institute for Excellence
South Essex Partnership NHS Foundation Trust
South London & Maudsley NHS Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
South West London and St George's Mental Health NHS Trust
St John's RC School
St Jude Medical UK Ltd.
Surrey and Border Partnership Trust
Sussex Partnership NHS Trust
Tavistock & Portman NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Trust
The Challenging Behaviour Foundaton
The Children's Trust
The College of Social Work
The Rotherham NHS Foundation Trust
The University of Glamorgan
Tourettes Action UK
Treating Autism
Turning Point
UK Young Autism Project
Unite - the Union
University Centre for Excellence in Developmental Disabilities
University of Birmingham

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.

University of Edinburgh
University of Nottingham
University of Wales, Bangor
Warrington Primary Care Trust
Welsh Government
Welsh Scientific Advisory Committee
Whitstone Head Educational
Wigan Council
Wirral University Teaching Hospital NHS Foundation Trust
Worcestershire Acute Hospitals Trust
York Hospitals NHS Foundation Trust
YoungMinds

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.