NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Autism

Date of Quality Standards Advisory Committee post-consultation meeting: 16th October 2013

2 Introduction

The draft quality standard for Autism was made available on the NICE website for a 4-week public consultation period between 2nd September and 30th September 2013. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 42 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include overarching outcomes, thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- There was support for the development of a quality standard on autism.
- There were some concerns raised about some of the language used, with some stakeholders suggesting that it was over medicalising autism.
- The role of families and carers was highlighted as important, recognising their role in supporting people with autism and also the need for families and carers in some instances to receive support themselves.

- Stakeholders highlighted that, as autism is a spectrum disorder the needs of people with autism vary significantly: some people with autism who are able to function well or who do not meet the eligibility thresholds to access some social care services, will not need, or be able to access some services which may be available to other people with autism. Stakeholders noted that this has implications for the relevance of some of the statements to some people with autism.

- Stakeholders suggested that the quality standard was overly focused on the management of behaviour, with 3 statements (5, 6 and 7) focused on behaviour management.
- Stakeholders were concerned about the feasibility of some of the statements. They suggested that in some areas the service infrastructure is not in place, and in areas where there are service, there was not sufficient capacity within current services to implement the quality standard.

Consultation comments on data collection

- Concerns were raised about how feasible it will be to successfully measure the quality statements. Stakeholders highlighted the lack of a universal service structure and corresponding data flows to enable accurate measurement.
- Some stakeholders asked for clarification about who would be responsible for measuring the quality statements.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People with possible autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Stakeholders asked for clarification about what constitutes the start of the assessment. There were concerns that services could do an initial assessment within 3 months, but the full diagnostic assessment would not be started until after this time.
- Some stakeholders explained that in some cases where funding needs to be identified for the assessment, delays can occur that are beyond the control of the service provider.
- Stakeholders asked for clarification about what criteria should be used during the initial assessment to decide whether someone should receive a full diagnostic assessment or not.

- Some stakeholders suggested that a time limit should be included concerning when the assessment should be completed by.

- The definition of what should be included in the diagnostic assessment was commented on by stakeholders, with some suggestions for additional factors to be considered.

- Stakeholders asked how education services would be formally engaged in this process

5.2 Draft statement 2

People having a diagnostic assessment for autism are assessed for coexisting physical health conditions and mental health problems

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Stakeholders asked for clarification about who should be responsible for carrying out these assessments. Stakeholders noted that professionals trained in diagnostic assessment of autism do not always have the expertise to assess physical and mental health problems.
- The checklist of what should be assessed for was identified by some stakeholders as needing some additional issues to be included. Specific reference was made to sensory impairments, the person social situation and attachment problems particularly in relation to looked after children and young people.

- Some stakeholders highlighted differences between the checklist for children and young people and the checklist for adults, suggesting that they should be made consistent.

- Stakeholders suggested that there should be reference to what to do if any other co-existing conditions or problems are identified

5.3 Draft statement 3

People with autism have a personalised management plan that takes into account their strengths and needs

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

Stakeholders asked:

  - how the plan would involve all possible service providers for people with autism in contact with services across sectors

  - how it would link to any plans a person may have such as an Education, Health and Care plan for children and young people identified with special educational needs who would be responsible for developing and implementing the plan.

  - what the plan would include, for example preventative strategies and how it should be structured

  - importance of the plan being fully understandable to the person with autism.

- One stakeholder commented on the terminology and suggested it should be called 'community plan'

- Concerns were raised that it wasn't explicit that the plan should be jointly developed with the relevant professionals and the person with autism and if appropriate their families or carers.

5.4 Draft statement 4

People with autism have a designated professional to oversee and coordinate their care and support.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

Stakeholders asked:

  - for clarity about who the designated professional can be and when they would get involved.

  - whether this person would be involved in co-ordinating the assessment process which can be complex.

  - how the professional would link with the education sector for children and young people

  - who would be responsible for identifying and agreeing the relevant professional,

  - how the person with autism would be involved in agreeing the designated professional

  - The level of contact required.

- Stakeholders suggested that the most appropriate person to be identified as a person’s designated professional may need to change when a person needs change. One stakeholder suggested that in some cases a shared care arrangement may need to be in place.

5.5 Draft statement 5

People with autism are not prescribed drugs to treat the core symptoms of their autism.

Consultation comments

- Stakeholders agreed with the principle of the statement, but noted that in some cases it can be hard to differentiate between core symptoms of autism and other behaviours that may respond to medication. Stakeholders also suggested that the core symptoms of autism can cause other problems, such as depression or anxiety that can respond to medication.

- Concern was raised about the use of the term 'symptoms' in the statement, as this was deemed to be overly medicalised.

- One stakeholder suggested that there needs to be reference made to the legitimate use of medication for co-existing conditions in people with autism.

5.6 Draft statement 6

People with autism who develop behaviour that challenges are assessed for possible triggers, including physical and medical problems, before any interventions for behaviour that challenges are started.

Consultation comments

- One stakeholder felt that this should already be current practice.

- Stakeholders suggested that the definitions concerning the possible triggers should be made more comprehensive: suggestions included sensory impairments and speech and language difficulties.

- It was argued that in some cases the trigger will be relatively obvious and an intervention should be implemented rather than waiting for a full functional analysis.

- Stakeholders suggested that the definitions concerning 'behaviour that challenges' needed to be more explicit. Stakeholders asked that consideration of the legislative framework with regard to capacity to consent to treatment is referenced in relation to this statement.

- Stakeholders suggested that this statement would be hard to measure.

5.7 Draft statement 7

People with autism and behaviour that challenges are offered drug treatment for their behaviour that challenges only if psychosocial interventions are not effective or appropriate

Consultation comments

- Stakeholders suggested that it needs to be made clearer that there are some people who it is felt would not be able to engage with psychosocial interventions initially and that drug treatment would be the first option.

- Stakeholders highlighted the needs for clarity on what 'not effective or appropriate' meant and who would make this decision.

- Stakeholders suggested that an additional measure should be added concerning assessment of the efficacy of the intervention at 6 weeks (in accordance with the NICE clinical guideline 170 and 142).

- Concern was raised about the inclusion of a statement that suggested the use of medication in this population.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements:

- The inclusion of statements concerning the local service infrastructure including statements on a local multiagency strategy group and a local specialist community based multidisciplinary team
- Improving referral practices in primary care, particularly with GP's.
- Post diagnostic counselling and support.
- Respite care and short breaks for families and carers.
- Training for parents or carers and other front line staff in helping to support people with autism.
- Ensuring people with autism have access to general health services, with a focus on services making reasonable adjustments to facilitate access.
- Better access to education and employment support.
- The development and use of a single neurodevelopmental assessment pathway.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Comment on	Comments
1	APA - Autism Parents for ABA	Statement 6	While welcoming the Quality Standards overall, and particularly the better timings being put on the diagnosis process, we autism parents do have questions related to Quality Standards 6) and 7) above
1	APA - Autism Parents for ABA	Statement 7	We just do not understand who is supposed to be delivering the "psychosocial" interventions mentioned, as we have been offered nothing for challenging behaviour within either the health or education contexts, but have rather paid privately ourselves for ABA consultants and tutors.
2	Step by Step School	Introduction	The text under the heading “why this quality standard is needed” is a cut and paste about autism. It does not explain why we need the quality standard! The reason we need a quality standard is that the quality and capacity of autism services in the NHS and Social Services varies significantly across the country. For example, we know of cases where it has taken up to 2 years for parents to get a diagnosis from the NHS. We also must address the situation today where some doctors are reluctant to investigate co-morbid conditions in autism, often because this is clinically challenging and time consuming. A quality standard is needed to ensure autism service capacity is configured based on current prevalence. The number of cases has increased significantly in the past 20 years, and today it often seems like capacity is based on prevalence in a former generation
2	Step by Step School	Statement 1	We very much welcome this quality standard. We believe it is important to define what constitutes the start of the diagnostic assessment. We recommend that assessment can only be counted as started once the person with potential autism sees a doctor face to face, and not when the person sees an administrator, nurse, receptionist, has been sent the date of a future appointment, has been sent a questionnaire to complete etc
2	Step by Step School	Statement 2	We are extremely grateful this is included. Looking at the list of proposed health and mental health assessments for each person, it is going to be challenging to determine once these are complete for a given patient. We are minded to be more specific for this quality standard and specify that these assessments, at least for children, are done by a consultant paediatrician with expertise in autism. It is unlikely many GPs would have time to conduct these assessments. We also suggest deleting words that imply social care professionals might be able to conduct such health and mental health

			assessments
2	Step by Step School	Statement 3	We are not sure what you mean by a “personalised management plan” for a child? Is there a template for this that you have in mind? How does it link to what documents exists today? How will there be a single plan across health, social care and education? In order to measure that these documents exist for each person, we suggest you are more specific about what the document looks like, who authors it, and who has access to it. If we can achieve that, then this measure should only be counted as complete once the patient/carer/family has seen it, rather than it being counted when available within a GP record or a Social Services IT system
2	Step by Step School	Statement 4	We welcome this quality standard. However, we advise further definition of what is meant by “designated professional” and what is the “event” that counts as a designation. We believe that this condition is only met for example, if the name of this designated professional has been communicated to the patient/carer/family. For example, this is not met if the default is for the person’s GP to be the designated professional, or worse, that it is any GP or nurse in their GP practice. We remain to be convinced that NICE clinical guideline 170 provides clarity on what specific current roles in health and social services these case managers / key workers can come from.
			We also recommend an addition to this standard specifying that the designated person would be expected to see the patient/carer/family at least once per year. Given that the objective is to ensure case management and coordination across services, if a year goes by without any contact, it seems unlikely that the designated professional is fulfilling the intended role.
2	Step by Step School	Statement 7	We believe that a step is missing. It first needs to be established through a differently worded separate quality standard that psychosocial interventions are to be offered by NHS first line to those who have challenging behaviour without obvious cause. This in itself will be a large change in current practice. The measurement process for this would then need to have a clear definition of counting those with challenging behaviour without obvious cause and then out of those which have been offered a psychosocial intervention informed by the functional assessment of behaviour. We remain to be convinced that NICE has defined this intervention sufficiently for it to be offered by NHS, but we agree that if you accept the NICE guideline as written, then it is important to be able to measure to whom such psychosocial interventions have been offered by NHS.
			Once a separate quality standard deals with offering psychosocial interventions by NHS first line, it is then indeed possible to have another quality standard stating that antipsychotic medication for challenging behaviour should only be tried after psychosocial interventions have failed. This could then be measured by looking at relative timing of initiating antipsychotic prescribing vs offering a psychosocial intervention

2	Step by Step School	Question 1	We are surprised that there is no quality standard regarding the setting up and effective operation of “local multi-agency strategy groups” for autism across England. This may be covered via another governance mechanism, but it seems to be an obvious standard to include in this quality standard
2	Step by Step School	Question 1	Ditto for “local specialist community-based multidisciplinary autism teams”. How do we know that CCGs will comply with funding and developing such teams? What is the mechanism to encourage local professionals to work together, rather than working in organisational silos as in some parts of the country?
2	Step by Step School	Question	Short breaks and respite. A key area for quality improvement is enhancing the capacity/quality of short breaks and other respite care provision, including during the school holidays. In our view, this issue was not dealt with satisfactorily in clinical guideline 170, and is an obvious topic to be dealt with in this national quality standard. Without this, the quality standard appears to refer almost exclusively to NHS activities and has no commitments to raise quality/capacity of autism services in social services. If it is published without any quality improvements from social services, that would be a missed opportunity and inconsistent with the broader remit of NICE and rationale for setting up Health & Well Being Boards
3	Queens University Belfast	Statement 1	It is encouraging that medication is not generally not recommended.
3	Queens University Belfast	General	It is very encouraging that functional analysis, including identifying and evaluating any factors that may trigger or maintain the behaviour, is written into these standards as a key to helping persons with ASD develop behaviours that will help with inclusion.
			What is really surprising though is that Board Certified Behaviour Analysts BCBAs (cf. BACB.com; attached) are not listed under Core Staff. All over USA, the BCBA is now recognised as a key and core professional involved in ASD services. This is based on the fact that applied behaviour analysis based interventions have an extensive evidence base (see National Standards Project report attached), in contrast to interventions used by many of the staff mentioned under core staff, e.g., there is no evidence that sensory integration therapy is effective, in fact is has been shown to be detrimental (see systematic review attached), SIT is one of the main methods used by Occupational Therapists, yet OTs are on the list of core staff.
3	Queens University Belfast	Statement 1	Increasingly BCBA are a licenced profession in the USA. Most, if not all, the requirements for dealing with behaviours that challenge are based on exactly the skills of BCBA, see Task list 4th Edition.

3	Queens University Belfast	Statement 1	The panel should consult with the professional body for behaviour analysts, i.e., the Association for Professional Behavior Analysts APBA (http://www.apbahome.net). Dr Gina Green (Hon Doctorate QUB) is the Chief Executive and I am sure she would be happy to help with any enquires. (Gina Green, PhD, BCBA ggreen3@cox.net)
3	Queens University Belfast	Statement 1	Also check with UK-Society for Behaviour Analysis http://uk-sba.org/behaviour-analysis/
3	Queens University Belfast	Statement 1	Among the long list of professionals, Board Certified Behaviour Analysts (BCBAs) have not included, despite Behaviour Analysis having proved to be the basis for the most effective interventions for individuals with Autism.
3	Queens University Belfast	Statement 6	Although the need for a thorough assessment of the variables that may maintain challenging behaviours is correctly identified (e.g., inadvertent reinforcement), functional analysis has not been explicitly endorsed and BCBAs who are the sole professionals adequately trained to conduct it are not mentioned.
3	Queens University Belfast	Statement 7	Functional analyses have proven to be the best practice in identifying the factors that maintain challenging behaviour and enhancing the design of effective treatment behaviour plans [e.g., Mace, F. C. (1994). The significance and future of functional analysis methodologies. Journal of Applied Behavior Analysis, 27, 385-392)]. Functional analyses were first used and have been thoroughly described in behaviour-analytic literature (e.g., Journal of Applied Behavior Analysis). However, effective interventions are called “psychosocial” in this draft and not “behaviour—analytic” a term that: a) is not the same as the one used in the scientific literature to describe the science from which functional analyses were derived and more importantly b) can be misleading to consumers, since it encompasses a wide range of interventions, which do not use functional analyses as a mean of addressing challenging behaviours and are not always effective in treating core symptoms of Autism.
4	UK Society for Behaviour Analysis	Statement 6	There is reference on p. 22 of the Quality Standards to the need to understand and assess behaviour that challenges. Yet in the core team requirements on pgs 7 and 8 there is no mention of a Behaviour Analyst, who would be one of the professionals with the specific and detailed training needed in order to undertake such an assessment
4	UK Society for Behaviour Analysis	Statement 7	We welcome the acknowledgement of the value of reinforcement. Reinforcement is an important principle of behaviour and it is used in almost all behaviour change programmes, including the teaching of new skills. To do this effectively requires a comprehensive understanding of those principles. The reference to reinforcement on pg 27 appears without discussion or acknowledgement of any other behaviour principles (reinforcement is seldom used in isolation) and the passage shows no understanding that reinforcement is not just rewarding appropriate behaviour is an important principle of behaviour and it

			is used in almost all behaviour change programmes, including the teaching of new skills. To do this effectively requires a comprehensive understanding of those principles. The reference to reinforcement on pg 27 appears without discussion or acknowledgement of any other behaviour principles (reinforcement is seldom used in isolation) and the passage shows no understanding that reinforcement is not just rewarding appropriate behaviour.
4	UK Society for Behaviour Analysis	General, all	Behaviour Analysts are the professionals with specific training in the behavioural methods detailed in the Quality Standards. This profession, though currently unrecognised in the UK, meets all criteria for HCPC registration, including having clear training and internationally-recognised credentials via the BACB (Behavior Analyst Certification Board - www.bacb.com). The UK-SBA is currently working towards getting professional recognition and regulation for this aspirant profession within the UK.
5	Tees Esk and Wear Valley NHS Trust	Outcomes framework indicators	Title – what about Children and Young People
5	Tees Esk and Wear Valley NHS Trust	Outcomes framework indicators	Should this be widened to carers i.e. supporting the management of the condition by carers?
5	Tees Esk and Wear Valley NHS Trust	Outcomes framework indicators	Is this employment by the NHS or is this the NHS supporting getting people into employment?
5	Tees Esk and Wear Valley NHS Trust	Outcomes framework indicators	Should this include patient experience of physical health care?
5	Tees Esk and Wear Valley NHS Trust	Statement 4	Should this be expanded to include the coordination of assessment too?
5	Tees Esk and Wear Valley NHS Trust	Statement 6 -	Functional analysis of the behaviour should be included too
5	Tees Esk and Wear Valley NHS Trust	Question 1	Generally yes- see post-its above for additional suggestions. Appropriate physical health care should also be a priority

5	Tees Esk and Wear Valley NHS Trust	Question 2	Yes, providing the right questions are asked and that carers can respond on behalf of those that have difficulties with communication. Communication aids / modified tools may be required for those with lower ability; otherwise results will be skewed to more able service users.
5	Tees Esk and Wear Valley NHS Trust	Statement 1	may be part of another service(s)
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Difficult if the team is coordinated/lead by education- no remit to adhere to NICE guidance.
5	Tees Esk and Wear Valley NHS Trust	Statement 1	perhaps need suggestions of pump-priming systems e.g. waiting list initiatives to reduce existing waiting times (clear the back-log)- may require health and local authority commissioning to include education (Educational psychology)
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Could this clarify? What about systems where there is a 2 stage process for assessments i.e. a filtering/triage (initial information gathering stage) which then advises full multiagency NICE compliant assessments. At what point does the clock start?
5	Tees Esk and Wear Valley NHS Trust	Statement 1	What happened to the Autism assessment coordinator role? And who commissions the educational psychology? This is neither social care nor health!
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Who commissions the teacher?
5	Tees Esk and Wear Valley NHS Trust	Statement 1	What about an assessment of physical health akin to the paediatric assessment in children and young people.
5	Tees Esk and Wear Valley NHS Trust	Statement 1	DSM-5 not DSM-V (roman numerals are now replaced)
			These now differ more than ICD-10 vs DSM-IV.
			Can the criteria be specified- to highlight the new levels and sensory aspects?
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Specify the essential and optional components.
5	Tees Esk and	statement 1	Include physical/genetic as well as mental; health differential diagnoses.

	Wear Valley NHS Trust		
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Specify verbal and written strengths and needs report.
5	Tees Esk and Wear Valley NHS Trust	Statement 1	Who by? Please specify to avoid interagency refusal to comply.
5	Tees Esk and Wear Valley NHS Trust	Statement 2	These should be assessed separately, since usually offered by different services.
5	Tees Esk and Wear Valley NHS Trust	Statement 2	Specify who by...
5	Tees Esk and Wear Valley NHS Trust	Statement 3	add conduct disorder
5	Tees Esk and Wear Valley NHS Trust	Statement 3	Stick to 1 phrase- challenging behaviour or behaviour that challenges.
5	Tees Esk and Wear Valley NHS Trust	Statement 4	Should this include assessment coordination too?
5	Tees Esk and Wear Valley NHS Trust	Statement 4	Who is responsible? Social care or health?
5	Tees Esk and Wear Valley NHS Trust	Statement 4	Define main service- scope for interagency disagreement and variability in structures for coordination of this.
5	Tees Esk and Wear Valley NHS Trust	Statement 5	Difficult to define difference between OCD symptoms and repetitive/ritualistic behaviours especially when ability is low and therefore the cognitive (obsessive thoughts) are limited.

5	Tees Esk and Wear Valley NHS Trust	Statement 6	Include a functional analysis of the behaviour.
5	Tees Esk and Wear Valley NHS Trust	Statement 6	and function of the behaviour
5	Tees Esk and Wear Valley NHS Trust	Statement 7	Does this include treatment of factors within an escalation chain or just the end challenging behaviour? e.g. trigger-anxiety-anger-challenging behaviour. Does treating the anxiety constitute Treating the challenging behaviour?
5	Tees Esk and Wear Valley NHS Trust	Statement 7	include proactive and reactive strategies
5	Tees Esk and Wear Valley NHS Trust	Statement 7	Actually Risperidone has a short-term license for both aggression in conduct disorder and ASD- see BNF.
5	Tees Esk and Wear Valley NHS Trust	Section 3	Can any audit tool be broken down into individual sections rather than clustering the standards. This allows a better analysis of compliance i.e. in the assessment of ASD NICE audit, the clustering of standards means that only 1 component needs to be failed to fail an entire section.
5	Tees Esk and Wear Valley NHS Trust	Policy Context	What about the Autism Act?
6	Axia ASD Ltd	INTRODUCTION	We have tried to comment on the draft quality standards are service providers who would be required to submit the required information for these standards to be monitored.
			For information purposes, we are Axia ASD Ltd (www.axia-asd.o.uk) providing NHS and private diagnoses to adults and children with Autism Spectrum Disorder and complex psychological intervention.

6	Axia ASD Ltd	statement 1	People with possible Autism needing a diagnostic assessment by an Autism Service have the assessment started within three months of their referral. These comment made are based on our experience of a service offering diagnosis to adults whose IQ would mean they would not be seen within the Learning Disability Service. Although we have contracts with a number of Clinical Commissioning Groups, funding has to be sought on an individual basis, going before a Bespoke Care Panel. We are also aware that this is a route that other tertiary services in the UK also have. We may receive a referral from a GP who has not yet applied for funding. If funding has not been obtained, the service cannot be at fault for not seeing the client within the time limit specified. The client will be seen within three months of referral with funding obtained. If funding has not been obtained, the client may be seen outside of this time frame, of which the service has no jurisdiction over. We are aware we are not the only service that functions in this way.
6	Axia ASD Ltd	statement 4	Care and Support Coordination. People have a designated professional to oversee and coordinate their care and support. In our experience many of the people who come to us for diagnosis, once they have received post-diagnostic support from our service will often choose not to have any services involved in their life and would certainly not wish to have a designated professional overseeing and coordinating their care and support. Perhaps this quality statement could give people some choice about whether they do want this to happen in their life. They certainly would have our details such as if they wish to be re-referred they would go back to their GP and funding obtained to return to our service. We note for this that in terms of definition of terms, the designated professional for adults who are not receiving care from the specialist Autism Team, Mental Health or Learning Disabilities Services that the designated professional should be a member of the Social Care or Primary Health Care Team. Many of the people we work for would not want a care plan developed for themselves and they would probably see their GP as the designated professional.

6	Axia ASD Ltd	Statement 5	People with Autism are not prescribed drugs to treat the core symptoms of their Autism. This, in our opinion, is quite a difficult quality standard to monitor. Many of the people we see are prescribed, for example, anti-depressants. One could argue that these are not prescribed for the core symptoms of Autism, however, it is clear that having Autism and the way people are treated in society causes them to become depressed and anxious. More reassuringly, we often find that people who come to us with a diagnosis of resistant treatment depression on obtaining the diagnosis find they may no longer require such medication. However, we have a number of people, for example, who are on Risperidone report that this "takes the edge off their anxiety" and enables them to cope better in a world that is at best confusing and at times frightening. We do find a number of people who are also prescribed medication to help them with what has been described as their obsessions and compulsions that seem to be on occasion effective in helping the person function on a day-to-day basis. We do, however, recognise that the population we are dealing with are people who are more than able to consent to their treatment and weigh up any positives, benefits and side effects of medication before choosing to proceed.
6	Axia ASD Ltd	General	In conclusion, we feel this is an excellent set of quality statements which, if followed, would improve the lives of people with Autism Spectrum Disorders and their families.
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Statement 1	As some services accept out of area referrals, such as our own, we hoped that this time scale should take into account the time it may take for funding to be secured following the initial referral, where relevant. That is, the assessment should start within 3 months of the cost-per-case funding being secured.
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Statement 2	As many Clinical Psychologists and other non-medical professionals are undertaking assessments for Autism, it may not be appropriate for these professionals to assess for co-existing physical health problems. Therefore, a solution may be for a diagnosis of Autism being a trigger for a physical health assessment from the client’s GP, as an example. Additionally, it may be useful for a more detailed checklist, possibly including digestive system disorders, to be drawn up for specific physical health problems to be looked into, as there is in the guidance for Children and Young People with Autism.
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Statement 3	Many adults with a High-Functioning Autism Spectrum Condition (commonly known as Asperger Syndrome) may feel that this should only be offered when wanted or appropriate, with this guideline appearing more Learning Disability-focused. Some adults in such a position may be looking solely for a diagnosis and not have other needs.
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Statement 4	Again, many adults with a High-Functioning Autism Spectrum Condition (commonly known as Asperger Syndrome) may feel that this should only be offered when wanted or appropriate, with this guideline appearing more Learning Disability-focused. For instance, they may be happy with this professional being the person’s GP if there are no additional needs following a diagnosis, who can

			refer to appropriate services when needed.
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Statement 6	The discussion in this statement only describes behavioural interventions, which, some would say, have a questionable evidence base, while commonly used. It has no discussion about systemic interventions e.g. staff systemic consultation, family therapy, solution-focused therapy etc., although we are aware these are not specifically named in the NICE Guidance for Autism in Adults (bar advice to family, partner or carer/s).
7	Sheffield Asperger Syndrome Service, Sheffield Health and Social Care	Question 1	We also were wondering as to whether this would this be an appropriate place to have other related standards e.g. those relevant to Fulfilling and Rewarding Lives. For instance, there could be outcomes to measure: proportions of social services assessments of need post-diagnosis (where relevant); increased access to mainstream health services; or support in education or employment among others.
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Autism is a lifelong developmental disability that has (can have) a significant impact on the person and their family or carer
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	- substitute ‘has’ with ‘can have’ – there are some people with autism where there isn’t a significant impact
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Access to specialist services - d) Befriending (where appropriate) - insert ‘where appropriate’ – Some people with autism would not want befriending services
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Organisation and delivery of care, NICE CG142 Recommendation 1.8.1 - ‘Flexible’ should be added to the first bullet point after ‘negotiable’
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Making services accessible and acceptable, SCIE Guide 43 p17- replace ‘one stop shop’ with ‘single point of access’ – some people with autism may see one stop shop as somewhere to go

8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Comprehensive (diagnosis, needs and risks) assessment of suspected autism CG142 Recommendation 1.2.10 – replace ‘assess for’ with ‘identify any’
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Current UK practice – add: ‘DISDAT tool should be used as an example of good practice in community and acute hospital settings’
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Advocacy (Adults) NICE CG142 Recommendation 1.1.4 – on second bullet point add ‘positive’ between ‘individual and relationships’
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Advocacy (Adults) SCIE Guide 43 p17 – replace ‘one stop shop’ with ‘single point of access’
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Current UK Practice, Sleep – Could refer to sleep hygiene strategies
8	Somerset County Council (Somerset Autism Planning Group)	Briefing paper	Adults, NICE CG142 Recommendations 1.1.3 – add extra bullet point: ‘* Impacts on sensory sensitivity’
9	Contact a Family	Statement 1	People with possible autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral.
			We are concerned this only measures how long people should wait for the start of the assessment process, rather than completion of the assessment process. We frequently hear from families in some areas of the country, where the assessment process has taken many months and even years. This is more likely to happen if the autism team have to refer to another agency for their input to the assessment process. For example CAMHS. These children are then left in limbo without a diagnosis, making it impossible for them to get the additional support their child needs at school. These children are then much more likely to be excluded from school for their behaviour - see

			http://www.cafamily.org.uk/news-and-media/disabled-children-illegally-excluded-from-school-every-week/
9	Contact a Family	Statement 6	People with autism who develop behaviour that challenges are assessed for possible triggers, including physical and medical problems, before any interventions for behaviour that challenges are started This statement focuses on reacting to people who developed behaviour that challenges, rather than to also trying to prevent it from happening. Challenging behaviour is often how people with autism communicate their distress about something they are unhappy with. There needs to be an additional statement, which reflects NICE guidance, in saying that people caring for people with autism should receive training in autism awareness and have skills in managing autism, to help them in anticipating and preventing behaviour that challenges. This is particular important in light of the Winterbourne review.
			This statement focuses on reacting to people who developed behaviour that challenges, rather than to also trying to prevent it from happening. Challenging behaviour is often how people with autism communicate their distress about something they are unhappy with. There needs to be an additional statement, which reflects NICE guidance, in saying that people caring for people with autism should receive training in autism awareness and have skills in managing autism, to help them in anticipating and preventing behaviour that challenges. This is particular important in light of the Winterbourne review.
10	Treating Autism	INTRODUCTION	It is stated that: “… people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, … and mental health problems such as anxiety, depression, problems with attention, sensory sensitivities, self-injurious behaviour and other challenging, sometimes aggressive, behaviours”. This statement misleading and heavily biased towards psychological and behavioural explanations, without firm basis. It is implied that these symptoms are always of psychological /mental health nature, in the absence of clear evidence base that this is the case. Indeed there is more evidence that self-harming and aggressive behaviour is due to pain or an abnormal reaction to pain than to any direct behavioural construct or indeed directly related to autistic pathophysiology. We have grave concerns regarding the impact such a statement would have on the care, access to care and prognosis of those with ASD. Evidence or at least pathophysiology behind self-injurous behaviour and aggression should be provided before such a far reaching statement is made with such authority.
			Separating out physical and mental illnesses, while admitting overlap of visible surface symptoms, would be greatly beneficial.

10	Treating Autism	Statement 2	‘Self-injurious behaviour’ is again listed under Mental and behavioural problems’. It should be stressed that such behaviours can often be manifestations of physical pain and discomfort.
			Whilst it is accepted that certain conditions falling into the ASD category can have self-harm as a consequence, the vast majority of those falling into the category will never be expected to experience self-harming behaviour. The bias towards psychological attribution of symptomology is potentially harmful, as given evidence identifies that self-injury can be a sign of physical pain (such as toothache, earache, reflux etc), and the encouragement given in this guideline/comment to assign such behaviour to autistic or ‘mental health’ behaviour is likely to lead to missing physical illnesses in this vulnerable patient group, leading in some cases to failed school and home placements, not to mention the trauma to patient and family.
10	Treating Autism	Statement 2	The list of ‘Medical or genetic problems and disorders’ should include mitochondrial disorders, as these are very prevalent in individuals with Autism Spectrum Disorders.
10	Treating Autism	Statement 2	The need for secondary referrals should be mentioned, such as: “if on going concerns remain regarding physical problems, for example abdominal pain or dental pain despite negative preliminary findings due consideration should be given for a specialist referral." The reason for this is that correctly identifying physical problems in individuals who are not able to clearly communicate, or have good understanding of, their physical sensation, or in those patients with autism and intellectual disability, can be difficult for health professionals who do not possess experience and specialism in the field.
10	Treating Autism	Question 1	This publication should discuss and warn health care professionals of the prevailing problem of ‘diagnostic over-shadowing’, where symptoms of physical ill health are mistakenly attributed to either a mental health or behavioural problem or as being inherent in the person’s learning disabilities. Diagnostic overshadowing is a major contributing factor to health care inequalities experienced by individuals with autism and their families.
			References:
			Emerson E, Baines S Health Inequalities & People with Learning Disabilities in the UK: 2010. The Public Health Learning Disabilities Observatory.
			Breau LM, Burkitt C (2009) Assessing pain in children with intellectual disabilities. Pain Res Manag. 2009 Mar-Apr; 14(2): 116–120.
			Buie T, Campbell D B, Fuchs GJ et al. (2010) Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics, 125: (Supplement 1): S1-S18.
			Annual Health Check for People with Learning Disability – A Step by Step Guide for GP practices, publication by Royal College of General Practitioners

			Tracy JM, Wallace R (2001) Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux. Med J Aust. Jul 16;175 (2):109-11
11	Royal Manchester Childrens Hospital	Statement 1	About the quality standard is this a generic standard purely for the management of children ,young people and adults management and diagnosis of autism ?
11	Royal Manchester Childrens Hospital	Question 1	Can this standard be adapted for children, young people with autism accessing the healthcare setting acute /tertiary community .to improve help quality improvements and management of care?
11	Royal Manchester Childrens Hospital	Question 1	Will there be an autism standard for children young people accessing Health and Social Care acute /tertiary, community settings?
11	Royal Manchester Childrens Hospital	Question 1	Suggested recommended coordinated transition from children to adult health care services [acute, secondary tertiary]
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	As Autism, ADHD, speech and language and Learning Difficulties are all so co morbid, it is not helpful to have totally different assessment pathways for each. We should have 1 Nuro developmental assessment pathway in the initial stages.
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	There should be a dedicated 1 organisation funded and responsible. In my experience multi-disciplinary teams do not work when there are many different employer organisations, as the greater priorities of that organisation prevent easy efficient joint working and ownership. Of course I think that organisation should be a dedicated provision within CAMHS due to the high level of associated mental health/ stress issues.
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	The standard should also focus beyond diagnosis. It should include provision for respite care/ social care, and specialist teaching/ educational provision. At present there is a conflict with Social care as their remit is to fix the family. There is little provision or understanding of the need for 18 year long provision.
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	Specialist provision for Children/ young people should sit within the same organisation until at least 20 due to the developmental delay issues.
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	The diagnostic thresholds need to be lowered, or the sub threshold clients need to be formally recognised in the guidance. As at present many sub threshold young people are in significant difficulty due to the high threshold, and not being able to manage the increasing sophistication of the modern world, yet are unable to access services. This has led to clinicians developing unofficial diagnosis for example Nuro developmental disorder not otherwise specified. The same incidentally

			applies to learning difficulties but that is another subject.
12	South West Yorkshire Partnership NHS Foundation Trust	Question 1	The Guidance should be specific on educational provision as at present each area, and in many cases schools do their own thing.
13	Ambitious about Autism	Statement 1	This is a welcome standard as recent research shows that 54% of people diagnosed with autism over the age of 18 found the process difficult, and 50% of those diagnosed over 18 found it too stressful[1].
			As well as ensuring that the diagnostic process is as fast as possible it is also essential that there is adequate information and advice available for families while they go through this process. Ambitious about Autism run an online forum, Talk about Autism. One of the most frequently discussed topics is the anxiety that families face while they are going through this process and the lack of information and support they receive[2]. It is important that that the Autism Service are able to put families in touch with a local family support worker.
13	Ambitious about Autism	Statement 3	A personalised management plan for children and young people with autism must be linked to the child or young person’s Statement of Special Educational Needs, Learning Difficulty Assessment, or Education Health and Care Plan (EHC Plan) as created by the Children and Families Bill. As there will be a duty on clinical commissioning groups to deliver the health provision in an EHC Plan, it is essential that the recommendations in a management plan are reflected in an EHC Plan. The Government’s intention is that the Children and Families Bill will create a holistic system for children and young people with special educational needs; it is therefore crucial that both plans work together.
			It is also important that a child or young person’s school or college is consulted when drawing up a management plan. Teachers and teaching assistants will often have a good understanding of the ways in which a child’s health needs affect their learning so it is important that schools are involved in this process.
13	Ambitious about Autism	Statement 4	This is a very welcome quality standard. Families can find it difficult to contact the right person when they have questions about the support they receive. A named professional with responsibility for co-ordinating their support could be a valuable tool for families. Although we recognise that schools are not within the jurisdiction of NICE quality standards it is important that this key contact is encouraged to contact the young person’s special educational needs co-ordinator as it is likely that some of a young person’s support may be delivered at school.

13	Ambitious about Autism	Statement 6	As with quality standards 3 & 4 it is very important that the any assessment for triggers of behaviour that challenges is done in partnership with the family and with schools As with quality standards 3 & 4, it is very important that any assessment done for triggers of challenging behaviour is done in partnership with a child’s family and school. Challenging behaviour, and schools’ ability to manage it, has a huge impact on children’s ability to learn and progress at school. Children with autism are disproportionately affected by exclusion,. 23% of families who responded to a survey run by Ambitious about Autism said that their child had been formally excluded in the last year and 40% had been asked to collect their child during the school day[3]. We know that ‘disruptive behaviour’ is the most common reason given for exclusion and that exclusion can mean children miss out on weeks, months or even years of schooling[4]. It is imperative that schools are able to feed in to any assessment of challenging behaviour and that where appropriate, information about advised interventions is shared. In our services, behavioural approaches such as Applied Behavioural Analysis (ABA) have proven an effective way of identifying triggers for young people with autism.
			It is important that adolescence is noted as a particular time when young people with autism may need support from mental health services. Changes to routine and personal circumstances can be anticipated in adolescence and particular consideration of a young person’s mental health should be encouraged when considering triggers during this time.
13	Ambitious about Autism	Statement 7	As above.
14	Devon Partnership Trust – Devon Autism and ADHD team	General	This response is from an ASC specialist team for people over 18, without a learning disability and will therefore be written from this perspective. We acknowledge that ASC span a wide range of ability and age and therefore understand that not all of the information in the quality standards will necessarily apply to the population we serve.
14	Devon Partnership Trust – Devon Autism and ADHD team	General	We feel positively about some of the recommendations that this standard makes, in particular the focus on the needs of the person with ASC.
			However it seems that they are most relevant to people who have cognitive impairment alongside an ASC. There is a general lack of consideration of the needs of people without a cognitive impairment. For example:
			1) Lack of application to general adult psychiatry

			We were surprised that the Quality Standards Advisory Committee /NICE project Team does not have representation from general adult psychiatry. Having this perspective may have brought a greater awareness of the difficult / urgent situations that arise in relation to people with ASC within generic settings. Merely transplanting guidelines derived from expertise developed in other settings is likely to exacerbate the impression of incompetence and deskilling that inpatient units etc. might be tending to feel.
			For example with emergency admissions to hospital for people who may have quite subtle ASC problems. These situations are very difficult to manage and having someone with experience of caring for people in these settings involved in thinking through how these standards might be met in this high risk situation where patients and families may be at their most distressed, frightened and angriest would have been very useful.
			2) Care- coordination and shared care across mental health services
			There is insufficient information about how the 'overseeing key person/health-professional' will be selected. It is only described as a need and that this may be someone from the Autism team, the community team, LD team or primary health team, without any decision tree how this occurs.
			It would be helpful if it were more explicit what would be offered in terms of care-coordination, otherwise this could mean that people have to have on-going input throughout their lives. This may lead to significant difficulties in services with no exit-strategies. We feel that it is important for this to be a time-limited option for those who need it, with the package periodically reviewed. This would finish at the request of the client or in agreement with the clinician. At the moment there is a lack of link between the specific needs of the client and the intervention offered.
			3) Lack of consideration of the complexity of issues faced by those with high-functioning conditions
			Whilst there was considerable attention paid to challenging behaviour, and necessarily so, we felt the needs of people who are diagnosed as adults and who do not have a cognitive impairment were under-developed. For example vulnerability and the safeguarding/ risk management issues that surround this.
14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 1	Although we commend having a target for people to be diagnosed in a timely way we are concerned that the standard set may mean that people are screened within 3 months and placed on a further waiting list. This could be extremely detrimental to the persons mental health and wellbeing especially given the difficulties of the client group who struggle with rigid thoughts and ‘grey areas’ and therefore may cause the person undue distress.
			We would welcome this standard if it came with additional resources to meet the needs of this population in a timely fashion. It would therefore need to be explicit what needs to be commissioned.

14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 2	We recognise the importance of the physical health of our client group and how their difficulties may impact on their ability to be able to recognise and seek help for health problems and therefore its implication on wellbeing and life expectancy. However it is not made clear in the standard who is responsible for this physical health assessment. Once again we would be concerned that a specialist team being responsible for physical health assessment alongside diagnosis would only seek to further isolate our clients from mainstream care. It would be helpful if the responsibility of this assessment were made more explicit. If this is to occur in specialist teams this has implications on the skills mix required for teams, time for assessment and financial cost. The concern re: the further isolation of the client group also extends to the need for an assessment of psychiatric comorbidity. If a full assessment of mental health needs is required then does this mean that assessments should occur within CMHT? If this is the case what implication does being seen in CMHT's have for people who do not necessarily associate with a mental health label and who may be disempowered by this? Have the implications for capacities of mental health services been considered in this?
14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 3 and 4	We are not sure whether everyone with a diagnosis of ASC needs a care-coordinator or whether this would promote their recovery, independence and wellbeing. We feel that this should be according to personal need. Further it is unclear where this care-coordination would sit. For example if this sat within specialist teams this may only serve to de-skill more generic services and create further division in service provision. However if there was a more integrated approach to care management advocated with consultancy support from experts/ embedded experts in teams in a 'hub and spoke' model this may improve people with ASC's fair access to services. Especially for those who have a psychiatric comorbidity. The capacity of teams responsible for this care coordination would need to be considered.
14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 5	We agree with this.
14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 6	We are very pleased to see the acknowledgement of the importance of sensory issues in the diagnostic assessment of people with ASC. However it appears to be neglected in relation to behaviours that challenge. We feel that whenever a person with ASC presents with difficulties (whether these are externalised or internalised) a re-visiting or checking that the sensory needs of the person should be central.

14	Devon Partnership Trust – Devon Autism and ADHD team	Statement 7	We are not sure whether it is always logical to have a hierarchical approach to this treatment starting with psychosocial interventions before medication if that might expose the person to risk. This would be common in general psychiatry. Crucially where there is a reasonable expectation based on evidence that medication might help. It seems to me that this is likely to be the case where there is a comorbid mental illness which would be the target of the treatment rather than the core features of ASD per se.
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 1	Who would be in the ‘specialist integrated autistic team’ for assessment? What assessments should be used?
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 3	Management plan should be accessible – in terms of the content – to the service user with consideration for pictorial or other aids, developed where possible with the user
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 6 and 7	Statement 6 & 7 - not sure of the difference
15	Greater Manchester West Mental Health NHS Foundation Trust	Introduction	The introduction fully explains the need for the quality standard and this is supported by other frameworks.
15	Greater Manchester West Mental Health NHS Foundation Trust	General	Each standard is explained fully and in detail

15	Greater Manchester West Mental Health NHS Foundation Trust	General	Each standard appears to have a measurable outcome and if the systems and structures were available then it would be possible to collate data in order to measure outcomes and quality.
15	Greater Manchester West Mental Health NHS Foundation Trust	General	Each standard seems realistic, achievable and measurable.
15	Greater Manchester West Mental Health NHS Foundation Trust	General	I thought the standards seemed reasonable, the last section deals with medication for challenging behaviour and seems to advise antipsychotics as the first line treatment for this, I think guidance about other medication should be included perhaps? This is my only comment.
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 1	I think 3 months is a realistic target to begin the assessment process. In many complex cases it may take longer than this but I am in favour the first assessment taking place within 3 months.
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 2	In my opinion the specialist autism services for adults should have consultant psychiatrist's (with experience in ASD) are within the core of the team. I note this is the case for children but not adults. This is to ensure that emerging psychotic illness, personality disorder (schizoid) and organic illnesses are ruled out which can also present with social communication and reciprocal interaction difficulties
15	Greater Manchester West Mental Health NHS Foundation Trust	Statement 5	If it is not financially feasible to ensure all adult autism assessments are seen by a suitably qualified psychiatrist I am of the opinion all cases with challenging behaviour should automatically be seen by one. This is to ensure a treatable mental or physical disorder is not missed. I have experience of assessing patients with a diagnosis of ASD and it is apparent there is an underlying mental disorder which is driving the behaviour. There can be negative consequences to a diagnosis of ASD in this group of patients because it results in resistance by mental health services to manage them unless a mental disorder is evident. I agree that challenging behaviour requires a functional analysis.

16	East and North Herts NHS Trust	Statement 1	In this trust, children are seen for a ‘general medical’ assessment before a ‘diagnostic’ assessment for autism. This first encounter includes the physical examination and the instigation of gathering of further information in addition to any already obtained. In accordance with NICE Guidance, in almost all cases, the assessment has technically started within 3 months of referral but there is then a delay of several months before it is completed at a more comprehensive assessment which includes parental questioning and assessment of the child using an autism-specific standardised tool (ADOS). We are probably not alone in this delay which may be reported differently in different areas. In fact, we have required (and obtained) additional funding to support the reduction of this unacceptable wait for the actual assessment. Would it be useful to give a TIME FRAME in which the assessment should be started and completed? It may lead to more accurate reporting, give a more realistic target which can be tailored to the different working practices in different areas and help parents and referrers understand that the pathway, with the gathering of appropriate and sufficient information, is an actual diagnostic process, rather than simply the assessment itself.
16	East and North Herts NHS Trust	Statement 2	With the support of a psychology student, we have conducted a comprehensive audit of our diagnostic assessment pathway over the last 3 months. We used the NICE audit tool but expanded out some domains to examine whether we assess children thoroughly. This was done because it is easy to consider that one is comprehensively assessing children without being sufficiently thorough about important items. An ASD assessment is long and complex: important detail can be lost in this complexity. The audit is attached, together with the expanded audit tool. In summary, it demonstrates some very good practice on our part in relation to questioning and assessment of most paediatric and developmental conditions as well as information gathering regarding the core features and educational issues. We need to improve the recording of our physical examination and the exploration of mental health issues. Would it be useful if statement 2 is expanded to ensure quality in this most important aspect of the diagnostic process? The quality statements that follow are all dependent on statement 2 being fulfilled to the highest possible level of accuracy in a difficult field. The management plan and any response to symptoms or behaviours are dependent on a comprehensive and accurate unpicking of any differential diagnoses and comorbid difficulties that the child may have.

16	East and North Herts NHS Trust	Statement 4	In neither the guideline or the quality standard draft is it clear who this designated professional should be. In the quality standard draft (page 17) it states, ‘The health or social care professional identified as the designated professional will depend on the severity and type of need the person has’. It is difficult for health to fulfil this remit since the management of children with autism mostly devolves to professionals in education once the diagnosis has been made, other than the provision of therapy based or drug interventions such as S&LT or melatonin. Social care may also find it difficult to meet this standard. If ‘social care’ in this context includes ‘education’ then this should be stated since it is possible that responsibility and the resources for this quality standard are unlikely to be met unless it is clear who is the provider.
17	Real Life Options	Question 1	We believe the quality statement doe accurately reflect the key areas for quality improvement. We are particularly pleased to note the emphasis on person centeredness and the taking into account the strengths as well as needs of an individual. We strongly support standard 6 which will ensure assessment seeks to identify triggers for behaviour that challenges and standard 7, the use of drug treatment only as a last resort.
17	Real Life Options	Question 2	RLO believes that the standards as laid out offer clear means of collecting data. We would want to ensure that systems and structures were available as we believe such information would make a considerable difference to the drive to improve quality.
18	Bristol Autism Spectrum Service	Statement 1	Quality Statement 1 stipulates that “people with autism needing a diagnostic assessment by an autism service have the assessment started within 3 months of their referral” This should be changed to 18 weeks in line with other NHS services maximum waiting list times.
18	Bristol Autism Spectrum Service	Statement 2	Quality Statement 2 stipulates that “Health professionals and social care practitioners ensure that when they carry out a diagnostic assessment for autism they also assess the person for coexisting physical health conditions and mental health problems”.
			If a full physical health screen is completed by the specialist autism clinicians, it will significantly inflate the time taken to complete the assessment (impacting on waiting list times). If any health concern is identified, the service user will need to be referred back to the GP anyway for a fuller assessment of the issue, and subsequent treatment. Therefore this screen would be better done by the GPs from the start. In addition the GPs may be more skilled and better equipped to complete these assessments. Physical health screenings may be a better fit as an initial part of care pathway carried out by G.P’s prior to referral to specialist teams. Finally, there is very little information about the morbidity of this population, outside of mental health issues. Although it is reasonable that this population do have generally worse health outcomes (as do similar populations like people with mental health conditions or learning disabilities) further research should be funded to ascertain if this is in fact true, if it is to be

			made a quality standard priority.
			I agree that specialist teams are well placed to screen for common mental health conditions as alternative or concurrent issues with autism.
18	Bristol Autism Spectrum Service	Statement 3	“People with autism have a personalised management plan that takes into account their strengths and needs” This should be reworded to “People with autism have access to a community care assessment that takes into account their strengths and needs”. Using the term ‘management plan’ suggests long term care that is diagnosis centred and not needs dependent or person centred. It is unclear what a “personalised management plan” would achieve, or how it would intersect with other statutory planning systems (SEN statements, CPA, community care plan etc).
18	Bristol Autism Spectrum Service	Statement 4	“People with autism have a designated professional to oversee and coordinate their care and support” This is again phrased in a diagnosis dependent and not needs dependent manner. Where someone who does not have needs which require on-going and long term support the designated professional should be their G.P, if one is required at all. Many people with autism do not need a designated professional to oversee their care, and would likely find this condescending.
18	Bristol Autism Spectrum Service	Question 1	There is currently no standard concerning post-diagnostic support in the Quality Standards. This is a guideline within the NICE standards, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum “Offer all adults who have received a diagnosis of autism additional support to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require” This should be added into the current draft Quality Standards. We believe that “fire and forget” diagnoses leave individuals confused and misinformed about their autism. A majority of the adults who we assess have requested diagnosis in order to understand themselves better, and therefore post diagnostic support is an integral part of the service which we deliver. We suggest that post diagnostic support is central to delivering a successful and meaningful diagnostic process, and that a key standard be that all diagnostic services offer post diagnostic support to understand the diagnosis and how it applies to the individual. This support should be commissioned as an integral part of the diagnostic process. The nature of the Post-Diagnostic Support will need to be locally defined but should reflect current best practice.
18	Bristol Autism Spectrum Service	Question 1	Commissioning of stepped training for all should be a key quality standard, as recommended in “Implementing Fulfilling and Rewarding Lives” and the NICE clinical guidance.
18	Bristol Autism Spectrum Service	Question 1	People with autism have traditionally fallen between the posts of mental health and learning disability services. A key quality standard could be to ensure that people with autism spectrum disorder are not excluded from any services due to their diagnosis, and that current services show that they are adapting to meet the needs of people with autism.

18	Bristol Autism Spectrum Service	Question 1	Employment and social support is not currently mentioned. For the many people with autism who do not meet FACS criteria, brief intervention employment and social support can ensure they remain independent and out of specialist services. The commissioning of these “light touch services” should be a priority due to their exponential impact.
18	Bristol Autism Spectrum Service	Statement 5 -7	Whilst the sentiments of these statements are valid, we feel that three statements on related behavioural issues may be an over-emphasis and be challenging to measure. We note the forthcoming NICE guidance on challenging behaviour and wander if these positive behavioural support principles will be covered in there.
19	MacIntyre	Statement 1	This seems to be a reasonable approach. It would be useful to ensure that there is no possible loophole here. It could be possible to start an assessment and then slow everything down. It may be useful to set a standard for assessment time while recognising that there will need to be some flexibility here. I appreciate that good inclusive assessment can take time.
			Data can be kept on this issue, although as discussed above, it may be useful to look at data on ‘completed’ assessments.
19	MacIntyre	Statement 2	This is strongly endorsed. This is essential as the appropriate management or treatment of other conditions is essential in providing appropriate treatment and support to individuals on the spectrum.
19	MacIntyre	Statement 3	This is strongly endorsed. We believe in a person first approach rather than a one size fits all method.
19	MacIntyre	Statement 4	This is an interesting point. We would ask the question as to who might be the best type of professional to lead this. It may not always be best to use a medical professional.
19	MacIntyre	Statement 5	We agree with this. However there may be issues related to autism such as depression and anxiety which might benefit from some medical intervention as part of the integrated programme.
19	MacIntyre	Statement 6	This is also agreed with. A proper functional assessment should be carried out to understand the causes of any behaviour that challenges to aid in the planning of multi element approach to living a life that makes sense.
19	MacIntyre	Statement 7	The use of medication is often problematic in this area. It may have a place but as an adjunct to proper functional analysis and a multi element approach to enable a person to live a life that makes sense. In reality this will be a very individual approach. In some cases it will be appropriate to try everything else and only use medication at the last possible moment. However there may be cases where medication for example for anxiety or depression are indicated at an earlier stage but always as part of an integrated, holistic plan.
19	MacIntyre	General	The draft quality standards are seen as positive and comprehensive and should be a force for improved diagnosis and support for individuals on the spectrum.
20	NeuroImmune	General	There is undoubtedly many types of autism with many different causes. The situation is made

	Science		complex by treating all patients carrying the autism diagnosis as if they shared common disease processes when the weight of empirical scientific evidence demonstrates that this is not the case.
20	NeuroImmune Science	General	The clinical picture is variable because patients actually have different illnesses with different causes and or underlying pathophysiology at work.
20	NeuroImmune Science	General	Too much use of vague ill defined or undefined terms. A complete absence of objective parameters and too great an emphasis on unscientific treatments without any empirical evidence in support of their effectiveness. This is tick box treatment.
20	NeuroImmune Science	General	There is little point in focussing on how to collect data when the rationale behind data collection is unscientific.
20	NeuroImmune Science	General	Nothing is defined and no concrete measures are used. The quality standard document is unscientific and not fit for purpose.
20	NeuroImmune Science	Statement 1	Diagnostic practices based on symptoms and behaviours are unscientific and unhelpful and do not lead to rational treatments or symptomatic improvements.
20	NeuroImmune Science	Statement 2	There is no attempt at investigating the underlying pathophysiology generating the individual’s symptoms and behaviours, therefore this is somewhat irrational as there is no scientific evidence that the types of support and interventions contemplated are effective in any way as far as treating the symptoms are concerned.
20	NeuroImmune Science	Statement 2	These outcomes are far too subjective. They need to be objectively measureable.
20	NeuroImmune Science	Statement 3	Nothing here is defined. Who decides what the patients needs are and what objective measures are involved in making this assessment. Who decides what is the best possible outcome and once again what objective measures are used to make this decision.
20	NeuroImmune Science	Statement 4	How is designated professional defined in this instance? What qualifications they must hold? How are they equipped to meet these changing needs?
20	NeuroImmune Science	Statement 4	These outcomes are far too subjective. They need to be objectively measureable.
20	NeuroImmune Science	Statement 5	Biomedical interventions have demonstrated considerable success in many people carrying this label and this should be stated here.
20	NeuroImmune Science	Statement 6	No mention here of behaviours generated by disease processes. This needs to be corrected.

20	NeuroImmune Science	Statement 6	Triggers are not always responsible for underlying pathology. HIV being an example.
20	NeuroImmune Science	Statement 6	Nothing is defined.
20	NeuroImmune Science	Statement 6	Cannot treat without assessing underlying biology, so why give preference to unscientific and discredited behavioural approaches?
20	NeuroImmune Science	Statement 7	An alternative to an unscientific disproven intervention cannot be chemical sedation.
20	NeuroImmune Science	Statement 7	People carrying the autism label do not have a psychiatric condition.
20	NeuroImmune Science	Statement 7	Severity is not synonymous with underlying pathology.
20	NeuroImmune Science	Statement 7	Nothing is defined and nothing objectively measureable.
21	The Royal College of Psychiatrists	Statement 1	The 3 month period to see patients is a service capacity requirement and not a clinically relevant quality point.
21	The Royal College of Psychiatrists	General	If this was to be selected as a topic there would need to be a decision whether to deal with the management of autism as a whole or to focus on one aspect. A broad approach to the management of autism cannot be developed by any agency (whether health, education, social services or the voluntary sector) on its own. The National Autism Plan (Children) is the result of a multiagency working party that consulted widely and produced a consensus of expert opinion. It might be given more emphasis in the briefing note.
			The NAP(C) does not go beyond childhood. While SIGN are developing a guideline for Scotland, it is only up to 18 years. The National Autistic Society is negotiating with the government to lead a multiagency group to develop guidelines for the management of adolescence / adulthood.
21	The Royal College of Psychiatrists	General	The management of autism is largely a matter of early diagnosis and subsequent education and support, both for the person with autism and for their family. Outcomes are unclear and success is limited so that myriad treatment approaches have been adopted by families – there are many more that have not been mentioned, notably the Son-Rise programme (developed by the Kaufman’s at the Option Institute) and the regimen of the Higashi residential schools (incidentally, ABA is the therapy developed by Lovaas – they are not different approaches). However, there is relatively little evidence

			to support or (with some important exceptions such as the use of secretin) to refute these approaches.
			It is often unclear as to which agency – health, social service or education – should provide the ‘treatment.’
			Factors which may affect outcomes have not been delineated in sufficient detail and accordingly, research in the area remains underdeveloped, under-resourced, and hence lacking rigorous evidence testing.
			These points are implicit in the Briefing Note but might be made more explicitly.
21	The Royal College of Psychiatrists	General	The document has some useful points as it recognises that children need assessment and treatment post diagnosis. Also that it is important that parents have information/ training. However the document reflects the lack of evidence in this area, and mostly reiterates what is already practiced by a clinician. The implications are probably more for services who feel their remit is to diagnose only and care pathways designed along these lines now look dated.
21	The Royal College of Psychiatrists	General	There is very limited reference to the role of psychotropic medications in the management of children with autism. Given the high rates of psychiatric co-morbidity and the difficulties that children with autism can have in accessing psychological therapies (because of limited language and the relative paucity of clinicians skilled in delivering psychological therapies to children with autism), this is an important omission. A wide range of psychotropic medications are helpful in managing children with autism and psychiatric co-morbidities, from SSRIs for children with anxiety and/or depression through the use of stimulants in the management of co-morbid ADHD to atypical antipsychotics for children with autism and aggressive behaviour. This area needs greater emphasis in the guidelines.
21	The Royal College of Psychiatrists	General	It would be helpful to include a reference to criminal justice agencies and their awareness of the prevalence and vulnerabilities of this population. One respondent suggested the following addition; ‘All the NICE standards have to pertain to and are relevant for all Criminal Justice Agencies in terms of access to and implementation of diagnostic and therapeutic guidance’.
22	Doncaster Metropolitan Borough Council	General	In general the standards would be a welcome addition to people providing autistic spectrum disorders.
22	Doncaster Metropolitan Borough Council	Statement 4	This statement could do with making clearer the need to be receiving on-going health and social care support. In addition it maybe that it is unrealistic, as there is not the resource, to provide all service users with a designated professional but that there should be an annual review.

22	Doncaster Metropolitan Borough Council	Question 2	Currently it would not be feasible to collect this data as our systems are not sufficiently subtle to easily obtain this data. They also require change in a number of systems across health and social care organisations involved. Nor do we currently seek to collect or record data in the specific ways the standards describe. This would describe a significant additional resource and process change to provide this data.
23	The British Psychological Society	General	The Society welcomes the development of the NICE quality standard on Autism. With regard to question 1 of the consultation, we think the draft quality standard reflects many of the key areas for quality improvement, however we have some suggestions for additions and modifications, as outlined below
23	The British Psychological Society	Question 1	The Society would like consideration to be given to the inclusion of an additional quality statement on the treatment of coexisting mental health difficulties for people with autism. The Society considers access to psychological interventions for mental health difficulties, as indicated in NICE guidance for specific mental health issues (see also NICE guideline on Autism in adults, recommendations 1.6.2 and 1.6.3), to be a integral to a quality service for people with autism. As an example, this additional statement could read: People with autism and coexisting mental health difficulties are offered psychological interventions informed by existing NICE guidance for the specific mental health issues.”
23	The British Psychological Society	Question 1	The NICE guideline on Autism in adults recommends a number of psychosocial interventions for the core features of autism and life skills (Recommendations 1.4.1 – 1.4.12). The Society believes that access to these psychosocial interventions is fundamental to provision of high quality service for people with autism and would therefore like consideration to be given to the inclusion of an additional quality statement on access to psychosocial interventions. As an example, this additional statement could read: People with autism who have identified psychosocial needs are offered the NICE-recommended psychosocial interventions
23	The British Psychological Society	Question 1	The Society recommends that consideration be given to the inclusion of an additional quality statement on the provision of training to health and social care staff in a local area. Training of staff who provide services to people with autism is one of the key areas in the guidance on implementing the autism strategy (Department of Health, 2010, pp. 11 -13), and ensuring the provision of multi-agency training is part of the NICE clinical guideline on Autism in adults (recommendation 1.8.2, p.33). The provision of training is also consistent with the Adult Social Care Outcomes Framework domain of “Ensuring that people have a positive experience of care” (p.3 of the draft quality standard). As an example, the quality statement could read: Health and Social Care staff have access to appropriate training in autism, leading to changes in behaviour and attitudes that improve the experience of care of people with autism.”

23	The British Psychological Society	Question 1	The Society also recommends that consideration be given to the inclusion of an additional quality statement on the provision of training to people who support people with autism – that is, direct care staff, carers and families. As an example, the quality statement could read: eople who are supporting people with autism have access to relevant training and support.”
23	The British Psychological Society	General	The NICE guidance on Autism in adults stresses the importance of the offer of follow-up after diagnosis to address emotional and practical issues (Recommendation 1.2.18). The Society suggest this should be reflected in the quality statements – either by including reference to it in the discussion of the existing draft quality statements or adding another quality statement such as: People with autism and their carers are offered the opportunity to discuss and understand their diagnosis with trained professionals”
23	The British Psychological Society	General	The use of the term ‘symptoms’ to describe core aspects of autism creates a medical tone within the guidelines, which is at variance with the emphasis on psychosocial interventions. The Society suggests replacing the term ‘symptoms’ with ‘features’ or similar throughout the guidelines.
23	The British Psychological Society	General	The Society would welcome an increased emphasis on service user inclusion, values and partnership working (co-production) throughout. This could be emphasised in the introductory sections of the quality standard (p.2-4) and reiterated in the sections on the quality statements.
23	The British Psychological Society	General	The Society notes that there is no mention in the document of the care and treatment of people with autism in prison settings. Whilst little research has been done in this area, it is suggested that they are over-represented in the criminal justice system, (Cashin & Newman, 2009). There is a lack of specific training on people with autism available for people working in prisons and Mental Health Prison In-Reach Services usually do not have specialist knowledge of autism. The Society recommends that it would be helpful for it to be specifically highlighted that the quality standard applies to people with autism in the prison system; in particular, that the commissioning of autism services should include a provision for diagnostic assessments for people in prisons, training in the recognition of / interventions for autism for prison staff and Mental Health Prison In-Reach Services, and the development of data collection systems to establish the number of people with autism in prison.
23	The British Psychological Society	Statement 1	Anecdotal evidence suggests that in some services a screening assessment is carried out relatively quickly, with this being counted as an “assessment” having started, but people can then have a long wait before a comprehensive specialist assessment is started. It would be helpful if it there was a clear statement in the quality statement that this should not happen. For example (suggested additions in italics): Evidence of local arrangements to ensure that people with possible autism needing a diagnostic assessment by an autism service have a comprehensive assessment (not just a screen) started within 3 months of their referral

23	The British Psychological Society	Statement 2	Assessment for hyper- and hypo-sensory sensitivities is included in the list for assessment for coexisting health and mental health conditions for adults (p.14), but not for children. The Society recommends that this be included for both groups.
23	The British Psychological Society	Statement 2	Assessment for genetic problems is included in the list for assessment for coexisting health and mental health conditions for children (p.13) but not adults. The Society recommends that this should be included for both groups.
23	The British Psychological Society	Statement 2	The Society would recommend that “behaviour that challenges” be added to the list of coexisting issues that should be included in the diagnostic assessment. For example (suggested additions in italics): Quality statement People having a diagnostic assessment for autism are assessed for coexisting physical health conditions, mental health problems and behaviour that challenges
23	The British Psychological Society	Statement 2	Oppositional Defiant Disorder (ODD), which is included in the list for assessment for coexisting physical and mental health conditions in children and young people (p.12), is a diagnosis that has been the subject of much critical discussion and is often not perceived as useful. For example, the Society is aware that many young people who satisfy the diagnostic criteria for autism would also satisfy ODD diagnostic criteria without this adding anything useful to either understanding that young person or putting satisfactory interventions into place. The Society would therefore recommend that ODD is removed from the list of mental and behaviour problems that should be included in assessment for coexisting conditions for children and young people
23	The British Psychological Society	Statement 3	The term ‘Personalised Management Plan’ could give the impression that the plan consists of things that are done to the person rather than with them, and does not emphasise the link between the plan, a person’s needs and a clear formulation of behaviour. The Society recommends that this be amended to, for example: “Quality statement People with autism have a personalised, biopsychosocial formulation and needs-based support plan that takes into account their strengths and needs and is developed in partnership with them.” It would also be helpful if the plan was referred to as a needs-based plan throughout the Quality statement, Rationale etc. sections on p.15 rather than just the ‘Definitions of terms’ section on p.16.
23	The British Psychological Society	Statement 4	The Society would welcome clarification that having a designated professional to oversee and coordinate the care and support of a person with autism is their choice. For example, on p.17, (suggested additions in italics): Quality Statement People with autism have a designated professional to oversee and coordinate their care and support, with their involvement and consent.”

23	The British Psychological Society	Statement 6	The NICE guideline on Autism in adults states that when assessing challenging behaviour a functional analysis should be completed (recommendations 1.2.20 and 1.5.3). Although this is mentioned in the 'Definitions of terms' section on p.24, the Society recommends greater emphasis on this more widely in the quality statement. For example (suggested additions in italics): Quality statement People with autism who develop behaviour that challenges are assessed for possible triggers, including physical and medical problems, and a formulation that includes a functional analysis of behaviour is developed, before any interventions for behaviour that challenges are started." "Structure Evidence of local arrangements to ensure that people with autism who develop behaviour that challenges are assessed for possible triggers, and that a formulation that includes a functional analysis of behaviour has been developed, before any interventions or behaviour that challenges are started." "Process The proportion of people with autism who develop behaviour that challenges who are assessed for possible triggers, and for whom a formulation that includes a functional analysis of behaviour has been developed, before any interventions or behaviour that challenges are started. Numerator – The number of people in the denominator who are assessed for possible triggers, and for whom a formulation that includes a functional analysis of behaviour has been developed, before any interventions or behaviour that challenges are started."
23	The British Psychological Society	Statement 6	Some people with autism have hyper- and/or hypo-sensory sensitivities, which can be a trigger for behaviour that challanges. The Society recommends that this highlighted in the rationale for the quality statement. For example (suggested additions in italics): Rationale People with autism can sometimes present with behaviour that is challenging to manage. The causes of behaviour that challenges for a person with autism can be multifactorial, and can involve physical, emotional, sensory and environmental factors. An assessment should take all these factors into account before appropriate interventions are agreed"

23	The British Psychological Society	Statement 7	The NICE guideline on Autism in adults states that psychosocial interventions for challenging behaviour should be informed by a functional analysis of behaviour (recommendation 1.5.5, p.29). This quality statement does not include reference to this in its discussion of psychosocial interventions. To avoid the potential for confusion, given the wide range of psychosocial interventions available, the Society recommends that the importance of formulation and functional analysis is made more explicit in the quality statement. For example (suggested additions in italics): p.25, - “Quality statement People with autism and behaviour that challenges are offered drug treatment for their behaviour that challenges only if psychosocial interventions based on a formulation that includes a functional analysis of the behaviour are not effective or appropriate” “Rationale The first line of intervention for behaviour that challenges should be psychosocial interventions. These should be informed by a formulation that includes a functional analysis of the behaviour. If people with behaviour that challenges…” p.27, line 6 (‘Psychosocial interventions’ section) – “Psychosocial interventions for challenging behaviour should be informed by a formulation that includes a functional analysis of the behaviour and should include:…”.
23	The British Psychological Society	Statement 7	The NICE guideline on autism in adults stresses that, if antipsychotic medication is prescribed for behaviour that challenges, and then it should be discontinued if there is no evidence of a clinically important response at 6 weeks (recommendation 1.5.8, p.30). The Society considers this to be a key safeguard in the use of such medication in this area, as concerns have been raised that it can be used excessively and with a lack of clarity of purpose (e.g. as in ‘Winterbourne View Hospital: A Serious Case Review’, 2012). We would therefore recommend the inclusion of an addition to the Process section to assess quality in this area. For example: Process The proportion of people with autism and behaviour that challenges having drug treatment for their behaviour that challenges for whom there was evidence of a clinically important response to the medication at 6 weeks Numerator – The number of people in the denominator for whom there was evidence of a clinically important response to the medication at 6 weeks Denominator – The number of people with autism and behaviour that challenges currently receiving

			drug treatment to manage their behaviour that challenges.”
23	The British Psychological Society	Statement 7	As outlined in the NICE guideline on Autism in adults (recommendation 1.5.7), antipsychotic medication can be used in conjunction with psychosocial interventions when there has been no or limited response to psychosocial or other interventions. This is not made explicit in the quality statement and it is unclear whether people in this group would be included in the ‘Numerator’ calculation as currently defined. This may therefore affect the quality of data collected using the Process calculation as currently outlined.
23	The British Psychological Society	Statement 7	The current ‘Quality statement’ section (p.25) makes reference to drug treatment being offered for behaviour that challenges only if psychosocial interventions are not effective or appropriate. The issue of appropriateness is clearly open to interpretation, which could affect the consistency of service offered. The Society would welcome clarification as to whether this means that “….if the behaviour that challenges is too frequent and / or has too high an impact for psychosocial interventions to be used appropriately in the first instance” (as is outlined in the ‘Psychosocial interventions’ section of the quality standard, p.27).
23	The British Psychological Society	Question 2	With regard to question 2 of the consultation, the Society believes that, if the systems and structures were available, it would be possible to collect the data for the proposed quality measures. However, given the number of agencies likely to be involved in the provision of services, development of the systems and structures to share pertinent information presents a significant challenge. We suggest, therefore, that it would be helpful to emphasise in the quality standard that the development of systems and structures for data collection, and the sharing of pertinent information between the agencies involved in delivering services, should be a clear part of commissioning arrangements.
24	Royal College of Paediatrics and Child Health	Question 1	We are wondering whether it is possible to also set a standard for the expected duration of the assessment. Admittedly, it is important to start the assessment within a reasonable timescale. Unfortunately, anecdotal feedback suggests that in some instances after an assessment is initiated there may follow a frustratingly protracted period of variable quality assessment that takes an inordinate time to come to a conclusion.

24	Royal College of Paediatrics and Child Health	Statement 2	Depending on how assessments are arranged locally, in those areas where ASD assessments are mainly undertaken by CAMHS teams then some of these teams may feel it necessary to refer on to paediatric colleagues for an assessment of co-existing physical health problems (and vice versa for the assessment of mental health problems in those localities where ASD assessments are largely undertaken by paediatricians). If a single team is to assess ASD then there may be resource and training needs for some teams to ensure competence in both physical and mental assessment. However, irrespective of the way in which assessments are organised in each locality, this is an important quality standard and these comments merely highlight some of the challenges it might pose – but this does not alter the value of this standard.
24	Royal College of Paediatrics and Child Health	Statement 3	Is it possible to mention that the personalised management plan should be a needs-based plan that includes a preventative element so that families can develop strategies to promote positive behaviour and reduce behaviour that challenges?
24	Royal College of Paediatrics and Child Health	Statement 5	This ought to be straightforward to measure (from current and recent drug history of relevant patients).
24	Royal College of Paediatrics and Child Health	Statement 6	This standard recommends that interventions should not start until an assessment of possible triggers, including physical and mental problems, has been completed. Sometimes, there may be a clear trigger that is very likely to explain the behaviour that challenges and undertaking a reasonably thorough assessment of physical and mental problems may merely delay starting useful intervention. So, could there be some qualification of this standard such as – However, where a clear trigger is apparent that is likely to explain the behaviour that challenges, this should be addressed first but if the response is unsatisfactory then an assessment of other potential triggers should be undertaken. Admittedly, this qualification would make it more difficult to measure this quality standard.
24	Royal College of Paediatrics and Child Health	Statement 5 and 7	Both statements, which are relevant to medications, are in accordance with NICE guidance which are appropriate.
25	Royal College of General Practitioners	Statement 1	There may be issues of access to adult autism services
25	Royal College of General Practitioners	Statement 1	‘ Near to home’ would benefit from clarification especially for remote and rural communities

25	Royal College of General Practitioners	Statement 4	A number of people can be the designated professional – it may be helpful to be more specific about appropriate person to take this role on, especially within the primary care team.
25	Royal College of General Practitioners	Performance measurement	100% aspiration is always what we hope for however it may be more realistic to have an achievable lower target in first instance.
25	Royal College of General Practitioners	Related quality standards	The areas of future work in relation to transitions both social and health care and also children/young people to adult will be helpful as this often causes issues and challenges for patients, families and professionals
25	Royal College of General Practitioners	General	I like this. Good for the group who wrote it.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Question 1	In principle we support the quality standards although we feel that they need more clarification and detail. They also raise issues regarding the current capacity particularly within mental health services for children where there are very little commissioned services specifically for children with Autism or query ASD.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Question 2	The statements appear to presuppose a more clearly identifiable ‘Autism Service’ which in reality operates locally as a virtual service for this care group. This virtual model for children & young people is quite appropriate as the it reflects the multi agency integrated model (Education/ Social Care & Health; including mental health) that is required to cover the broad level of need ,ranging from mild to severe autistic presentations and the diverse range of family / carer needs. At various times in a child or adults life these agencies may play a much greater role than other agencies.
			However services are often patchy and provided within some agencies as part of existing generic provision rather than specialist provision. This poses significant challenges in measuring the specific quality standards.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 1	This statement presupposes that a specialist Autism service exists. Despite ongoing planning and development an equitable service or provision for ensuring assessment across children and adults services has not yet been commissioned.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 1	The time frame needs to consider that many children are referred for other concerns or reasons e.g. Paediatric assessment and that the question or query of Autism arises from this work. The time frame for assessment needs to ensure that this is taken into consideration.

26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 1	At the point of referral there maybe other formulations that indicate the need for intervention or support prior to undertaking lengthy diagnostic interventions. For example some children or families may need interventions around parenting support which are impacting on a child’s presentation and which may be the first line of consideration in understanding a child’s presentation or behaviour.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 2	In principle a comprehensive assessment considering physical health and mental health needs should occur and by professionals who are skilled in undertaking this work.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 2	However this statement does not reflect the current care pathways in place for diagnostic assessment as children and young people are often diagnosed within Community Paediatrics in the absence of any mental health input or assessment.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 2	At present current systems to not have the resources necessary to consider alternative formulations or explanations for understanding a child’s social communication difficulties e.g. Attachment disorder as the mental health expertise is not available.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 2	Due to current commissioning mental health resources are often only incorporated into diagnostic assessments for very complex presentations or post diagnosis. Mental health expertise is often only made available further down the care pathway.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 3	All children and adults in receipt of services should have a personalised management plan. For children and young people it is essential that this plan is integrated within their education & health plans.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 4	This statement needs qualifying to reflect changes in need over the lifespan for some people with autism (mild and high functioning) as they may not always need a designated professional; unless this could include the GP or a school professional while they attend school.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 5	Medication should only be considered in conjunction with other interventions / support.
			It should be evaluated and reviewed regularly.

26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 6	All interventions should arise from an initial comprehensive assessment that is revisited over time in response to changes in maturation and environments.
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 7	Psychosocial interventions should be the first line of treatment; however as with other conditions a course of medication for older children and adults may enable them to engage in psychological therapies e.g. extreme states .of mood disturbance
26	Nottinghamshire Healthcare NHS – CAMHS Psychology	Statement 7	Medication should not be an automatic consideration if psychosocial interventions are not successful. Medication should be considered on an individual basis in response to the individual's needs.
			Psychosocial and psychological interventions may need to be timed appropriately and readiness for such interventions needed to be revisited over the individual's life span.
27	Oxford Health NHS Foundation Trust	Question 1	Generally yes but we would like to see some mention of transition for young people in to adulthood, including appropriate training, work placements and accessibility to appropriate services.
27	Oxford Health NHS Foundation Trust	Question 2	Responses were sceptical about the feasibility of this given the range of services, including the voluntary sector involved with people with an ASD. Also the scope would need to be across the lifespan.
28	British Medical Association	Statement 1	We believe that people with possible autism needing a diagnostic assessment by an autism service should have the assessment started within 6 weeks of their referral; 3 months is too long to wait for an assessment to start.
28	British Medical Association	Statement 4	Where appropriate some patients would benefit from having a designated consultant to oversee and co-ordinate their care and provide support in conjunction with their designated general practitioner. This might take the form of a shared care agreement as for some other chronic conditions.
28	British Medical Association	Question 1	Yes, this draft quality standard does accurately reflect the key areas for quality improvement but without a more rapid diagnostic assessment and, where appropriate, a designated consultant to oversee and coordinate care and support, this quality standard will add little value in practice.

28	British Medical Association	Question 2	We do not think it would be possible to collect the data for the proposed quality measures as it would be too cumbersome and time consuming which would outweigh the potential benefit of hands-on action by professionals and therapists.
28	British Medical Association	General	There is a distinct and worrying lack of reference to the role of psychiatrists in the draft quality standard document. The accountability of the service needs a lead and, where appropriate, that should come from a consultant.
28	British Medical Association	General	There is little emphasis on involving parents or other family members - autism is diagnosed in childhood and parents are aware of behaviour patterns long before the professionals are involved. Their knowledge of their child's likes, dislikes and behaviour patterns may be ignored or dismissed as irrelevant when this knowledge is crucial to good care.
			Autism is a wide-ranging disorder and some people with autism are never able to communicate at a meaningful level so all information has to involve their parents / family members. The NICE report makes little mention of this.
28	British Medical Association	General	We would like to see more prominence given to hand-over arrangements. It is vital that every area has a designated transition team. Transition is difficult for most people but more so for those with autism. The change from child to adult services must be planned in advance with at least three years, if not more, given to the achievement of a smooth handover so that the teenager has time to get accustomed to new arrangements before being abandoned by the professional they have come to rely on.
29	Oxfordshire Clinical Commissioning Group (Oxfordshire CCG)	Statement 3	Regarding Statement 3 in the Consultation, we feel as commissioners that it is important to extend the quality standard – The statement would be extended as so: People with autism have a personalised management plan that takes into account their strengths and needs and has a goal orientated approach to maximise independence
29	Oxfordshire Clinical Commissioning Group (Oxfordshire CCG)	Statement 2	Regarding data collection in this area – As a CCG we feel the data collection described would need further work with the current systems we use. For example, if autism is co-morbid then it is not routinely recorded. Systems like SHFT, RiO are what we use.
30	Autism Rights Group Highland	introduction	The term autism describes much more then just a diagnostic criteria - no mention of issues with diagnostic definitions, or autistic identity or anything else.

30	Autism Rights Group Highland	Introduction	'People with autism' linked to a whole list of 'problems' - ending in 'emotional and behavioural problems' - this is behaviourist nonsense and is framing autism within this paradigm which is theoretically moribund, does not have a good evidence-base (see Michelle Dawson and co's work) and is highly damaging to autistic people (also see work by Damian Milton on this). Assumptions linked to observational data rather than deep understanding of Autistic people is unhelpful.
30	Autism Rights Group Highland	Introduction	‘Difficulty understanding other people’: Or double empathy problem (DEP) of differing dispositions - this is reifying theory of mind theory as fact, when it is a theory - a partial heuristic etc. This centres the ‘problem’ firmly onto the Autistic person, this way of thinking is unhelpful and inaccurate because the ‘problem’ in understanding is a two way issue and therefore any move to find a solution must start with the acceptance of this.
30	Autism Rights Group Highland	Introduction	‘mental health problems’: Mental health problems listed without being socially situated at all - e.g. we end up with mental health problems because of being viewed and treated in ways informed by documents such as this one.
30	Autism Rights Group Highland	Introduction	'Sometimes aggressive, behaviours' - again not socially situated, seen as a 'problem to be remediated' with no understanding whatsoever. Environment (sensitivity to stimuli or lack of stimuli), lack of access to communication supports, pain, inappropriate treatment by those around them, self advocacy attempts being misunderstood as challenging behaviour: all of these things are relevant here but the implication is that the problem is the Autistic person’s, that they are the issue not poor support or lack of understanding / respect from trained sensitive staff.
30	Autism Rights Group Highland	Introduction	‘These can substantially affect the person’s quality of life’ Blaming the victim - this paragraph is damaging to autistic people. We suggest reading the intro sections to the AET education standards or competencies document for an official document that has taken on board comments from autistic people seriously, and has not reified behaviourist dogma.
30	Autism Rights Group Highland	Introduction	‘different levels of cognitive ability’: Our differences are not defined by IQ alone - other than in documents such as this one.
30	Autism Rights Group Highland	Introduction	‘70% of people..’ Possible misquote of statistic – possibly should say that 70% did meet criteria for psychiatric illness at some point in their lives, but reference not here so unable to check – need to supply references in document next to figures or as footnote in same document.
30	Autism Rights Group Highland	Introduction	‘50% of people…’ Again, according to which study? Where is the evidence-base for this document?
30	Autism Rights Group Highland	General	Some of the statements listed will cause harm and are dangerous standards to set, that completely disregard critical autistic voices from Autistic professionals and academics and all of the work that they have done in this area (eg. Jim Sinclair, Damian Milton etc)

			Also - suggesting 'interventions' have more of an evidence-base of effectiveness than they do - see Michelle Dawson's critiques.
30	Autism Rights Group Highland	General	‘Improving functional ability..’ This kind of normative statement is out of place here.
30	Autism Rights Group Highland	Introduction	Coordinated services: This document is not person-centred - but a normalising, stereotyping and stigmatising one. In practice how is this to be done? (we need to have an eye on and address failings such as the Neary case and the death of ‘LB’)
30	Autism Rights Group Highland	Statement 4	How will these people be trained, and what involvement will autistic people have in this training?
30	Autism Rights Group Highland	Statement 6	Behaviour that challenges is a damaging ideology, this needs to be changed to change thinking on what communication is and what’s going wrong for Autistic people when they are not understood by people around them, includes non verbal speech ways of communicating. Also, what interventions, on what evidence.
30	Autism Rights Group Highland	Statement 7	A highly dangerous and damaging statement, considering what poor evidence there is for such interventions, and evidence of how some interventions can lead to increases in such issues (i.e. ABA based practices). There is no drug to be shown to be effective in the eyes of autistic people regarding this issue. Thus who is benefitting from this statement? Not the 'service-user' at all, it is doing them potential harm.
30	Autism Rights Group Highland	Question 1	No, see above.
30	Autism Rights Group Highland	Question 2	No - and they should not be the measures used either.
30	Autism Rights Group Highland	Statement 1	‘The autism team should either include or have regular access to..’ these lists, both child and adult should include an Autistic consultant.
30	Autism Rights Group Highland	Statement 1	‘behavioural problems’ define this – not the best way to put this.
30	Autism Rights Group Highland	Statement 1	Education and employment framed as 'personal functioning' - socially situated this document is not.
30	Autism Rights Group Highland	Statement 1	We would like to query how they propose to observe adults in social situations as part of any assessment
30	Autism Rights Group Highland	Statement 2	A lot of health screening mentioned in the children / young people section is relevant here too, why leave it out – a full screening is needed for adults also, or at least a consideration of whether it is needed person by person.

30	Autism Rights Group Highland	Statement 3	Horrendous wording – do not need to 'manage my own autism' as if it is something separate to myself.
30	Autism Rights Group Highland	Statement 5	Psychosocial interventions – such as?
30	Autism Rights Group Highland	Statement 6	Needs total re-writing - see recent Research Autism conference regarding Stress as an example of what this should be concentrating on more.
30	Autism Rights Group Highland	Statement 7	Rationale: What would 'appropriate intervention' look like here? Very worrying that this is framed in behaviourist language
			and as a major issue. It is only a major issue due to the number of meltdowns people are having in care situations, and the lack of understanding people have regarding autism. Training of professionals is of importance - but by whom and with what focus?
30	Autism Rights Group Highland	Statement 7	Structure: How about asking the autistic person through whatever communication method, as to why things are not going well for them? And acting upon it?
30	Autism Rights Group Highland	Statement 7	People with autism who behave in a challenging way…. Does not need treatment - needs practitioners to reflect on what they are doing to cause the autistic person such stress etc.
30	Autism Rights Group Highland	Statement 7	This is worrying as the listed seem to imply a core misunderstanding of what's going on – that autistic people may use things such as rocking etc to self soothe and that communication is lacking here and a genuine interest / will to understand autistic people as people who may resist and may be 'defiant' but with good reason and needing to be treated with respect and understood. There are advocacy issues here that are not being addressed.
30	Autism Rights Group Highland	Statement 7	Page 25'Drug treatment can help manage the behaviour..Not person centered at all: NO - it means you have totally failed as carer's to understand the needs of the person in your care - and drugging them is further dehumanising and harming them for no reason. There is no 'drug for autism' - so this is 'drugging for social control'. This is totally inappropriate guidance. Rather than drugs use proper communication approaches and recognise that the behaviour reflects the fact that staff etc are failing rather than the individual.
30	Autism Rights Group Highland	Statement 7	Page 25 Structure How about being offered contact with autistic communities and culture?
30	Autism Rights Group Highland	Statement 7	Page 26 NO - and what psycho-social interventions exactly? This is all about controlling the actions of autistic people for the benefit of others - thus - has nothing to do with what service-users want to see. Highlights fundamental lack of autism understanding.
30	Autism Rights Group Highland	Statement 7	Page 27 'focus on outcomes linked to quality of life' according to whom? How will safeguards be put in place to know that the autistic persons quality of life and their wishes are what really matters.

30	Autism Rights Group Highland	Using the quality standard	Page 29. Using other national guidance and policy documents: Not the AET documents? Where are the references? How many autistic scholars in that list? Any critical ones, or ones within the last 6 or so years?
30	Autism Rights Group Highland	Using the quality standard	Page 29. ‘Good communication….. is essential’ It is our opinion that this document will damage this and it is essential
30	Autism Rights Group Highland	General	Page 30 Autism and Education Trust (2011) What Is Good Practice in Autism Education: And old document - if one looks at the standards and competencies delivered last year - one will see a different and more Autistic led rhetoric.
30	Autism Rights Group Highland	General	Page 31 & whole reference list: More up to date references needed, to avoid mistakes of the past.
30	Autism Rights Group Highland	General	Page 32: NICE team; No autistic specialist or consultant
30	Autism Rights Group Highland	General	Wording throughout still person first – as if autism is somehow separate or an appendage, should be using identity first language: Autistic people
30	Autism Rights Group Highland	General	We would like to see more consideration given to fatigue as a symptom / consequence; it is rarely mentioned, sleep disturbance being the nearest these criteria come.
31	NHS Direct	General	NHS Direct welcome this standard and has not comments as part of the consultation
32	Liverpool Community Health	Question 1	The statement is made that ‘services should be commissioned from and coordinated across all relevant agencies encompassing the whole autism care pathway’, but this is not one of the specific quality indicators measured. The 7 quality statements presume that this is the case (referred to throughout the document as the ‘autism service’ (defined on p7)), when, in fact, many areas do not yet have integrated coordinated pathways such as the one described. I think that there should be a specific quality measure linked to commissioning and delivery of integrated services.
32	Liverpool Community Health	Statement 6	I think that the areas chosen are indeed valid and crucial areas for quality improvement, apart from: • statement 6 – I can’t imagine in what scenario intervention for challenging behaviour would start without triggers being assessed, so I’m not sure that this would yield particularly useful information that would improve quality? Perhaps wider practice is worse than I am aware of?! my point above about coordinated services needing to be specifically measured I can’t imagine in what scenario intervention for challenging behaviour would start without triggers being assessed, so I’m not sure that this would yield particularly useful information that would improve quality? Perhaps wider practice is worse than I am aware of?!
32	Liverpool Community Health	Statements 6 and 7	Most of the data collection suggested sounds possible, except for quality statements 6 and 7(outlined below).

32	Liverpool Community Health	Statement 6	The denominator is stated as ‘the number of people with autism who develop behaviour that challenges’. I think this data would be problematic to collect for a number of reasons: I don’t think this descriptor is specific enough to count – how severe does the behaviour have to be to count as behaviour that challenges? where there is no integrated team, who are you going to ask for this information? Especially when these children wouldn’t as a matter of course be referred to CAMHS, so you couldn’t just count CAMHS referrals. I don’t think we are collecting this data as a matter of course at the moment. Without going through individual casenotes/ case histories/ reports it would be difficult to come up with a figure.
32	Liverpool Community Health	Statement 7	The numerator is stated as: ‘the number of people in the denominator for whom psychosocial interventions were deemed to be ineffective or not appropriate’. I think this data would be problematic to collect for a number of reasons: How do you measure whether an intervention has worked ‘well enough’? Different teams will measure this in different ways. How long should psychosocial interventions be tried for before it is decided that they are ineffective? Again, practice will vary. I suppose it won’t matter if different teams measure differently as long as individual teams can show improvements when they audit themselves against the quality standards, but it will make pooling the data to give regional/ national outcomes impossible as the data will not be comparable.
32	Liverpool Community Health	Statement 2	We have difficulties in getting referrals accepted by CAMHS sometimes to assess a child’s mental health or make a differential diagnosis. Only the most severe cases (self-harm; threatened suicide) seem to be accepted. CAMHS are quite clear that they are not commissioned to contribute to the ASD diagnostic pathway. This can result in a child’s in a child’s mental health difficulties being unidentified and will not improve unless specifically commissioned.
32	Liverpool Community Health	Statement 2	Not all areas have access to Occupational Therapists who specialise in sensory processing to contribute to the assessment process. This can result in a child’s in a child’s sensory processing differences being unidentified and will not change unless specifically commissioned.
32	Liverpool Community Health	General	While I know it is not specifically the concern of NICE how these quality standards are met, there are huge resource implications for delivering many of these quality indicators. I do agree strongly that the setting of quality should not be resource-driven; however, in practice, quality is unavoidably compromised by resources and cannot always be improved to the required standard without additional investment (eg. CAMHS input; OT input; integrated services).

33	British Association for Adoption and Fostering	General	This response is being submitted on behalf of the BAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for 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. Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people.
33	British Association for Adoption and Fostering	General	The Quality Standards would be considerably strengthened if they addressed the competencies of health practitioners as well as their needs for high quality training and supervision, as this is a highly specialised area of medical practice. Similarly there are significant financial and resource implications inherent in delivering the standards and this should be acknowledged and addressed to improve their effectiveness.
33	British Association for Adoption and Fostering	Statement 1	The statement talks about ‘People who are referred for and accepted for an assessment for autism’ but does not specify criteria or process to make a decision not to accept a referral, nor does it address what will happen to these individuals. We are particularly concerned about how this may affect looked after children, where the differential diagnosis frequently includes autism, attachment difficulties, ADHD, anxiety and oppositional defiant behaviour.
33	British Association for Adoption and Fostering	Statement 2	There appears to be an underlying assumption that it will be clear which children are affected by autism, yet particularly for looked after and adopted children it can be very difficult to distinguish autism from attachment difficulties, as well as other conditions listed here. There should be more focus on access to the expertise required to consider the full differential diagnosis and consideration of attachment difficulties needs to be addressed in the quality standards.
33	British Association for Adoption and Fostering	Statement 4	The issues of workforce capacity and appropriate training need to be addressed here. It is insufficient to simply have a person named as key worker/designated professional; they must have sufficient competency and resources to carry out the role.
33	British Association for Adoption and Fostering	Statement 4	The terminology of ‘designated professional’ is confusing, as this term is used for health roles in safeguarding and looked after children where these professionals have a strategic role for health service planning and delivery for large populations of children.
33	British Association for Adoption and Fostering	Statement 5	Workforce competencies and need for sufficient resources to provide high quality care should be addressed here, as those with expertise as well as sufficient time, along with availability of appropriate alternatives, will be less inclined towards ‘drugs as a quick fix’.

33	British Association for Adoption and Fostering	Statement 6	It would be helpful to acknowledge 1) the resources and 2) the workforce competencies/expertise required to provide this kind of detailed assessment process.
34	Association of Directors of Adult Social Care	Statement 1	It is very likely that it will take quite some time across most areas to achieve this standard. Some councils report that there are potentially large numbers of people who haven't sought assessment to-date and building these numbers in to the system will create additional demand pressures, and it is noted that assessments take a considerable time to complete (as multi-disciplinary and specialised). There is a risk that initial assessments will be completed within proposed timescales but the more detailed assessments will take much longer
34	Association of Directors of Adult Social Care	Statements 1 and 2	The diagnostic assessment should only identify existing and the potential for other conditions (screening) and where required arrange access to more detail appropriate assessment using existing diagnostic pathways, unless suitably qualified. The knowledge and skill set is not the same for diagnosing autism, schizophrenia or muscular dystrophy.
34	Association of Directors of Adult Social Care	Statement 3	Further clarity is required to determine to whom these standards will apply (many individuals with autism do not meet FACs eligibility) and where applied, what a personalised management plan will look like . We support the proposals that at the point of diagnosis that a post support plan should be provided and where appropriate, there is a referral to community care assessment for adult services or mental health services, or that there is provision of self-help tools or advice for those assessed as requiring less formal care and support.
34	Association of Directors of Adult Social Care	Statement 4	Further clarity required to confirm that a social worker will not be the designated worker, unless the individual has been assessed as meeting FACs eligibility criteria. It is suggested that the consideration of the inclusion of Threshold of need and risk should be applied to determine the level and degree of specific case management whilst promoting equal access to core services through awareness and reasonable adjustments. Further clarity is required beyond the function of Primary care practitioner in understanding Autism and supporting their navigation as required
34	Association of Directors of Adult Social Care	Statement 5	Agree with the principle BUT in order to represent both health and social care the language is too medical and the term treating the symptoms of Autism is likely to be offensive to the Autistic community who are promoting a strengths based approach to assessment.
34	Association of Directors of Adult Social Care	Statements 6 and 7	Need to be careful with language, drug treatment is to manage the risk not the behaviour... Communication of Managing behaviour via pharmaceuticals is appropriately open for challenge. Who is this aimed at? Again does this need to refer to a threshold of risk and need? Key consideration to be given regarding capacity of the individual and their right to refuse. If they do not have capacity who

			gives authorisation, is a best interests assessment required, is their IMCA, parents advocate, legal guardian etc. Appropriate legislative framework need to be applied when managing behaviours as referred to in the standards document such as the Mental Capacity Act and the Mental Health Act. Need for a more robust definition of "behaviours that challenge" to ensure consistency and transparency across the system. Need for further clarity as to decisions that psychosocial interventions are ineffective or inappropriate- suggested that benchmarking of decisions would help determine best practice
34	Association of Directors of Adult Social Care	General	There needs to be the clarity of the definition of the threshold of need and risk when recommending case management and advising on the use pharmaceutical interventions .
34	Association of Directors of Adult Social Care	General	Current systems do not consistently record diagnosis of autism and there is no records of those with who have not been assessed/ diagnosed for autism related services or support
35	The National Autistic Society	General	The National Autistic Society welcomes the opportunity to respond to this consultation. We firmly believe that the development of the Quality Standard provides an important opportunity to drive up the quality of support for people of autism of all ages and across the spectrum. However, we have concerns that the current draft of the standards both misses out key areas where more work needs to be done to drive up quality and is also divorced from how services are actually structured and delivered at a local level.
35	The National Autistic Society	General	To ensure better outcomes and support for people with autism, it will be essential to ensure that the health and social care system is much better joined up, so that firstly professionals are able to identify potential autism early and refer for diagnosis, then once a diagnostic assessment has taken place, people are referred easily on to other services and support. For example, the Autism Act statutory guidance makes it clear that any adult who accesses a diagnosis should be made aware of their right to a community care assessment and that any diagnosing professional should contact adult social services to make them aware that they have diagnosed someone on the spectrum, who should be contacted for an assessment, if they want one. The pathways from identification to referral and from diagnosis to support appear to be missing from the quality standard.
35	The National Autistic Society	Statement 1	We support the inclusion of this statement, which is designed to ensure much quicker access to diagnosis for children and adults with suspected autism. In early 2012, we surveyed over 8,000 people with autism, carers responding with on their behalf and parents/carers responding from their own perspective. A third of respondents reported having waited 3 years or more for a diagnosis after first raising concerns, with an additional third stating it had taken between one and two years. While it is important to remember many of these people will not have experienced diagnosis in the last few

			years, we do regularly hear of the challenges that people with autism and their families face in trying to access diagnosis, demonstrating just how important it is to drive up standards in this area. By highlighting the importance of a service that can commission this quickly, NICE are sending a clear message to commissioners that specialist autism teams are needed in every area if a quality service is to be delivered for people with autism. This is very welcome
35	The National Autistic Society	Statement 1	However, a key challenge, particularly for undiagnosed adults is the lack of understanding of autism among GPs, who are key gatekeepers in terms of referral for diagnosis. A National Audit Office in 2009 survey found that 80% of GPs said they needed additional guidance and training in autism to manage patients on the spectrum effectively. We regularly hear from people with autism and their families who have had difficulties communicating with GPs and have had to battle for referral to diagnosis. Therefore, it seems that there is a step missing in the quality standard and we would welcome an additional statement that looks at referral from primary care to a diagnostic assessment.
35	The National Autistic Society	Statement 1	We have significant concerns that post-diagnostic support is missing from the quality standard. In our 2012 survey of over 8,000 people with autism and their families, just 28% of respondents said they received good information post-diagnosis about where to go for support. Yet, information and support post-diagnosis is one of the key things that parents and people with autism tell us that they want, but are unable to access. In some recent work we have done on older people with autism, we looked particularly at the experiences of getting a diagnosis in older age (40s+). While individuals described what a relief it was and how it helped explain years of difficulties, many also described how difficult it was to come to terms with, particularly where people felt they could have overcome challenges in earlier life if they had understood their autism. This group talked about the importance of counselling, yet few were able to access it. In our 2012 survey, 41% of respondent said they would like access to counselling, yet only 15% accessed it.
35	The National Autistic Society	Statement 1	It would be helpful if it was much clearer in the statement itself that the ‘autism service’ was a multidisciplinary team.
35	The National Autistic Society	Statement 2	Looking at co-existing conditions is incredibly important and welcome. However, one of the key gaps for children and adults with autism is the lack of mental health support received for co-occuring mental health problems. Yet the quality standard as currently written does little to demand improved quality of and access to mental health services that can appropriately support people with autism. Our You Need to Know report revealed particular inadequacies in Child and Adolescent Mental Health (CAMHS) services for children and young people with autism. Just one third of parents responding to our survey said that CAMHS had improved their child’s mental health and less than half felt that CAMHS professionals knew how to communicate with their child. Professionals also reported that their colleagues did not have autism training and that a specialist understanding of the condition was

			needed in order to appropriately adapt treatments so that they would work for children and young people on the spectrum. The research also found specific difficulties for families in accessing mental health support in time of crisis. We therefore strongly believe that additional quality statements are needed to drive up quality in mental health services for people with autism. We would suggest: people with autism can access local mental health services, as needed, which are able to adapt treatments to meet the specific needs of people with autism.
35	The National Autistic Society	Statement 3	The importance of a personalised management plan is clear. However, this statement appears to be divorced from the reality of how services are structured and delivered locally. Is this plan something that should be developed as part of the diagnostic process and if so how does it actually link to the delivery of services? If it is developed as part of the diagnostic process in isolation from local education, health and social care services, then how can we ensure that support described in the plan is available and can be delivered? To ensure delivery of the personalised management plan, it would make sense for this to be part of and not separate to any statement or education, health and care plan that is developed for a child or young person with autism and part of any care plan for any adult. However, not very child or adult with autism will be eligible for either a statement/education health and care plan or for adult social care support. If this is the case, who will be responsible for delivering the support needed? It should also be made clear that the person drawing up the plan has training in autism. The adult autism strategy identifies community care assessors as well as GPs as two priority groups for training. To address this issue, we believe that an additional quality statement could look at whether individuals are actually getting the help described in the plan. This would help ensure accountability for what is in the plan. This could be measured by surveying a sample of local people with a diagnosis of autism.
35	The National Autistic Society	Statement 3	In addition to comments above about how personalised management plans are linked to statements or adult social care plans, it would be helpful if there was an additional statement that highlighted the importance of the personalised plan linking with other parts of the system and ensuring that referral is made to appropriate other professionals for support.
35	The National Autistic Society	Statement 4	Like statement 3, we believe it should be clearer who this designated professional is. For many children with autism, the most appropriate individual might be in education and not health or social care. This may be difficult to reflect in the statement, given NICE's remit for health and social care, but we believe this should be reflected in some way.
35	The National Autistic Society	Statements 5, 6 and 7	We very much welcome the sentiment behind these three statements. It is clear that drugs should not be used to 'treat' the core symptoms of autism. However, given that the quality standard is intended to cover children and adults across the spectrum, if there is a limit on the number of quality statements, we would have some questions around whether all three statements are needed.

35	The National Autistic Society	Statement 6	We believe that this statement should be amended so that talks not about ‘triggers’, but more widely about ensuring that an individual has a holistic assessment to understand their needs and why their behaviour may be challenging. The term ‘triggers’ suggests a much lighter touch understanding of the individual and their needs, rather than gathering a full picture.
35	The National Autistic Society	General	A key challenge for both children and adults in accessing the help they need locally is that often they are discriminated against on the basis of their diagnosis. We regularly hear from parents of children with Asperger syndrome or high functioning autism that the local children with disabilities team within a local authority does not support children with autism who have an IQ above 70. These children are sometimes referred to other teams within the local authority, but their skills set and expectations about the types of help needed will be quite different to those within the children with disabilities team. For adults, the so called “mental health, learning disability gap” was recognised by the Government when they developed the adult autism strategy for England and statutory guidance. The 2009 National Audit Office report ‘Supporting people with autism through adulthood’ is highly critical and concluded that not only are a great many adults with autism missing out on essential services to ensure that they are able to reach their full potential but that this failure to provide support costs the public purse tens of millions of pounds. The report found that if local services identified and supported just 4% of adults with high functioning autism and Asperger syndrome the outlay would become cost neutral over time. If they did the same for just 8% it could save the Government £67 million each year.
			The adult autism strategy sets out clearly that a local authority cannot turn someone away from assessment and support because they are too “high functioning”. However, this remains a reality for a significant number of adults with Asperger syndrome or high functioning autism. Research carried out by the NAS in 2013 shows that 70% of adults with autism are still not receiving the help they need from statutory services. We firmly believe that a statement reflecting the need for a comprehensive health and social care service for people with autism would be particularly helpful to overcome this challenge.
			This would require local authorities and local health bodies to work together to identify the numbers and needs of people with autism in their area and to draw up commissioning plans, with the involvement of local people with autism, for the services and support needed to meet identified needs.
35	The National Autistic Society	General	A significant challenge for people with autism trying to access the care and support they need is the real lack of understanding across health and social care of the condition. Skills for Health and Skills for Care have developed a framework for the levels of understanding needed by different professionals across health and social care.

			An obvious additional quality statement would be: People with autism are supported by health and care staff that understand autism and their specific needs. We would be happy to work with NICE further to look at how to measure this appropriately
36	Royal College of Speech and Language Therapists	Statement 2	Communication difficulties should be communication disorders. Hearing impairment should be mentioned as it is for children. In general, the difficulties experienced by children persist into adulthood.
36	Royal College of Speech and Language Therapists	Statement 3	The person's communication skills should be referred to specifically.
36	Royal College of Speech and Language Therapists	Statement 4	The role of specialist speech and language therapy should be mentioned here.
36	Royal College of Speech and Language Therapists	Statement 4	Add the words in bold: "the designated professional should be an appropriately trained and experienced member of the social care or primary healthcare team".
36	Royal College of Speech and Language Therapists	Statement 5	Add the following sentence: "Psychosocial alternatives should be implemented across the person's day under the guidance of an experienced multi-disciplinary team including a speech and language therapist, a psychologist and an occupational therapist trained in sensory integration implementation." It should be made clear that other members of the team must have training and supervision in implementing psychosocial interventions.
36	Royal College of Speech and Language Therapists	Statement 6	Mention communication problems as well as physical and medical problems as possible triggers.

36	Royal College of Speech and Language Therapists	Statement 6	We are concerned about the suggestion that people with behaviour that challenges should have to wait before any proactive autism strategies are put in place. However, we agree that service providers should ensure that all psychosocial and communication strategies are in place as directed by the speech and language therapist, psychologist and occupational therapist before any reactive strategies or medication are started. Health professionals should seek expert advice from the speech and language therapist, psychologist and occupational therapist where behaviour that challenges continues.
36	Royal College of Speech and Language Therapists	Statement 6	Replace “communication problems” with “lack of functional communication (including expressive and receptive language difficulties and social interaction difficulties)”.
			Add the words in bold: “absence of predictability and structure communicated in a manner appropriate to the person’s communication needs”.
			Add the following as bullet points: “changes in the staffing, environment or approach of people around the person”; “sensory integration disorders”.
36	Royal College of Speech and Language Therapists	Statement 7	It should be made clear that it is the multi-disciplinary team which decides whether psychosocial interventions are effective or appropriate. These interventions should be continued even when medication is used or the behaviour is likely to be ongoing.
36	Royal College of Speech and Language Therapists	Statement 7	Add: “A multidisciplinary approach should be adopted to ensure appropriate psychosocial interventions are implemented in all areas of the persons’ life.”
37	The Royal College of Psychiatrists in Wales	General	In Wales, the diagnosis of ASD has to be considered within the wider introduction of the Mental Health (Wales) Measure, a new area of statutory law which aims to strengthen mental health services in both primary and secondary care for people of all ages. Under the Measure, Primary Care Mental Health Support Services (PCMHSS) work either with or alongside GP practices to provide an in-depth mental health assessment for those who have been referred to by their GP. PCMHSS also support the onward referral and co-ordination of next steps with secondary mental health services, where appropriate. The Local Health Boards and Local Health Authorities are required under law to provide for PCMHSS.
			Our concern is the need for better quality referrals along with the dissemination of appropriate information, which we believe can be achieved through regular consultation between Professionals. Training for primary care and guidance for referrers needs to be developed as this will ensure better quality referrals and may decrease waiting times to some extent.

37	The Royal College of Psychiatrists in Wales	Statement 1	In Wales, the ASD Implementation Plan outlines the development of a National adult diagnostic service. The aims of the service include agreeing and facilitating a standardised process of assessment and diagnosis, developing and delivering training to clinicians, and maintaining an expert reference group to develop local improvements and share best practice. [i] The implementation aims to have a tertiary resource available such as an "autism team" but it also aims to make the diagnosis and interventions for people with ASD mainstream competencies within specialist adult mental health and learning disability services.
			The Quality Standard as currently written could be interpreted as limiting diagnostic practice solely to an autism team and does not recognise the high quality assessment work already in place in some areas such as specialist LD services and community paediatrics. Perhaps it would be better to aspire to standards of training and competency available in services assessing people with emotional, mental and physical health needs.
			The timescale must be proportionate to need and perverse incentives must not be put in place, otherwise people may be diagnosed as Autistic as a way to access services more quickly. The timescale may also be unrealistic due to limited resources or, in the case of children, depending on the child and family's needs. Similarly, this timescale may be inappropriate depending on the child and family's needs (See Appendix 1). It is important that the NHS waiting time for assessment for an individual is proportionate depending on clinical priority and risk. For example, the three month target is too ambitious for children with other developmental disorders with potentially greater or more imminent risk to the child.[ii]
37	The Royal College of Psychiatrists in Wales	Statement 1	Maintaining a common database with other agencies, such as social services and education, will ensure smooth processing of referrals and prevent duplication of information. However, to ensure that the database holds good quality information, we need closer working and cooperation with other agencies.
			For children and young people, despite the assessment process being a multi-agency process, many view the health input as the initiation of assessment. If such a short time is required then assessment could be defined as starting when initial education assessments have commenced, although this may skew priorities overall. There is a need to clarify when the waiting target starts. For example, there is a difference between referrals made by a Tier 1 professional who has made initial screening and gathered information (to assist quality standard 2 and in part commence the assessment process) and requests direct from service users and carers.

37	The Royal College of Psychiatrists in Wales	Statement 2	We would support the principal that the process of the diagnostic assessment should include clinicians trained to recognise the co morbidities. However, the Quality Statement as currently written may insinuate that ASD diagnostic assessments would undertake an exhaustive mental and physical health assessment. We are sure the intention is not to set standards where people with ASD have separate or parallel services to meet their mental and physical health needs. The ASD Implementation Plan for Wales illustrates an ambitious programme of education, which includes the ASD Aware scheme.[iii] We have designed training packs to be used at primary and secondary MH/LD care which highlight areas of co morbidity to augment the basic awareness training. Wales led in the UK the development of a system of primary care led health checks for people with mental disorders, We would aspire to people with ASD accessing such initiatives.
37	The Royal College of Psychiatrists in Wales	Statement 3	The development of the Adult Diagnostic Service offers pre and post counselling to ensure that the diagnostic process is highly personalised (see Appendix 2). The ASD implementation plan has included the development of post diagnostic packs for children and adults
			The development of “About Me” (personal hand held patient record for children and young people referred for a specialist autism assessment in Aneurin Bevan Health Board) supports the development of the personalised management plan. (http://www.rcpsych.ac.uk/workinpsychiatry/divisions/rcpsychinwales/news/enewsletterjanuary2013.aspx)
37	The Royal College of Psychiatrists in Wales	Statement 4	There needs to be proportionality to this Statement and it must make reference more clearly to other statutory systems for care coordination, for example Unified Assessments and the Mental Health (Wales) Measure (see below).
37	The Royal College of Psychiatrists in Wales	Statement 4	Under the Measure, all patients receiving care and treatment within secondary mental health services will be designated a Care Coordinator. The Care Coordinator role is dependent on needs of the patient outlined in their care and treatment plan.
			Education and Local authorities may need to become the “designated care coordinator” in certain circumstances, for example looked after children.
			There should be a designated Case Coordinator for children and young people being assessed for autism who would be able to support the child and family during the assessment process and be their point of contact.
			The ASD implementation plan has recognised the need for this function by developing projects officers in some areas to augment the local authority leads already funded to deliver the services.
37	The Royal College of Psychiatrists in	Statement 5	We support this Statement. We would suggest that initiatives to measure this and Statement 7 need to include consideration of prescribing patterns on a population basis involving community pharmacists.

	Wales		We would suggest there needs to be a Standard with a more public health perspective; the number of people prescribed off licence psychotropics. Such a target would expose prescribing practice to vulnerable groups with challenging behaviour and neurocognitive disorders.
37	The Royal College of Psychiatrists in Wales	Statement 6	Such approaches are mainstream aspirations of specialist adult LD services. However despite significant progress there are ongoing high profile deficits such as Winterbourne.
37	The Royal College of Psychiatrists in Wales	Statement 6	The adult diagnostic network is currently organising a Community of Practice for ASD diagnosis and intervention, this will augment the existing Community of Practice for challenging behaviour.[iv]
			The use of behaviour analysis is too often at a rudimentary level in non-LD services. Unfortunately, it has not been included as part of the introduction of more psychosocial interventions (IAPT in England) or in Primary Care MH Schemes (MH Measure in Wales)
37	The Royal College of Psychiatrists in Wales	Statement 7	The Statement appears too simplistic. Unfortunately, due to the general lack of resources, along with pressure from other professionals and (in the case of children) often the families this can lead to initiation of medication prematurely to treat behaviour that challenges.
			Furthermore, once medication has been commenced there are significant difficulties and sometimes resistance to drug withdrawal; the reluctance coming from the patient, families and carers. We need to see significant developments to enhance and maintain competency in this area.
37	The Royal College of Psychiatrists in Wales	Statements 5,6 and 7	There is a need for offering a diagnostic and assessment service for patients and a need for professionals to be able to signpost and advise for future needs and intervention.
38	Royal College of Nursing	Statement 1	This is welcomed. However requires some clarification, is this assessment measuring the whole journey?
38	Royal College of Nursing	Statement 1	What would be the action plan following the assessment and how would it be measured?
38	Royal College of Nursing	Statement 1	What the quality statement means ... – this should include family and carers. Their co-operation and collaboration is important to put things in place
38	Royal College of Nursing	Statement 2	Agree. Particularly pertinent is the recent report on mental health and co-existing medical conditions.
			Coexisting physical conditions such as asthma or diabetes need to be specified more prominently so that regular NHS care for these conditions will be adequately resourced.
38	Royal College of Nursing	Statement 2	The measurement criteria are not clear. As this is going to involve multi agencies, who would co-ordinate this to ensure that it happens and that the client is given appropriate support needed for their health and well being, for example a liaison nurse, health assessment co-ordinator, family nurse etc to reflect the Valuing Health document.

38	Royal College of Nursing	Statement 2	List of medical or generic problems and disorders should include: multi co-existing conditions such as diabetes, asthma, eating disorder, coronary heart disease, chronic obstructive pulmonary disease, cancers, and sexually transmitted diseases.
			Also need help to promote this to ensure wellbeing is maintained.
38	Royal College of Nursing	Statement 3	Agree. However, there should be a named person/co-ordinator between service providers and families to signpost them to what services are available for needs assessment in order to advise if things do not happen.
38	Royal College of Nursing	Statement 3	Personalised care plan should include education not only health and social services, some young people with autism spend a lot of their time within the education system. Also provision of Special Educational Needs (SEN) and statements need to be very evident in the personalised care plan.
38	Royal College of Nursing	Statement 3	Personalised plan must include the need for extra time for routine monitoring and management of physical long term coexisting conditions such as asthma or diabetes.
38	Royal College of Nursing	Statement 3	Integration of care between social care e.g. local authorities and the NHS is key here. For example SEN needs of the children have to be specified.
38	Royal College of Nursing	Statement 4	Need to recognise the involvement of families here especially for children and young people who rely on their families. Suggest that the statement reads – People with autism and their families have a designated professional to oversee and co-ordinate their care and support.
38	Royal College of Nursing	Statement 4	Local areas, who will oversee the care provision? The person needs to work in a multidisciplinary team with regular team briefings so as to identify measures to cater for this. The services of specialist nurses are key here.
38	Royal College of Nursing	Statement 5	Agree. However, they should be given treatment for co-morbidities and any other interventions for example speech and language therapy, occupational therapy, physiotherapy and behavioural therapy.
38	Royal College of Nursing	Statement 6	Agree
38	Royal College of Nursing	Statement 6	What quality statement means for service providers, health professionals... Who will co-ordinate this assessment? What level of assessment is referred to here? Is it progressive with intervention or one-off? All need to be made clear of the framework for assessment and who will be responsible for it i.e. counsellor, cognitive behavioural therapist?
			What is the families' involvement here? This is not mentioned but is important.
38	Royal College of Nursing	Statement 6	What the quality statement means for service users and carers? What about environmental factors – need to be assessed for adequate facilities for the wellbeing of the client and the health of the carer.
			What about social activities – boredom can trigger behavioural problems

38	Royal College of Nursing	Statement 6	The families' involvement will in help identify what the triggers to this are and the effects this is having on them. The families' welfare also needs to be taken into consideration. Emotional problems can also be triggers.
38	Royal College of Nursing	Statement 7	What are the psychological interventions, these need to be made clearer and specific so it can act as an aide memoire for commissioners.
38	Royal College of Nursing	Statement 7	What is the length of the intervention and assessment? Who by – psychiatrist? Community practice nurse/mental health nurse/learning disability nurse? Other specialist? Who will give the final assessment for drug treatment to start?
38	Royal College of Nursing	Statement 7	What is the level of family involvement in this?
38	Royal College of Nursing	Statement 7	Need to specify that drug treatment has to be done by suitably qualified personnel – who is this person?
38	Royal College of Nursing	General	Using the quality standard: We are concerned that this quality standard is not mandatory, it means it would be a post code provision and would not result in equality of service delivery. Would there be sanctions or would it be left to local providers to determine if they are able to provide the service as suggested in the quality standards? If not, this will lead to inequality.
38	Royal College of Nursing	General	Levels of achievement: As above, if there are no national indicators or definitions for this, how does one measure for safety, choice, uniformity of provision?
38	Royal College of Nursing	General	Diversity, equality and language: The principle here seems contradictory as providers locally decide what to do, because there are no binding national targets this seems to contradict the equality legislation. Either there are national frameworks that all will abide by and use to prevent inequality of service delivery in all aspects of care or it seems a missed opportunity, so if a person were to challenge poor provision of care, there should be a national policy to refer to. It therefore needs to be nationally applicable and mandatory.
38	Royal College of Nursing	General	All in all, it is a good draft but there are issues to be addressed in order that there is fairness and equality of provision. It has to be applied equally irrespective of where one lives.
39	Optical Confederation	General	This is a joint response from the Optical Confederation, and the Local Optical Committee Support Unit. The Local Optical Committee Support Unit (LOCSU) provides quality, practical support to Local Optical Committees in England, to help them to develop and implement local objectives, in respect of primary eye care services. LOCSU has developed a number of eye care pathways including cataract and low vision to provide expert advice, associated business cases, clinical training packages and implementation tools to assist with the commissioning of these pathways. For more information, please visit: www.locsu.co.uk

			The Optical Confederation represents the 12,000 optometrists, the 6,000 dispensing opticians, and 7,000 optical businesses and 45,000 ancillary staff in the UK, who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of five optical representative bodies: the Association of British Dispensing Opticians (ABDO), the Association of Contact Lens Manufacturers (ACLM), the Association of Optometrists (AOP), the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.
			The Optical Confederation responded to the NICE consultation on both the guideline; Autism diagnosis in children and young people, and the guideline; Autism: recognition, referral, diagnosis and management of adults on the autism spectrum encouraging the inclusion of vision assessments into the assessment of people with Autism. We were pleased to see that both guidelines recognised the need for the identification and correction of vision defects if they existed.
39	Optical Confederation	Quality Statement 2	The Optical Confederation works closely with charities such as SeeAbility who provide specialist services for people with learning disabilities, autism, acquired brain injury, cerebral palsy, and epilepsy. The vast majority of the people supported by SeeAbility also suffer from a visual impairment. Despite being more prevalent amongst people with learning disabilities, such as autism, visual impairment is all too often undetected in such people, adding to their sense of isolation and frustration. It is crucial that support staff working with people with both sight loss and autism, are able to use effective and individualised strategies.
			We recognise that people with an Autism Spectrum Disorder (ASD) face challenges with: • Communication • Invasion of personal space • Disruption of routine • Introduction of strangers • Introduction of equipment

			As recognised in both the guideline; Autism diagnosis in children and young people, and the guideline; Autism: recognition, referral, diagnosis and management of adults on the autism spectrum, the identification and correction of visual defects is important in the care and support of people with ASD. We welcome the inclusion in Quality Standard 2 of a requirement to ensure that as part of a diagnostic assessment for autism, people are assessed for “coexisting physical health conditions and mental health problems” and particularly welcome the inclusion of vision or hearing impairment in the definition of functional problems and disorders. However, we have concerns that the quality standard is not specific enough to ensure that these necessary assessments will actually take place. Unfortunately the two guidelines from which the quality standard is derived are, we believe, rather vague in their requirements. Indeed in the Autism diagnosis in children and young people guideline Social interaction and communication behaviours section, reduced or absent eye contact can only be determined if it is based on an assumption of adequate vision. We do not believe this provides sufficient encouragement to health and social care organisations to ensure that physical impairments such as reduced vision are properly identified.
			The Local Optical Committee Support Unit (LOCSU) has developed a pathway for a specialist sight test (or community eye service) for people with autism and other learning disabilities. The pathway is designed to provide information, support and improve access to eye care services, thus ensuring that people with autism have good vision (with refractive correction supplied, as appropriate) and that any sight-threatening problems are detected and treated at an early stage. People with autism often require longer appointment times and several visits to the optical practice to become familiar with the environment and may need additional time with the optometrist so that the results of the eye examination can be explained. Information obtained during such an assessment could and should then be fed back to other health and social care professionals involved in the care of that person.
			We believe that the quality standard should be much more specific about the assessment of relevant physical impairments, such as defects of vision that might impact on a person with ASD. We would be willing and delighted to work with NICE, the Department of Health, NHS England and CCG’s to determine a more formal pathway for the assessment of people with ASD to ensure that vision is formally assessed, defects are identified and corrected, and the results used to ensure the best care is provided for that person.

40	Association for Family Therapy & Systemic Practice	General	This response is submitted by AFT, the Association for Family Therapy and Systemic Practice (www.aft.org.uk). AFT is committed to supporting developments in practice, research, training and delivery of high quality therapeutic services for children, young people, adults and their families and other networks of care. It is the UK's leading organisation for professionals working systemically with individuals, couples, families and other networks of care across the lifespan. AFT's membership is multi-disciplinary and includes Family and Systemic Psychotherapists (aka family therapists), clinical psychologists, psychiatrists, GPs, nurses, social workers, teachers, occupational therapists, health visitors and others committed to developing their systemic practice skills and understandings.
40	Association for Family Therapy & Systemic Practice	Quality Statement 1	For those who need an assessment & diagnosis, they should receive such services on recommendation by any health or social care professional, regardless of any threshold of acceptance by a specialist service.
40	Association for Family Therapy & Systemic Practice	Statement 1	For those who may need an assessment & diagnosis, their consent or refusal should be elicited following information being provided about such services, including likely consequences of providing information and receiving such services and the likely consequences of not providing information and/or refusing such services, suitable to their age and understanding. Specialist services should verify this informed consent process prior to accepting referral.
40	Association for Family Therapy & Systemic Practice	Statement 1	Diagnostic assessments must limit direct questions of the referred person and their families and should not duplicate any existing assessment. Apparent diverse and contradictory information should be recorded and considered.
40	Association for Family Therapy & Systemic Practice	Statement 1	The three month time limit for starting diagnostic assessments should be the time limit for starting the full assessment. This will prevent specialist agencies using 'initial assessments' and 'secondary waiting lists'.
40	Association for Family Therapy & Systemic Practice	Statement 1	The use of checklists and diagnostic assessment protocols should not be privileged over the narratives of the referred person and their family: "If you have seen one person with autism then you have seen one person with autism"
40	Association for Family Therapy & Systemic Practice	Statement 1	Formulations and diagnoses should be negotiated with the referred person and their family. Language and semantics matter; what may be acceptable to one may not be acceptable to another – within families as much as between families. The implications of formulations and diagnoses (whether autism or not) should be explored and choices offered.
40	Association for Family Therapy & Systemic Practice	Statement 2	Where physical and mental health problems appear there may be considerable overlap with signs and symptoms of autism. Such overlap might provoke a diagnostic and treatment either/or rather than a both/and. It may be harmful to privilege autism problems over physical / mental health problems and vice-versa.

40	Association for Family Therapy & Systemic Practice	Statement 2	This Statement appears medically oriented omitting consideration of a social model of disability. It should include diagnostic assessment of psychosocial problems. What may appear as a mental health problem may also appear as a relationship and/or social problem requiring relationship and/or psychosocial interventions.
40	Association for Family Therapy & Systemic Practice	Statement 3	A needs based management plan should prioritise interventions that promote strengths as well as interventions to reduce risks. Risk reduction interventions may be perceived as coercive rather than interventions based on an obliquity approach.
40	Association for Family Therapy & Systemic Practice	Statement 3	This Statement should emphasise the strengths of the referred person's family and social network as well as the referred person's strengths. Family oriented interventions should be routinely considered to promote the coping of individuals and their networks.
40	Association for Family Therapy & Systemic Practice	Statement 4	Care and support coordination should be negotiated with the referred person and their network. The choice of care and support co-ordinator should be shared with the referred person and their network. The Common Factors evidence based approach in psychotherapy suggests that the professional relationship itself contributes the most significant positive outcome of all therapeutic factors.
40	Association for Family Therapy & Systemic Practice	Statement 4	This Standard's provision of a named 'professional' should preclude the allocation of an unqualified service worker as a care and support coordinator and this should be stated.
40	Association for Family Therapy & Systemic Practice	Statement 5	Psychosocial interventions as an alternative to drugs should only be delivered or supervised by professionals trained and qualified in psychosocial interventions. The danger in allowing unqualified service workers to attempt psychosocial interventions is that any failure in the intervention to achieved desired outcomes might provoke a trial of drug treatment.
40	Association for Family Therapy & Systemic Practice	Statement 6	It is essential that this statement includes psychosocial factors e.g. "People with autism who develop behaviour that challenges are assessed for possible triggers, including psychosocial, physical and medical problems, before any interventions for behaviour that challenges are started." Although such consideration appears under the heading "Assessment for possible triggers" the word 'psychosocial' should be included together with the words 'physical' and 'medical' to describe possible triggers. This is especially important as psychosocial interventions are preferred alternatives to drug treatments e.g. risperidone.
40	Association for Family Therapy & Systemic Practice	Statement 7	As for Quality Statement 5: Psychosocial interventions as an alternative to drugs should only be delivered or supervised by professionals trained and qualified in psychosocial interventions. The danger in allowing unqualified service workers to attempt psychosocial interventions is that any failure in the intervention to achieved desired outcomes might provoke a trial of drug treatment.

40	Association for Family Therapy & Systemic Practice	Statement 7	The behavioural orientation of the Statement especially as listed as ‘psychosocial interventions’ on page 27 omits relationship interventions. Relationship interventions form part of the recommended evidence based ‘Multi-Systemic Therapy’ approach and should be included, especially as attachment needs appear relevant to many ‘behaviours that challenge’.
41	NHS England	General	It would be ideal to focus on the importance of service user involvement in the design and delivery of services within this guidance – we know that service user involvement significantly enhances the quality of experience.
41	NHS England	General	The importance of feedback/surveys/focus groups on experience of care should also be included so that providers and commissioners embed this into service design and delivery.
42	The disabilities trust		In principle the Trust would agree with all the quality standards listed in this document to ensure the correct level of support is given to those with autism.
42	The disabilities trust	General	However there is a risk that the standards could be used as a ‘tick box’ approach,it needs to be emphasised that they should be used in conjunction with the existing ‘Autism in young people and adults’ Guideline. For example, we would be concerned that there is a lack of 'how to,' in terms of analysing an individual’s behaviour and its causes and some service providers may be able to navigate around this rather than fully investigating an individual's condition and their behavioural triggers.
42	The disabilities trust	General	For example, if behaviour is not properly analysed, a provider could decide to put an individual on anti-psychotic medication when in fact other aspects eg environment, communication issues have not been fully considered. We have case studies of service users who have previously been under Section with other providers, where behaviour has markedly improved purely because of a change in environment and communications approach taken by staff. This is linked to our concern that communication methods can be bypassed and instead medicalor physical intervention is used as a first choice, rather than exhausting communication methods first. Staff, carers and families need to be supported to understand the behaviour which, at its most fundamental level, is a form of communication. This holistic approach needs to be made more explicit within the standards