NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Challenging behaviour and learning disabilities

Date of Quality Standards Advisory Committee post-consultation meeting:
14 July 2015

1. Introduction

The draft quality standard for challenging behaviour and learning disabilities was made available on the NICE website for a 4-week public consultation period between 29th May and 26th June 2015. 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 32 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 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 appendices 1 and 2.

1. 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?

3. For each quality statement what do you think could be done to support improvement and help overcome barriers?

4. What are the 6 most important quality improvement areas from the 10 statements in this quality standard?

Stakeholders were also invited to respond to the following statement specific questions:

5. For draft quality placeholder statement 1: Do you know of any relevant evidence-based guidance that could be used to develop this placeholder statement? If so, please provide details. If not, would new evidence-based guidance relating to early support and training for families and those who support children with learning disabilities have the potential to improve practice? If so, please provide details.

6. For draft quality statement 3: How far is a comprehensive annual health assessment for people with learning disabilities who display behaviour that challenges already happening in practice?

7. For draft quality statement 3: An annual health assessment for adults is commissioned as part of a Directed Enhanced Service. Therefore, should this statement be targeted at under 14s only?

8. For draft quality statement 4: Is the identification of a designated coordinator who is responsible for the behaviour support plan currently happening in practice?

9. For draft quality statement 4: Who would be the designated coordinator responsible for this?

10. For draft quality statement 6: Are there any tools or methods for assessing the quality of the behaviour support plan in a review that could be referenced?

11. For draft quality statement 7: Who is responsible for carrying out the review? How soon should it take place after the intervention?

1. General comments

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

* Comments were generally supportive of this quality standard. Feedback suggested that the key areas for quality improvement were addressed by the quality statements and the emphasis on positive behaviour support and quality of life was welcomed.
* Several stakeholders highlighted related legislation and guidance that should be referenced and advocated a joined up approach between guidance and standards.
* It was suggested that there should be a statement on having a positive behaviour support plan with elements derived from a functional assessment process.
* Some comments indicate a number of barriers to implementation highlighting a lack of resources, training, culture and leadership.
* It was suggested that the Equality impact assessment should specify actions to support people from BME communities who may be unknown to services.

### Consultation comments on data collection

* Comments indicated that generally data collection against the quality measures is viewed as possible and some stakeholders highlighted existing mechanisms that could be used for this purpose.
* Barriers to data collection were identified as responses to quality of life/satisfaction surveys being too low, definition with this group, the resource implications of collecting data and the fact that narrative data may be needed, which would be difficult to gather.
* Suggestions for to overcome issues that would need addressing to enable collection included the need to have one recoding system per person used by both health and social care and the need for a multi-disciplinary team approach.
* The definition of challenging behaviour was identified as an issue and it was stated that the definition used is too loose to be measured

### Consultation comments on identification of the 6 key areas for quality improvement (Question 4)

* The following five quality statements emerged as the most frequently cited:
	+ Statements 1, 2, 5, 7 and 8.

Statements 3 and 9 were cited equally.

* A number of comments suggested merging statements as follows:
	+ merge 2, 3 and 6 - Statement 2 as a comprehensive assessment of an individual must include a full health check for the person; thus statement 3 should form part of the quality statement outlining what is meant by this approach.
	+ merge 4 and 5
	+ merge 7 and 8
	+ merge 8 and 9 to describe the process of diagnosis, prescription and review.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

### (placeholder) Early (0-5 years) support with behaviour that challenges for children with learning disabilities

### Consultation comments

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

* Stakeholders questioned why the statement specifies 0-5 years and suggested that it should be considered at any stage that challenging behaviour or the potential for challenging behaviour is first noted.
* There was a suggestion for consideration of the needs of children born into families with learning disabilities.

### Consultation question 5 Do you know of any relevant evidence-based guidance that could be used to develop this placeholder statement? If so, please provide details. If not, would new evidence-based guidance relating to early support and training for families and those who support children with learning disabilities have the potential to improve practice? If so, please provide details.

Stakeholders made the following comments in relation to consultation question 5:

* It was stated that some existing mechanisms could be used to collect data about intervention with under 5s.
* Evidence suggested included Paving the Way, an early intervention programme, evidence from the Portage programme and Sure Start programmes and specific resources such as Contact a Family Briefing Paper.
	1. Draft statement 2

### People with learning disabilities and behaviour that challenges have an initial assessment to identify possible triggers for the behaviour.

### Consultation comments

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

* Assessment is mandated in the Care Act, so should be happening in practice, but there is a need to identify who would carry out the assessment.
* Stakeholders called for more detail of what the assessment would consist of and gave a number of suggested areas it should include:
	+ sensory issues
	+ health issues
	+ communication style and capability of the person
	+ when the problem behaviour started, and its relation to the ways the person communicates
	+ risk assessment
	+ behaviour outcomes.
* Comments indicated that there were elements of this process described in the guideline that had not been included in the quality statement. It was recommended that the section entitled ‘Functional Assessment’ (recommendation 1.5.9), or some variant of, be reproduced in the quality statement.
* There were two suggestions to reword the statement. Firstly, to replace ‘triggers’ with ‘factors’ throughout and use the word ‘developing’ in the second and third bullet points in line with the source guidance. Alternatively, to reword the statement using wording from the section on what means for service users and carers: “have an assessment as soon as there are signs of behaviour that challenges”
* A specific suggestion to reword the measure, i.e. newly referred episodes of people presenting with behavioural problems. Numerator should be the proportion of these where a satisfactory assessment is completed.
	1. Draft statement 3

### People with learning disabilities and behaviour that challenges have a comprehensive annual health assessment from their GP.

### Consultation comments

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

* It was suggested that the population referred to in this statement should be amended to people with learning disabilities, not learning disabilities and behaviour that challenges, to reflect the issue that an assessment can be a preventative measure.
* While some stakeholders stated that a more frequent check at six months would be more appropriate for severe cases, others suggested the focus should be on identifying and managing physical health problems routinely, not only at an annual health check.
* Stakeholders identified a number of areas that should be specified as included in the annual health assessment including:
	+ communication and behaviour support needs, e.g. if going into hospital – reasonable adjustments
	+ specific sensory impairment, particularly sight
	+ discussion of the risks and benefits of medication
	+ a focus on physical health needs
	+ mental health needs
	+ discussion with family with person’s permission
* There was one suggestion to operationalise the measure as: “the number referred to a secondary or tertiary service for challenging behaviour.

### Consultation question 6 How far is a comprehensive annual health assessment for people with learning disabilities who display behaviour that challenges already happening in practice?

Stakeholders made the following comments in relation to consultation question 6:

* Most responses suggested that there was variation in practice. Several responses highlighted the data gathered by Public Health England. It was stated that the Direct Enhanced Service (DES) helps this issue and cited the example of Portsmouth where all service users receive a health check. One stakeholder stated that it only happened when the GP was signed up to the assessment, as they are not obliged to provide the health checks
* The question of who conducts the assessment was raised in responses. It was suggested that it was not always the GP who conducted the assessment, but could be a Community Paediatrician or the Learning Disabilities team. It was also suggested that health checks for children can be performed by school nurses.

### Consultation question 7 An annual health assessment for adults is commissioned as part of a Directed Enhanced Service. Therefore, should this statement be targeted at under 14s only?

Stakeholders made the following comments in relation to consultation question 7:

* The majority of responses to this question stated that the statement should be aimed at all ages, not only under 14s, as many people do not receive the assessment.
* It was suggested that there should be an explicit statement saying that the annual health assessment in the quality statement would not be in addition to, or replace, the DES, to avoid any potential confusion.
	1. Draft statement 4

### People with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

### Consultation comments

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

* Stakeholders were generally supportive of the statement, but it was stated that a designated coordinator may be difficult when multiple services are involved or when people are moving between services.
* It was stated that the standard should make clear if all service users will have a behaviour support plan and also clarify if it is the co-ordinator’s role to ensure this is carried out. One stakeholder commented that identifying one named person was unrealistic given sickness and staff turnover rates and different ways of working should be considered to establish the same outcome.
* It was suggested that the behaviour support plan definition should include positive risk-taking.

Consultation question 8 Is the identification of a designated coordinator who is responsible for the behaviour support plan currently happening in practice?

Stakeholders made the following comments in relation to consultation question 8:

* Comments indicated that there was inconsistency in whether a designated coordinator was identified .It was highlighted that the roles that would perform this have been recently cut. It was stated that a key person to co-ordinate and update the behaviour support plan is generally agreed at service level, but not at professional level.

### Consultation question 9 Who would be the designated coordinator responsible for this?

Stakeholders made the following comments in relation to consultation question 9:

* Responses were mixed without one consistent response. One stakeholder responded that the person best placed to co-ordinate will differ for each person as their unique needs require a range of solutions. One stakeholder suggested that matching with an appropriate skilled professional rather than a professional group in particular would be a better way of working.
* Specific suggestions for who could fulfil the role included the Care Programme Approach (CPA) coordinator role, which it was suggested appeared to be consistent with the designated coordinator, and for children a key worker, with the quality standard linked to the SEND work and co-ordination of the Education Health and Care Plan.
* It was also stated that the person fulfilling the role should be chosen by the individual where possible and should be someone who knows the person with learning disabilities well.
	1. Draft statement 5

### People with learning disabilities and behaviour that challenges have personalised daily activities planned and documented in their behaviour support plan.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

* Responses were generally supportive of this statement, but there were a small number of suggested amendments. One comment called for the statement to specify that daily activities should be meaningful, whilst another suggested amendments to the statement and rationale to place focus on the importance of the personalised daily activities.
* Several stakeholders commented on how the statement could be made more specific. It was commented that people would benefit from both a behaviour support plan and a meaningful daily activity schedule (as in Active Support), but on some occasions just the behaviour support plan would be needed, and occasionally only the Active Support plan would be needed. It was suggested therefore that the measures for this statement needed to reflect only the provision of daily activities not behaviour support plans. Moreover, it was suggested that there should be more of an emphasis on person centred active support (PCAS) and the statement would be clarified by a definition of a Personalised Daily Activity Schedule.
	1. Draft statement 6

### People with learning disabilities and behaviour that challenges have their behaviour support plan reviewed every other week for the first 2 months and then every month.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

* Several responses suggested that stakeholder were not fully supportive of this statement.
* The main issue raised was the achievability of the statement, particularly for reviews that would involve a range of professionals. The two weekly reviews were seen as unachievable and it was suggested that monthly reviews could not be performed by local specialist learning disability teams, due to a lack of resource.
* It was also highlighted that reviews of this frequency may not be appropriate in all cases and it depends on the severity. It was suggested that it may be necessary to prioritise reviewing only certain plans at this level of frequently, such as those which include the use of restrictive interventions and/or deprivation of liberty.
* Only one stakeholder suggested an alternative for a fixed time period of review, stating that continual monitoring should be expected, but regular reviews could take place at a minimum of four weekly for the first six months.
* Clarification was called for on what constitutes a ‘review and how it should be performed. It was stated that further recommendations from the guidance could be used to give detail to the Behaviour Support Plan.
* One response suggested an amendment to the statement to include the phrase ‘the effectiveness of the behaviour support plan’ to show that the review needs to understand how plan is working.

### Consultation question 10 Are there any tools or methods for assessing the quality of the behaviour support plan in a review that could be referenced?

Stakeholders made the following comments in relation to consultation question 10:

* Qualitative measures could include asking the service user if they feel their Positive Behaviour Support plan is working. One stakeholder suggested that identification of the frequency of reactive strategies utilised would be a useful measure and the level/intensity and frequency of restrictive practices, as you would expect to see these reduce over time.
* A number of stakeholders suggested specific tools or measures:
	+ The guidance in Ensuring Quality services
	+ BILD are developing a user friendly tool
	+ CaF or MindEd.
	+ measures developed by the Tizard Centre at the University of Kent
	+ Royal College of Psychiatrists Evidence outcome framework
	+ Abertawe Bro Morgannwg University Health Board tool for reviewing Positive Behaviour Support Plans
	+ Quality of Life outcome measures
	+ momentary time sampling observations as used to measure the effectiveness of PCAS.
	1. Draft statement 7

### People with learning disabilities and behaviour that challenges have a documented review every time a restrictive intervention is used.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

* Comments were supportive of having a quality statement for this issue, but called for a clearer definition of restrictive intervention.
* Some responses questioned the frequency of reviews, with people stating that a review every time may not be achievable and it should be included as part of a monthly review. Others suggested the statement focus on either the level of review required or trigger points such as where injury occurs.
* The issue of age was raised and inclusion of a clearer differentiation between the management of and level of a restriction with a small child and that of an adult was suggested.
* A number of comments concerned the need to define who carries out the review. .
* A number of other issues were raised around what the review should include:
	+ need for consideration of sensory impairment
	+ whether the review would include as and when required medication.
	+ completion of an impact and risk assessment to assesses the level of restraint and make a judgement on the level of need for monitoring
	+ consideration of how the person should be supported to understand the restrictive intervention.
* Specific additional points for suggested amendments were:
	+ Reference to Deprivation of Liberties
	+ amendment of the rationale to state that ‘restrictive interventions should ONLY be used as a last resort’
	+ Reword the denominator to the number receiving any type of intervention for reasons of behaviour.

### Consultation question 11 Who is responsible for carrying out the review? How soon should it take place after the intervention?

Stakeholders made the following comments in relation to consultation question 11:

* A number of stakeholders highlighted the Deprivation of Liberty Safeguard assessments that are already undertaken for several of the restrictive intervention purposes outlined in the definition in accordance with the Mental Capacity Act (2005). However, stakeholders commented that resources for conducting these assessments are limited and over-stretched.
* Stakeholders’ responses were mixed in relation to who should conduct the review. Some comments identified particular roles: the community paediatrician leading an expert multi-disciplinary team including the GP; the person responsible for or the author of the Behaviour Support Plan; the named Coordinator; the service provider with the involvement of the coordinator; the person responsible for the intervention. One stakeholder stated that the review should be with the clinician author initially, then the care provider.
* Responses suggested that stakeholders may have interpreted the statement differently. Whilst some responses emphasised the need for an immediate incident review and focussed on a single occurrence of a restrictive practice, others viewed the statement as concerning the ongoing review of restrictive practices and stated that these interventions should be reviewed on an annual basis. Therefore, with regard to timing of the review, responses were mixed.
* Some comments echoed previous responses stating that the review timescale should not be too prescriptive, because there may be a need to review a plan daily. Other responses gave broad suggested frequencies, from daily or weekly initially to fortnightly and monthly over time. Some were more prescriptive as follows: a local review within 48 hrs; within 72 hours of an incident; carried out after 3 days; within a week; local review needed after 1 month. Other stakeholders stated that the frequency should depend on the intervention and a formal review could be monthly, 3-monthly or 6-monthly.
	1. Draft statement 8

### People with learning disabilities and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 8:

* Most stakeholders were supportive of the statement.
* It was suggested that defining when exceptions might be clinically appropriate should be considered. In contrast other stakeholders felt that including the caveat ‘or when the risk to the person or others is very severe’ may allow for the justification of using antipsychotic medication due to poor practices. It was suggested that it may be more appropriate to state that antipsychotic medication should only be used as a treatment relating to a diagnosis of psychosis rather than for medical restraint.
* One comment suggested that the measures could be clearer about the status of prn prescribing. It was perceived to be uncertain whether this was included and suggested that recording of prn medication for control of acute behavioural disturbance should be recorded separately from continuous administration intended to prevent behaviours.
	1. Draft statement 9

### People with learning disabilities and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 9:

* All stakeholders were fully supportive of this statement. Only one stakeholder commented that the aim and expectation in management of behavioural problems should be resolution.
* It was suggested that the statement should be widened to encompass all medication, not just antipsychotic medication.
* Some stakeholders commented that the review should not occur in isolation. It was suggested that it should happen at the same time as the review of the Behaviour Support Plan and also that it should be aligned with the social care review for new services, for which the intervals of 6 weeks and 3 months are set out in national guidance.
* Stakeholders commented on who should be included in the review. It was stated that it must involve families and advocates. Also, that the role of non-specialist provision, e.g. from GPs, should be emphasised in the quality statement and lastly that allied health professionals should be included where relevant. However, other stakeholders called for the composition of the multi-disciplinary team to be less specific about members, as people that might be relevant includes parents, teachers and a variety of other staff, depending on local service provision.
* One stakeholder suggested that care reviews should be framed around the circumstances in which the source guidance considers antipsychotic use appropriate and the measures in the statement should be reworded to state ‘a review fully covering the relevant issues set out in NG11 section 12.3’.
* It was suggested that the quality statement could be improved by specifically stating that such reviews should be ‘data-driven’ or ‘based on evidence from practice’. For example clear data on behaviour presentations, episodic severity of incidents and the extent to which restrictive interventions are applied should be included.
* The statement should reference the need for accessible information about the medication, side effect, benefits and any monitoring arrangements.
	1. Draft statement 10

### Parents or carers of children aged under 12 years with learning disabilities and at risk of developing behaviour that challenges are referred to a parent training programme for challenging behaviour.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 10:

* Stakeholders were supportive of the need for support for parents, but suggested that use of the word ‘referred’ should be replaced with ‘offered’ to ensure that there is no implied criticism of parents of children with challenging behaviour and that both parents and medical professionals know that attendance at these programmes is voluntary.
* The statement was welcomed as there is a reported lack of parent training schemes.
* A number of responses suggested that the statement should be widened beyond children under 12 to all ages.
* One stakeholder commented that the quality statement should include a definite timescale, so that parents can know when they will be offered the choice of additional support.
* The particular training programmes suggested in the statement was questioned and one stakeholder recommended that the standard should be less specific in its prescription, or, if the Committee does wish to endorse a particular programme, it should give examples, such as sessions of 120 minutes or more or examples of recommended training manuals.

# Appendix 1: Quality standard consultation comments table – registered stakeholders

| **ID** | **Stakeholder** | **Statement number** | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1 | Association of Directors of Adult Social Services (ADASS) | General | ADASS welcomes these quality standards as a means to support improved outcomes for people, and ensuring that positive assessment leads to personalised care planning and access to meaningful activities, and that the approaches used by staff to support people with learning disabilities follow the least restrictive practice and promote privacy and dignity.  |
| 2 | Royal College of Nursing  | General | This is to inform you that the Royal College of Nursing have no comments to submit to inform on the above draft quality standards consultation. |
| 3 | Hftrust | General | Hft is a leading national charity that supports people with learning disabilities. Every day our creative and resourceful thinking helps people to get the most out of life. Founded by pioneering families over fifty years ago, we continue to work in partnership with the people we support and their family and friends to understand their individual needs and goals. Our staff expertise includes supporting people with complex needs, challenging behaviour and specific syndromes like Autism. Our person centred support, combined with our leadership in using personalised technology, enables people with learning disabilities to live more fulfilling lives. |
| 4 | Department of Health  | General | I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation. |
| 5 | Department of Health  | General | I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation. |
| 6 | The Royal College of Surgeons of England  | GeneralGeneral | The RCS will not be sending feedback to this consultation |
| 7 | NHS England  | General | Thank you for the opportunity to comment on the above Quality Standard. I wish to confirm that NHS England has no substantive comments regarding this consultation. |
| 8 | Swanton Care and Community  | General | I would endorse the recommendations and state that whilst we support the recommendations and the quality standard further requirements cannot be imposed without consideration of commensurate funding.  |
| 9 | Avenues Group  | General | Avenues has been providing support to adults and young people with learning disabilities and challenging behaviour for over 20 years in their own homes, residential care homes and the local community. We welcome the NICE quality standard, particularly the emphasis on positive behaviour support and quality of life. However we feel further consideration needs to be given to the resources that will be required to meet the quality standard. |
| 10 | Mencap | General | It is important people with a learning disability and behaviour that challenges and their families get good support early on.We know that there is a lack of the right support and services in local areas for people with a learning disability and behaviour that challenges and a clear quality standard should help ensure that good quality local services are developed.Some overarching themes around what good support looks like:There must be a real focus on prevention and early intervention. Too often individuals and their families are not getting the right support leading to crisis situations and admission to inpatient units.There must be a focus on joint working between health and social care and children and adults services. It is crucial that families are listened to and the expertise and knowledge they have about their family member used/acted up. We know that too often the knowledge of families is not being used to inform decisions. It is crucial that individuals and families get information in a timely manner, including information about rights.It is important there is a focus on outcomes for individuals. Quality measures must go beyond a tick box exercise focusing on process (e.g. recording whether the person has had an assessment, has a behaviour support plan, has had a review, whether they have had an annual health check, whether they have a coordinator) – they must focus on outcomes for individuals.The thinking behind all decisions relating to individuals (e.g. detention, treatment, and restrictive practices) should be explicit and recorded in a timely way. It must be clear what the desired outcomes are. This will help ensure people get appropriate care and treatment and will help challenge where they are not getting this. The underpinning principles of the Human Rights Act 1998, the Mental Capacity Act 2005 and the Equality Act 2010 (reasonable adjustments) are crucial in ensuring people with a learning disability and behaviour that challenges - who are at risk of receiving restrictive practices and being sent far from their family and friends - get good support. They should be referred to explicitly in the quality standard. |
| 11 | NHS Protect | General | * NHS Protect has responsibility for leading on work to protect the NHS from crime, and this responsibility includes tackling violence, harassment, abuse and anti-social behaviour against the NHS.NHS Protect provides policy, guidance and operational support to enable NHS health bodies to address their responsibilities in relation to the safety and security of their staff.
* Local Security Management Specialists (LSMS) are trained and accredited to deliver this strategy at a local level. We *strongly recommend* that this challenging behaviour guideline references the work of NHS Protect, the role of their LSMS, and points staff to their LSMS for advice, guidance and support on safety and security matters (including violence). We can provide assistance with a contribution in the guideline.
 |
|  | Mencap | General | It is important people with a learning disability and behaviour that challenges and their families get good support early on.We know that there is a lack of the right support and services in local areas for people with a learning disability and behaviour that challenges and a clear quality standard should help ensure that good quality local services are developed.Some overarching themes around what good support looks like:There must be a real focus on prevention and early intervention. Too often individuals and their families are not getting the right support leading to crisis situations and admission to inpatient units.There must be a focus on joint working between health and social care and children and adults services. It is crucial that families are listened to and the expertise and knowledge they have about their family member used/acted up. We know that too often the knowledge of families is not being used to inform decisions. It is crucial that individuals and families get information in a timely manner, including information about rights.It is important there is a focus on outcomes for individuals. Quality measures must go beyond a tick box exercise focusing on process (eg. recording whether the person has had an assessment, has a behaviour support plan, has had a review, whether they have had an annual health check, whether they have a coordinator) – they must focus on outcomes for individuals.The thinking behind all decisions relating to individuals (eg. detention, treatment, restrictive practices) should be explicit and recorded in a timely way. It must be clear what the desired outcomes are. This will help ensure people get appropriate care and treatment and will help challenge where they are not getting this. The underpinning principles of the Human Rights Act 1998, the Mental Capacity Act 2005 and the Equality Act 2010 (reasonable adjustments) are crucial in ensuring people with a learning disability and behaviour that challenges - who are at risk of receiving restrictive practices and being sent far from their family and friends - get good support. They should be referred to explicitly in the quality standard. |
|  | The Huntercombe Group  | General | THG were pleased to see the learning disability and challenging behaviour guidance published at the end of May 2015, and the emphasis placed on the application of Applied Behaviour analysis in developing, evaluating and revising individualised behaviour management plans for this population. We note that while Positive Behaviour Support (PBS) has grown significantly in popularity, it is actually best viewed as an application of Applied Behaviour Analysis, and understand that the absence of random control trials using PBS meant that it was barely mentioned in the NICE Guidance document or these quality standards. However, many of the values specifically promulgated within PBS such as least restrictive practices, personalised assessment and treatment based around individual choice, respect and dignity, and the provision of meaningful activity such as Active Support, are mentioned in the NICE Guidance and the current quality standards, which we endorse.*Note: intellectual disability and learning disability are used interchangeably in this response.* |
|  | The Royal College of Psychiatrists | General | The Guidance makes it clear that the threshold for challenging behaviour is ill defined. Consequently, so is the point at which it becomes sufficiently frequent/intense to be considered potentially harmful and subject to the formal procedures of this Guidance and its standards. Given its ill-defined nature, the quality statements need to include some provision for the response to be proportional to the problem as it unfolds. |
|  | Association for Real Change (ARC) | General | ARC is supportive of this standard. We feel that the emphasis on ensuring that an assessment, decision making and care planning is to be conducted with a family member, carer or healthcare professional or social care practitioner who knows the person; on the importance of dignity and opportunity for individuals to express their preferences is what our members would want to see. |
|  | Hearing and Learning Disabilities Special Interest Group (HaLD SIG) | General | At least 40% of adults with learning disabilities will have a hearing loss, though most remain undiagnosed. Undetected hearing loss may be incorrectly labelled as challenging behaviour (Miller & Kiani, 2008). There is an association between sensory impairment and challenging behaviour in people with learning disabilities (Timehin & Timehin, 2004). McShea et al (2014) describe a powerful case study highlighting the relationship between undiagnosed hearing loss and challenging behaviour, which saved significant sums of money and transformed the life of the individual. Hearing assessments are recommended for individuals with behaviour change.*Miller H & Kiani R (2008) Inter-relationships between hearing impairment, learning disability services and mental health: are learning disability services “deaf” to hearing impairments? Advances in Mental Health and Learning Disabilites 2(2): 25 – 30.**Timehin C & Timehin E (2004) Prevalence of hearing impairment in a community population of adults with learning disability: access to audiology and impact on behaviour. British Journal of Learning Disabilities 32: 128 – 132.**McShea L, Corkish C, McAnelly S (2014) Audiology services: Access, assessment and aftercare. Learning Disability Practice 17(2): 20 - 25.* |
|  | The Challenging Behaviour Foundation  | General | • This is an area (learning disability and challenging behaviour) where clear improvements are required.• There is a need to invest in prevention and early intervention, rather than the crisis management approach commonly employed.• There is a need to provide accessible, practical and timely information to families.• There is a need to focus on (and measure) outcomes for individuals - rather than process.• There is a need to improve local mainstream support and services to cater for the needs of children and adults with learning disabilities who display behaviour described as challenging (including implementing reasonable adjustments)– as well as providing a range of co-ordinated local specialist support and services when required.• Equality and diversity considerations – these should go beyond communication difficulties. Disabled people from minority groups can experience additional isolation, social exclusion, discrimination and poverty (see <http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Over-looked-communities-over-due-change.pdf?ext=.pdf>) People with learning disabilities from BME communities may be unknown to services. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | General | We support the development and use of quality standards. However, as an organisation looking to measure quality outcomes for people with learning disabilities who present with behaviours that challenge, we are very disappointed that these quality standards are written as inputs to be counted rather than focusing on measuring outcomes.  |
|  | The Royal College of General Practitioners  | General | The emphasis should be on enabling parents (and other carers, school staff) to manage behaviour. I understand that schools sometimes soak up the personal budgets for such LD children. There should be more child/adolescent centres advice, especially over emerging sexuality. This often causes school staff to freak out and raise safeguarding concerns. (JA)The quality statements and document appears to make no reference to the Mental Capacity Act 2005, reasonable adjustments and Deprivation of Liberty Safeguards. (MH) |
|  | NHS Protect | General | NHS Protect has responsibility for leading on work to protect the NHS from crime, and this responsibility includes tackling violence, harassment, abuse and anti-social behaviour against the NHS. NHS Protect provides policy, guidance and operational support to enable NHS health bodies to address their responsibilities in relation to the safety and security of their staff. • • Local Security Management Specialists (LSMS) are trained and accredited to deliver this strategy at a local level. We strongly recommend that this challenging behaviour guideline references the work of NHS Protect, the role of their LSMS, and points staff to their LSMS for advice, guidance and support on safety and security matters (including violence). We can provide assistance with a contribution in the guideline. For inclusion in the Introduction – NHS Protect reports on incidents of physical assault which were / were not as a result of medical factors (including mental ill health and learning disability). Please consider including the latest Reported Physical Assault figures published by NHS Protect for 2013/14 to provide a further context to these guidelines: http://www.nhsbsa.nhs.uk/Documents/SecurityManagement/Reported\_Physical\_Assaults\_2013-14.pdf |
|  | NHS Protect | General | There is nothing specific in the guideline about the responsibility on all staff and organisations to report and record all incidents of violence and aggression through the incident reporting system, including those that involve medical factors. We strongly recommend that this responsibility to report incidents via the incident reporting system and onto their LSMS for investigation is included in the guideline. Reference to creating a positive reporting culture and governance arrangements within organisations to analyse reported incidents in order to minimise the risks of violence against staff would also be welcome.For consideration as a reference in the guideline, we recognise that most behaviours will be due to someone’s distress and unmet needs. Where however a crime is suspected, we recommend that this should be reported to the police for initial consideration and possible management of the person through the criminal justice system. This can have therapeutic benefits of ensuring that the individual can access more appropriate levels of treatment and care, delivered in a safe environment. |
|  | NHS Protect | General | NHS Protect managed a clinically led expert group to produce guidance for the prevention and management of challenging behaviour: NHS Protect (2013) *Meeting needs and reducing distress: guidance for the prevention and management of clinically related challenging behaviour in NHS settings*. This comprehensive guidance, website and training DVDs provides organisations with practical strategies on how to prevent a person’s distress by understanding the causes, designing better personalised care to meet their needs, and where an incident occurs to manage the risks of challenging behaviour in healthcare settings. This guidance has been very well received by NHS organisations and we recommend that at the very least it is referenced in this guideline: <http://www.nhsprotect.nhs.uk/reducingdistress>  |
|  | Leonard Cheshire Disability  | General | The current standards do not effectively recognise the need not just for general training, but also for training in the specific needs of people with challenging behaviour. For example, managing the challenging behaviour of people with learning disabilities can be made much easier if staff are aware that particular foods, events or environmental factors (for example) tend to trigger challenging behaviour.Further, understanding how individuals with learning disabilities communicate is a key element of correctly identifying and dealing with challenging behaviour. For example, some people may scream when they are happy rather than when they are scared. Treating such a scream as challenging behaviour is likely to cause both staff and service users additional problems. Sometimes, only by understanding what a person with a learning disability is trying to communicate can effective alternatives to difficult or challenging behaviour be suggested or supported. |
|  | Leonard Cheshire Disability  | General | It would be helpful to include more details of what constitutes challenging behaviour in the introduction. A clear framework setting out exactly what the guidance is intended to support professionals to prevent and manage would be beneficial.Clear mention of how challenging behaviour can overlap with, and sometimes disguise, mental health issues in people with learning disabilities would also be helpful. Too often, mental health issues remain unaddressed when efforts are made to tackle challenging behaviour. This makes managing challenging behaviour itself more difficult, as well as having a significant negative impact on the quality of life of individuals with learning disabilities and challenging behaviour, as they struggle with unaddressed mental health needs. |
|  | College of Occupational Therapists  | General | Regarding quality of life measurement it is important to realise that to measure quality of life both subjective and objective measurements must be taken and including an individual’s life. These measurements need to be taken over the various domains of living (Shalock, Hughes etc) There are very few quality of life measures currently available that meet the needs of an individual with a learning disability. |
|  | College of Occupational Therapists  | General | ‘everyone enjoys physical safety and feels secure’ – this will be hard to measure and conceptualise as feeling secure is an abstract concept and will be difficult to measure. |
|  | Southern Health NHS Foundation Trust  | General | Regarding quality of life measurement it is important to realise that to measure Quality of life both subjective and objective measurements must be taken and including an individual’s perceptions. These measurements need to be taken over the various domains of QOL (Shalock, Hughes etc) There are very few QOL measures currently available that meet the needs of an individual with a learning Disability and these will not be applicable to all services (WHO QOL, MANS LD etc) |
|  | Southern Health NHS Foundation Trust  | General | ‘everyone enjoys physical safety and feels secure’ – this will be hard to measure and conceptualise as feeling ‘secure’ is an abstract concept and will be difficult to measure |
|  | The Challenging Behaviour Foundation  | General | On page 3, as well as relevant Department of Health outcome frameworks, the children’s health outcome framework should also be included. |
|  | NHS Protect | General | For inclusion in the Introduction – NHS Protect reports on incidents of physical assault which were / were not as a result of medical factors (including mental ill health and learning disability). Please consider including the latest Reported Physical Assault figures published by NHS Protect for 2013/14 to provide a further context to these guidelines: <http://www.nhsbsa.nhs.uk/Documents/SecurityManagement/Reported_Physical_Assaults_2013-14.pdf> |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | General | Under service user experience and safety issues it should say assessment, care planning and decision making is conducted with the person with learning disabilities, family member…P7 para 3 – It is noted that service user experience is not usually included in topic specific quality standards. This may be ok for services people not who do not have learning disabilities because there are effective service user surveys for them. However these don’t effectively cover people with learning disabilities. So this needs to be considered here. This is my reaction to what I understand to be the meaning of this part of the paragraph, but it is far from clear what the document is saying here |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | General | Under role of families and carers it should say – unless there are good reasons otherwise, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and follow up. |
|  | National Development Team for Inclusion  | General | Under service user experience and safety issues it should say assessment, care planning and decision making is conducted with the person with learning disabilities, family member… |
|  | National Development Team for Inclusion  | General | Under role of families and carers it should say – unless there are good reasons otherwise, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and |
|  | United Response  | General | Recommend changing “…a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability…” to “…a challenge to services, family members or carers, it serves a purpose for the person with a learning disability” in order to remove ambiguity and to strengthen the point. |
|  | United Response  | General | Recommend changing “This behaviour often results from the interaction…” to “…This behaviour results from the interaction” in order to remove ambiguity and to strengthen the point. |
|  | United Response  | General | Recommend changing “if appropriate, health and social care practitioners should ensure family…” to “Wherever possible, health and social care practitioners must ensure family…” in order to strengthen the statement and the role played by families. |
|  | Future Directions CIC  | Q1 | **Q: Do the standards accurately reflect the key areas for quality Improvement?** Yes they cover the ‘key areas’ and the following are generally comments:* When you are referring to care also write support as social care services don’t only care for people they support them to have a better life, to be more independent, ne healthier etc.
* There is no mention of MCA or DOLs.
* Q: Do the standards cover ASC as the standards statement do fit?
 |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q1 | We believe that most of the areas are included, however we were surprised not to see a separate quality standard about having a positive behaviour support plan.  |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q1 | We were surprised that apart from parent training there is not more emphasis on promotion and prevention of behaviour that challenges in the quality standards. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q1 | The successful implementation of this quality standard requires full integration of all aspects of health and social care, and this needs to be explicit. Often commissioners will not fund the required social care e.g. for the person to have sufficient support for day activities. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q1 | We believe that most of the areas are included, however we were surprised not to see a separate quality standard about having a positive behaviour support plan.  |
|  | Leonard Cheshire Disability  | Q1 | The guidance should be made more explicit that behaviour support plans, assessments etc. should seek to identify ways in which proactive rather than restrictive interventions can be used. E.g. people with challenging behaviours should be encouraged to communicate, rather than (for example) have their access to peers/support be restricted. |
|  | Leonard Cheshire Disability  | Q1 | The guidance does not capture the training needs of general NHS staff. When people with challenging behaviour enter hospitals and other medical settings, staff often have very little understanding of their needs. This, combined with the inherent anxiety of such settings, can result in an increase in challenging behaviour. Often care support staff find they have to travel with people with challenging behaviour to hospital to ensure that their needs are met – this represents a significant additional cost to care services at a time when budgets are extremely tight. |
|  | Leonard Cheshire Disability  | Q1 | The guidance currently fails to recognise the high importance of involving families in review and assessment processes. It also does not effectively establish that a range of appropriate interventions should be discussed and offered for people with challenging behaviour – it is not enough that a medical professionals preferred choice is imposed on people with learning disabilities with little or no choice. |
|  | Leonard Cheshire Disability  | Q1 | It is vital to spell out that effective management of challenging behaviours is a step towards independence for people with learning disabilities, and that where support is delivered effectively the need for care and support will usually decrease. Further, when delivered effectively, either the quantity or the severity of incidents of challenging behaviours should also reduce.In order to acknowledge these keys measures, it is our view that the quality statements should include clear reference to increased independence and reduced support (related to challenging behaviour) being the end goal for those supporting those with challenging behaviour. |
|  | British Institute of Learning Disabilities  | Q1 | Yes we think it covers important areas although it does not mention skills and competencies for staff and carers and professionals in PBS |
|  | Hftrust | Q1 | We welcome standards that safeguard people who have a learning disability and challenging behaviour.However; we also highlight the increasing number of initiatives resulting in guidance and standards for this group, including the recent Department of Health consultation; No Voice Unheard, No Right Ignored. It is paramount that individuals, their family carers and professional support services have unambiguous, joined up guidance and quality standards that are understood by all; irrespective of their background or profession. The drive for pooled budgets between health and social care necessitates an approach that brings together the unique cultures of both parties, therefore standard’s that cross health and social care settings are required..The standards identified start to develop a holistic approach when supporting individuals. We believe the following areas should be added.**Mental Capacity and Deprivation of Liberty**Whilst the standards refer to these the expectation of involvement, capacity assessment and where necessary best interest must be reflected as overarching principles. A simple link is not sufficient.Impact assessments: many interventions identified during assessment benefit from an impact assessment to ascertain if the intervention is in the best interest or least restrictive. **Standard 1 and Standard 10**Support must be provided to all family carers irrespective of the age of the individual. We welcome an expectation for families with very young children to receive early support. Often adults with challenging behaviour have experienced poor support during their formative years, including inadequate care planning and positive behavioural support. This results in an increase in the intensity and frequency of very challenging behaviour. Early intervention can minimise this. However, the availability of support to family carers, irrespective of their relative’s age, will ensure great support is provided and families understand how to respond. Within Hft we invite family members to participate in Positive Behaviour Support and management sessions; creating an environment where solutions are generated together and support is shared We believe standards must include the offer of support and training to family carers.The standards recognise the positive impact of good day activities, but do not highlight the need for individuals to have access to the **right living environment** that meets their unique needs. We know that environmental factors greatly influence a person’s probability to exhibit challenging behaviour. We also know that the over use of admission to assessment centres exacerbate behaviours, as individuals cope in incompatible groups. Any standards must include a quality statement that includes* Each person is supported to achieve an assessment of the most suitable environment for the person that reflects their unique needs.
* When living with family carers support and advice is given, including how to access grants to adapt/change accommodation to provide the right environment for the person, and so their family can provide the right support.
* When individuals want other forms of accommodation individuals are supported to identify this in the most appropriate setting for them.

**PRN medication**PRN medication is often not monitored as well as physical or mechanical interventions. Whilst the standards call for the continual assessment and review of antipsychotic medication, the use and effects of PRN medication can get missed.The use of PRN medication must be monitored for use and the effect it has on a situation. Often a placebo effect occurs as family carers/support and individuals relax immediately following administration; unless this is administered intravenously the effect on behaviour does not reflect the time lapse.PRN medication does not always carry the same expectation of least restriction for the least possible time than physical or mechanical restraint; even through the latter interventions may deliver the least restriction for a shorter time.Services and Consultants must have robust monitoring systems in place that include frequency including over time (to ascertain patterns) intensity of situation, the time from administration to effect and the consequences experienced by the person whilst the drug is still in their system..**Staff training:** linking up with other standards within this sector such as Skills for Care; NICE Quality standards should expect support to receive as a minimum; understanding **Positive Behavioural Support** and where necessary data driven **Positive Behavioural Management** instruction. |
|  | The Royal College of Psychiatrists | Q1 | The quality standard accurately reflects the key areas for quality improvement except there is no specific standard on transition planning into adult services for young people with challenging behaviours |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | Q1 | I agree about the importance of early intervention 0-5 – but this needs to form part of a life course approach for children/young people and adults who challenge and their family. This doesn’t come through in the quality standards. On a general note, the guidance seems to be very woolly about the wide range of situations involved. In some cases clinicians will be asked to review new cases of behaviour carers find difficult. In some of these a clear external cause will be findable, in others not. In some cases management in the short term will be all that is required, in others, longer term risks become apparent. In some cases active treatment programmes will be in place with a definable intended outcome. In many cases people will be currently receiving mainly drug treatments which they have been receiving for many years. No new referral will be being made because things are quite at present, however treatment is happening and needs to be reviewed. This type of continuing situation is likely to be common. A recent study (Glover et al, Learning Disabilities Observatory) Indicates that more than 12.7% of adults known to their GPs to have a learning disability are currently taking an antipsychotic in the absence of a psychosis. So the majority of cases teams are likely to come in contact with are not new referrals but existing treatment programmes. Standard should address managing both new episodes and a continuing care caseload distinctly as these are two very different types of problem. |
|  | SeeAbility | Q1 | It has long been known that people with learning disabilities are at increased risk of sight problems.[[2]](#footnote-2) A study funded by SeeAbility and RNIB gave, for the first time, an estimate of the number of people with learning disabilities and seeing difficulties in each of the four countries of the UK.[[3]](#footnote-3) These are the best estimates currently available in the UK:**Adults*** Adults with a learning disability are 10 times more likely to have a serious sight problem than other adults.
* 579,000 of adults with learning disabilities have refractive error. This means 6 out 10 people with learning disabilities need glasses.
* An estimated 96,500 adults with learning disabilities are blind or partially sighted. This is about 1 in 10 of the adult learning disabilities population.

**Children (age 0-19 years)*** Children with a learning disability are 28 times more likely to have a serious sight problem than other children.
* An estimated 191,600 children with learning disabilities have refractive error.
* An estimated 23,175 children with learning disabilities are blind or partially sighted.

It has been suggested that all persons with severe or profound intellectual disabilities, and all older adults with Down's syndrome, should be considered visually impaired until proved otherwise.[[4]](#footnote-4) More targeted clinical surveillance of adults with learning disabilities is endorsed by the Royal College of Ophthalmologists.[[5]](#footnote-5)People with the most profound and multiple learning disabilities may not realise they have a sight problem or be able to tell someone about it. Reporting of sight problems is often symptom led[[6]](#footnote-6) so this puts people with communication difficulties at major risk of not getting the eye care they need. People who know the person best may think they can see perfectly well and yet the person’s sight may be at major risk[[7]](#footnote-7), or there may be a belief that a person with profound disabilities could not complete a “typical” sight test. Awareness of the eye care needs of people with learning disabilities amongst staff in residential and day care services can be low, perpetuating problems in identification and management of sight problems in these environments.[[8]](#footnote-8) Some people can also miss out on eye care as it can be seen as a secondary need and not the main cause of disability. It does not mean that the person does not need to access sight-related services just because they may already be receiving care and support for other reasons. The result of these factors is that behaviour may be wrongly attributed to the diagnosis of a learning disability, rather than a sight problem. In our experience, for some people with learning disabilities, unrecognised or unnoticed sight loss and its impact can lead to challenging behaviour occurring or exacerbate challenging behaviour, with consequent danger to self and others. Studies have linked visual impairment to an increased risk of self-injurious behaviour.[[9]](#footnote-9),[[10]](#footnote-10) Acute changes in behaviour could in fact be attributable to sight threatening conditions.Late presentation of potentially blinding conditions is associated with poor prognosis. If there is poor access to eye care, subsequent visual impairment may compound pre-existing disability in some people with learning disabilities.[[11]](#footnote-11)In our experience of providing rehabilitation and support for people with sight loss and complex needs in the community, mental health professionals rarely seem to carry knowledge or insight of visual impairment and the impact of it on behaviour in their initial intervention thoughts. Yet if staff have insight and awareness in visual impairment, and its impact upon mental health and anxiety then they are more likely to be able to reduce the likelihood of behaviour occurring in the first place. In our experience when visual impairment is identified and addressed, there can be significant changes in behaviour/reduction in challenges.For these reasons we are very disappointed the draft quality standard contains no reference to vision. **See our next comments on two particular Standards where we believe vision and eye care should be highlighted.** |
|  | The British Psychological Society  | Q1 | The Society welcomes this quality standard and believes that it provides a broad framework for assuring that processes for positive assessment, personalised care planning and access to meaningful activities are in place. We do have some recommendations to improve the likelihood of the standard having these desired outcomes however, and these are outlined below. We note that the proposed quality standard statements focus on ‘inputs’ (e.g. whether an assessment has taken place) rather than the outcomes resulting from these. We have made some specific suggestions for the proposed quality statements in relation to this. Our opinion however, is that in general, quality statements reflecting outcomes and more detail as to the quality of the inputs are more likely to drive significant service change (e.g. Changes in quality of life and distress are measured and lead to positive change for an individual).  |
|  | Association for Real Change (ARC) | Q1 | We agree that the quality statement does accurately reflect the key areas for quality improvement. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | Q1 | Yes we feel it does reflect the key areas for quality improvement. |
|  | Rotherham Doncaster and South Humber NHS FT | Q1 | Yes |
|  | UK Society for Behaviour Analysis (UK-SBA) | Q1 | The UK-SBA recommends the inclusion of an additional statement or statements that specifically address the content of a Behaviour Support Plan. The existing quality statements do not ensure adherence to the guideline recommendation that a Behaviour Support Plan be derived from the functional assessment process (“*Develop a written behaviour support plan… …that is based on a shared understanding about the function of the behaviour*”; recommendation 1.6.1, and *“personalised interventions…..that are based on behavioural principles and a functional assessment of behavior;* recommendation 1.7.5*)* and there is no reference to the provision of skill building interventions that are related to the identified function of behaviour (*“develop alternative behaviour to achieve the function of the behaviour that challenges by developing a new skill*” (recommendation 1.6.1). Furthermore, none of the existing statements cover the requirement for measurement of implementation fidelity: “*supported by data that measure the accurate implementation of the plan”* (recommendation 1.6.1). |
|  | College of Occupational Therapists  | Q1 | The College of Occupational Therapists (COT) believes that the draft quality standard accurately reflects most of the key areas for quality improvement. We would suggest adding slightly more emphasis on good mental health. We would note that an area not included appears to be NHS commissioned residential care – such as commissioned under continuing health care arrangements (CHC). Should there be a statement about holding providers of such care to account for outcomes? |
|  | Oxfordshire County Council  | Q1 | We think it generally reflects the key areas for quality improvement, however it needs to link more closely to the principles and requirements of the special educational needs and disability (SEND) reforms. It should also be recognised and set out clearly that families and carers will need support and training to make these standards a reality. As covered below, an important element of this which is missing from the draft is positive behaviour support for parents and families.  |
|  | Southern Health NHS Foundation Trust  | Q1 | This draft quality standard reflects some of the key areas for improvement, however an area not included appears to be NHS commissioned residential care – such as commissioned services under continuing health care arrangements (CHC). Should there be a statement about holding providers of such care to account for outcomes? There is also no references to mental health within document – as this can be a cause of challenging behaviours perhaps this should be included even if this is only as part of the complex assessment. |
|  | The Challenging Behaviour Foundation  | Q1 | The key areas for quality improvement are: early intervention and prevention; practical accessible and timely support for families; co-ordinated support and approaches across education, health and social care – and across child and adult services; consistent standards of and access to local support and services in all areas; a positive behavioural support approach; a reduction in restrictive practices including the over use of medication; better access to mainstream health services to ensure health needs are met; access to local specialist input when required; co-ordination across systems and services with a consistent approach. But most of all there is a need to focus on support, services and systems delivering improved outcomes for individuals. |
|  | National Development Team for Inclusion  | Q1 | I agree about the importance of early intervention 0-5 – but this needs to form part of a life course approach for children/young people and adults who challenge and their family. This doesn’t come through in the quality standards. For statement one – I am unclear what this looks like. There is good evidence about what helps – see below. I think there is a need for it to be much more specific. There is nothing about the role of positive behaviour support (PBS) – this is very important and should be specified |
|  | Leonard Cheshire Disability  | Q1 | The guidance does not capture the training needs of general NHS staff. When people with challenging behaviour enter hospitals and other medical settings, staff often have very little understanding of their needs. This, combined with the inherent anxiety of such settings, can result in an increase in challenging behaviour. Often care support staff find they have to travel with people with challenging behaviour to hospital to ensure that their needs are met – this represents a significant additional cost to care services at a time when budgets are extremely tight. |
|  | Leonard Cheshire Disability  | Q1 | The guidance currently fails to recognise the high importance of involving families in review and assessment processes. It also does not effectively establish that a range of appropriate interventions should be discussed and offered for people with challenging behaviour – it is not enough that a medical professionals preferred choice is imposed on people with learning disabilities with little or no choice. |
|  | NHS Protect | Q1 | There is nothing specific in the guideline about the responsibility on all staff and organisations to report and record all incidents of violence and aggression through the incident reporting system, including those that involve medical factors. We *strongly recommend* that this responsibility to report incidents via the incident reporting system and onto their LSMS for investigation is included in the guideline. Reference to creating a positive reporting culture and governance arrangements within organisations to analyse reported incidents in order to minimise the risks of violence against staff would also be welcome.For consideration as a reference in the guideline, we recognise that most behaviours will be due to someone’s distress and unmet needs. Where however a crime is suspected, we recommend that this should be reported to the police for initial consideration and possible management of the person through the criminal justice system. This can have therapeutic benefits of ensuring that the individual can access more appropriate levels of treatment and care, delivered in a safe environment. |
|  | British Institute of Learning Disabilities  | Q2 | Yes if it was well enough resourced and made as easy as possible  |
|  | Hftrust | Q2 | Good support to people who can challenge is evidence based and data driven. Research has proven the importance of this approach, when working to decrease individuals challenging behaviour. Any quality standard must have this requirement at the heart of the document so that data collection is a natural part of the support process. The move to a shared approach for responsibility and funding between Health and Social Care for challenging behaviour services should include the use of **one** recoding system for that person. Achieving this would allow for data collection and reduction of risk of double entries. |
|  | Hftrust | Q2 | To support people well a comprehensive understanding of the person is required. The best outcome is using a comprehensive **functional behavioural assessment** that develops a robust **Positive Behavioural Support Plan**. The use of these resources to support an individual’s creates data. PBS plans must be data driven. Good support is already able to provide this data.Hft as leaders in using technology to enhance our support are already in the process of developing systems that allow for real time data collection. |
|  | The Royal College of Psychiatrists | Q2 | With the right system it should be possible to collect data for the proposed quality measures. Narratives may be required in some cases and this may be a barrier to data collecting using establish electronic systems. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | Q2 | Yes – with the appropriate systems and structures in place, it should be possible to collect information on the quality standards – but some need to be more specific – see above. The obvious mechanism for the collection of data is the mental health and learning disabilities minimum dataset (MHLDMDS). However this will need adjustment for new rating instruments so this will not be immediate. However this is a circular question. The bigger question is whether NHS England and the CQC would take effective sanctions when providers, particularly private sector providers do not supply mandated data (as currently they don’t supply HES or MHLDMDS data). It would also need an alliance of professional and managerial leadership to persuade clinicians to record regular structured assessments and clinical events. Collecting these responses through the MHLDMDS (the mental health and Learning Disabilities Dataset) should be fine, but only if people do the required ratings and record the findings in local clinical systems. The MHLDMDS should also be used to record episodes of restrictive interventions. These have been recorded regularly for the in-patient censuses. Failure to record these should be a major quality standards breach as it effectively prevents proper clinical audit of adverse events. |
|  | The British Psychological Society  | Q2 | The Society believes that local services would be able to develop systems to collect most of the data outlined. Where this data is held would, however, affect whether local commissioners, NHS and Social Services would be able to report on it. For example, if paid or family carers are responsible for the roles outlined in quality statements 4, 5 and 6, it is unlikely that robust data on this will be able to be reliably collected by local commissioners, NHS and Social Services. |
|  | Association for Real Change (ARC) | Q2 | We feel this would be possible but it would require a concentrated multi-disciplinary approach. We would want to know who the coordinators of such data would be? |
|  | Sheffield Health and Social Care NHS Foundation Trust  | Q2 | Yes but would need very clear governance frameworks both locally and nationally.Would be difficult to audit without this, also need to be able to evidence both quantitative and qualitative data |
|  | United Response  | Q2 | We would question the accuracy of some of the existing denominator data currently held by the NHS and local authorities on challenging behaviour and learning disabilities, and therefore its usefulness in developing the proposed quality measures. We believe that clear systems, definitions and criteria would need to be developed from which the data could be collected. |
|  | Rotherham Doncaster and South Humber NHS FT | Q2 | Yes |
|  | College of Occupational Therapists  | Q2 | COT would raise the point that the unreliable, unstandardized definition of ‘challenging behaviour’ will impact the validity of gathering data on people with LD and challenging behaviour – i.e. variability in how people are attributed the label of challenging behaviour between settings.There are also difficulties in gathering data such as satisfaction of service users and carers and quality of life in specific services for any comparison purpose as there may be low caseloads of people with highly complex behaviours and an additional low response rate to surveys regarding these issues.COT consider that is should be possible to collect this data if there was a commissioning requirement to record specific information related to the standard that could be feedback centrally. |
|  | Southern Health NHS Foundation Trust  | Q2 | There is an issue in the unreliable, unstandardized definition of ‘challenging behaviour’ which will impact the validity of gathering data on people with LD and challenging behaviour – i.e. variability in how people are attributed the label of challenging behaviour between settings.There is also an issue in gathering data such as satisfaction of service users and carers quality of life in specific services for any comparison purpose as there may be low caseloads of people with highly complex behaviours and an additional low response rate to surveys regarding these issues.I think it maybe possible to collect this data if there was a commissioning requirement to record specific information related to the standard that could be feedback centrally.  |
|  | The Challenging Behaviour Foundation  | Q2 | The quality measures need to be more outcome focussed. It is possible to collect data for outcome measures, but these may need to be specifically designed. It is possible to collect data for the standards as proposed (e.g. number of individuals who have a co-ordinator) but there is a risk that this is a paper exercise (e.g. you have a co-ordinator but that doesn’t deliver anything, because they don’t have the right skills, the capacity etc.) |
|  | National Development Team for Inclusion  | Q2 | Yes – with the appropriate systems and structures in place, it should be possible to collect information on the quality standards – but some need to be more specific – see above. |
|  | Future Directions CIC  | Q2 | **Q: If systems and structures were available, do you think it would be possible to collect date for the proposed quality measures? –** Yes data could be collected as part of the Local Authority contract monitoring processes. Providers currently do returns for other outcomes. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q2 | Yes we do believe that this would be possible, but as they are written as inputs not outcomes, they would not measure quality. However, there would be a resource implication in collecting the data. |
|  | The Royal College of General Practitioners  | Q2 | Such data has to be recorded at school as part of the learning plan. It would need the parents’ engagement to checking that they know where to record and what needs to be recorded, to manage it at home. (JA) |
|  | Future Directions CIC  | Q3 | **Q: For each quality statement what do you think could be done to support improvement and help overcome barriers?** Some brief thoughts: * **Staff training and development** - in PBS, RPs & Positive Risk Taking & an idiots guides to MCA and DOLs. Organisation need to support staff to help them understand and change practice. As part of the care certificate a new standard unit could be developed which could support future more in-depth training but would give people underpinning knowledge.
* **Organisational culture** – organisation need to be clear about their PBS and RP values which needs to be communicated & maintained across the whole organisation.
* **Leadership –** front-line leaders need time not only to manage (focusing on the tasks of the job) but also to lead and support staff. Leaderships training and development needs to reflect the changing horizon.
 |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q3 | For each quality statement there needs to be clear focus on the outcomes that need to be achieved, so that data can be compared across services. We believe that integration of health and social care commissioning and services together with workforce development are key issues. |
|  | The Royal College of General Practitioners  | Q3 | Barriers would have to be overcome between school and home; also between home and the LD unit. All these relationships can be confrontational. Through peer pressure and the school environment, challenging behaviour may be more straightforward to deal with at school. (JA)At present, parents struggle as educational psychological assessments at school and health assessments can take a considerable time to complete with lack of a co-ordinated response from the two services. A single point of assess would help. (MH) |
|  | British Institute of Learning Disabilities  | Q3 | 1 Better training for health visitors and early years workers to aid early intervention and identification. Early intervention could take place within mainstream nurseries.2 This needs clarity about who can do an assessment and at what level The barrier is there are not enough experts or specialists. There needs to be an easily accessible and available method of skills development in these areas for some direct contact workers core professionals who need to understand how to undertake a behaviour assessment. BILD are piloting some training for this and there is an online course developed by ABMU.3 Specialist GPs could visit people at home where necessary to carry this out or a specially trained LD nurse.4 A similar answer to question 2 we need to upskill people to do this but it needs to be an accessible and available training BILD are currently piloting this training.5 Professor Kathy Lowe and Dr Edwin Jones ABMU have very simple system designed to capture exactly this and can feed into outcomes measures on a bigger scale.6 There are questions about who oversees the review and what expertise to they need and the content of the review BILD are currently developing and piloting a standardised reviewing tool.7 See Leitch and Deveau 2014 research which documents the barriers after a study into the implementation of this process in children services. This needs to be a clear standardised simple process that is normalised into service culture but is flexible enough to for different service models it needs some guidance. We have developed a format for this at BILD.8 Same answer as above not enough expertise in health education or care need to upskill a level of staff to be able to develop and carry out psychosocial interventions .BILD have a suite of training programme designed to upskill this group.9 Sounds like a good idea enough resources would need to be available to carry this out.10 This should have some quality standards for this training it may be seems as a business opportunity for some commercial enterprises. |
|  | The Royal College of Psychiatrists | Q3 | * Acceptance of these standards nationally by community teams, hands on care providers and primary care services who need to work together to meet these standards
* Improved access to wider clinical team with an agreed multidisciplinary formulation
* Strengthen advocacy and provide support to people with challenging behaviour to agree treatment plans for preventing and managing behaviour
 |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | Q3 | For statement 1 – there is good information in Paving the way (see below) that could be used to support improvement.For statement 2 – the initial assessment should be based on PBS and there is no mention of Person Centred Planning (PCP)? Surely this should be at the heart of everythingPlaceholder statement seems to have the idea of challenging behaviour as an episodic phenomenon – something that appears and presumably also resolves. In other places, andStatement 3 – There is already plenty of information about what constitutes a good quality health check – but it isn’t always used. Some areas do audits of health checks to ensure they are comprehensive.Statement 4 – what about the link to the Care Programme Approach? There is no mention of this (which also requires a co-ordinator). Yes – a co-ordinator is very important – one who the person (and their family) knows and trusts. Statement 4 – It is important to clarify the relationship of the co-ordinator, with the senior clinical consultant (of whatever discipline) in charge of the persons care from their home community provider. These two roles are both essential and both are provider NOT commissioner roles. Statement 5 – yes – from their PCPStatement 6 – regular reviews are very important, but there needs to be a link with statement 7Statement 10 – see Paving the Way for information about what works. |
|  | The British Psychological Society  | Q3 | The Society has no comment to make on this question at present. |
|  | Association for Real Change (ARC) | Q3 | In order to support improvement it is essential that there is a coordinated approach to commissioning. Whilst the principles of the guidance have been stated as ensuring there are always people who know the person present in the assessment process the individual quality statements occasionally lose sight of this. It is important that people who know the individual, for example those who may be providing community based support, are kept in the loop if an individual is being treated in an NHS setting and visa versa. It is absolutely essential that both commissioners and regulators are active participants in the prevention and management of challenging behaviour in people with learning disabilities. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | Q3 | Q2 Would need an increase in resources for the availability of both professional support and increase in support networksQ3 Need a comprehensive health check and time to do this, not sure if the DES actually does what it should. Standardising is required.Q4 Q5 funding may need to be relooked at due to reductions in social care budgets.Q6 Time needs to be freed up to do this properly, also should be reviewed by someone other than the writer, to ensure it is a person centred comprehensive document.Q7 Need protocols that ensure it is reviewed by more people than just those involved in the incident.Q8 Education for care providers and families around medication, usage limits, clear understanding of prn is and that it can be used unfortunately as a restrictive intervention.Q9 Clear protocols between primary and secondary care, not endless repeat prescriptions without a review with the person being present.Q10  |
|  | United Response  | Q3 | We believe that there needs to be a wholesale requirement for Active Support to be implemented into services for people with learning disabilities, and support for families to implement it in the home setting. |
|  | Rotherham Doncaster and South Humber NHS FT | Q3 | Nationally recognised training in reducing restrictive interventions and psychosocial interventions. |
|  | College of Occupational Therapists  | Q3 | In relation to statement 6, it would be helpful to add mechanisms for reviewing into the quality standard, such as the Periodic Service Review (La Vigna et al, 1994).In relation to statements 8 and 9, it would be helpful to specify that reviews should be conducted within the auspices of the Care Programme Approach (CPA).Statement 3: There could be difficulties for GP’s in providing a comprehensive annual health assessment due to a lack of specialised knowledge on LD and relating co morbidities and risk. Input from specialised learning disability nurses would help to overcome this barrier. |
|  | Southern Health NHS Foundation Trust  | Q3 | In relation to statement 6, it would be helpful to add mechanisms for reviewing into the quality standard, such as the Periodic Service Review (La Vigna et al, 1994).In relation to statements 8 and 9, it would be helpful to specify that reviews should be conducted within the auspices of the Care Programme Approach.Statement 3: Difficulties with for GPs to complete a comprehensive annual health assessment due to a lack of specialised knowledge on LD and relating co morbidities and risk. Input from specialised learning disability nurses would help to overcome this barrier |
|  | The Challenging Behaviour Foundation  | Q3 | Our experience is that it is helpful to provide short, clear “how to” guidance – including signposting to specific resources that can help, or more detailed information if needed. A “what do I need to do…” type resource – not 50 page documents that no one has time to read! See adult commissioners resource as an example. |
|  | National Development Team for Inclusion  | Q3 | For statement 1 – there is good information in Paving the way (see below) that could be used to support improvement.For statement 2 – the initial assessment should be based on PBS and there is no mention of Person Centred Planning (PCP)? Surely this should be at the heart of everythingStatement 3 – There is already plenty of information about what constitutes a good quality health check – but it isn’t always used. Some areas do audits of health checks to ensure they are comprehensive.Statement 4 – what about the link to the Care Programme Approach? There is no mention of this (which also requires a co-ordinator). Yes – a co-ordinator is very important – one who the person (and their family) knows and trusts.Statement 5 – yes – from their PCPStatement 6 – regular reviews are very important, but there needs to be a link with statement 7Statement 10 – see Paving the Way for information about what works. |
|  | Future Directions CIC  | Q4 | **Q: What are the 6 most important quality improvement areas from the 10 statements? -** Provider services:1) **Behavioural Support Plans:** For all people using the service to have person centred or holistic behavioural support plans that are based on a Functional Analysis.2) **Health Support Plans:** For all people using the service to have a person centred health action and support plans to manage existing and/or prevent other health conditions developing, which are reviewed at least annual by a GP or skilled Health Nurse, 3) **Activities:** That people have something to do during the day / occupation / activities that are important to them / they enjoy.4) **Live Plans:** Support plans are live and change with the person to reflect current need and that they are reviewed with everyone who is important to and for the person.5) **Right Services:** Specifically commissioned and monitored services.6) **Training:** for support staff, manager and involved families in PBS, Restrictive Practices, Human Rights, DOLs and MCA, which are all a really important component. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | Q4 | Statements 1,2,5,7,8,9 |
|  | The Royal College of General Practitioners  | Q4 | The most important quality statements are 1, 2, 3, 7, 8, & 9. (JA) |
|  | British Institute of Learning Disabilities  | Q4 | All equally important 4 and 5 could be merged and so could 7 and 8 |
|  | Hftrust | Q4 | Hft welcomes the quality standards and believe that all hold their own merit. However we also call for a joined up approach and the merging of work being completed by various agencies including; NICE, BILD and the NHS consultation following Winterbourne View. Whilst all have differing starting points the end products will reach the same individuals and their support team. A call for co-operation when developing guidelines and processes will support rather than hinder the work achieved.In respect of this consultation we feel there is scope to merge some statements as the requirements and outcomes are related. **Statement 4 Designated co-ordinator.** We feel the importance of this role means it should come as one of the first standards Where this works well an individual, their family carers and if in place their paid support, is able to support the person to maintain their lifestyle, without the need for intervention, including removal from home. However; often the person allocated this role is not able to provide the support necessary or their position is transitory.**We believe that standard 2, 3 and 6 should merge****Statement 2** a comprehensive assessment of an individual must include a full health check for the person; thus **statement 3** should form part of the quality statement outlining what is meant by this approach. An assessment is only the start of an ongoing process, to separate this from the development of a **Positive Behaviour Support** plan (**statement 6**) and continuous **review**(**statement 6)** suggests the natural flow of this approach is missing. By creating a standard that calls for the whole process/cycle of support; consisting of assessment – plan – implementation- monitoring - data based review will demonstrate an approach that puts the person at the centre and provides opportunity for real change. **Statement 5**Providing meaningful, productive and personalised day activities is paramount when supporting an individual with behaviour that challenges. This must include suitable venues that allow for recovery and rest when required. Services should have competent team members who are able to identify the unique needs of each person and respond appropriately. **Statement 7 Review of restrictive practices**This statement is fundamental to ensure approach and practices are least restrictive and applied for the minimum time. Without the requirement for continual monitoring and review practices can continue beyond need, and restrictive interventions can become the first, rather than the last option. When this happens the potential for abusive situations to develop increases.A national register of restraint requiring the highest level of restrictive intervention to be recorded would enable regulators to maintain an overview, and use this intelligence when auditing service quality.**We believe standards 8 and 9 should merge** as they form a natural process of good diagnosis, prescription and review.The aspiration must be that antipsychotic medication is only prescribed for challenging behaviour in situations where the individual is presenting extreme danger to themselves and others (where this is not caused by a diagnosed mental health or syndrome specific condition).It must be the responsibility of the multi-disciplinary team to only support the use of antipsychotic medication when all other alternatives have been exhausted or as a short term solution to enable psychosocial interventions to embed. A culture should be encouraged where overuse is challenged, medication must not be an alternative to good support.Medication plans should include how any prescription of antipsychotic medication will be faded out of the person’s plan. As stated regular reviews must be held and include a record of why medication is continued. Antipsychotic medication prescribed for challenging behaviour should be subject to the same expectations as physical restraint; least restrictive and for the least time possible. By applying this expectation of ongoing monitoring and reporting a reduction in use should be evident.In addition more robust review and monitoring of the use of PRN medication is required; often the extent of use does not form part of the review; only its impact on the situation. Front line staff can correctly follow the criteria for administration, however; without good recording and analysis by the prescribing physician, individuals can find the dosage and or frequency increasing. |
|  | The Royal College of Psychiatrists | Q4 | 1,2,3,4,5 and 8. |
|  | The Royal College of Psychiatrists | Q4 | The designated coordinator sounds similar to the key worker that has been identified in other guidelines. In practice, this role is taken on by a variety of professionals – a teacher, community nurse, social worker or other members of CAMHS. However, it is not necessarily happening nor is there a comprehensive behaviour support plan being developed |
|  | The British Psychological Society  | Q4 | The Society believes that all the standards are important in driving quality improvement, and is unclear as to the rationale for a ‘top 6’, as different standards are likely to drive a greater degree of quality improvement for different groups. |
|  | Association for Real Change (ARC) | Q4 | We believe all the standards are of equal importance. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | Q4 | Questions 2,3,4,5,6,8But Q10 should be offered beyond 12 years. |
|  | United Response  | Q4 | 1,2,5,8,9,10 |
|  | Rotherham Doncaster and South Humber NHS FT | Q4 | Statements,1,2,3,7,9,10. |
|  | College of Occupational Therapists  | Q4 | COT considers that the most important standards are: Standard 2, 4, 5, 6, 7, 8 and 10. |
|  | Southern Health NHS Foundation Trust  | Q4 | Six most important areas from the 10 statements: (not in any order) 2, 3, 5, 6, 8, 10 |
|  | Future Directions CIC  | 1 | * **Specific to Statement 1:** Don’t work in the children’s field but what about schools they are also key. Do you need to reference the ‘child and families act’ and the greater co-operation of families, education and social care and how this will support this quality statement. Need to think about children born into families where their parents also have learning disabled / difficulties and how will be supported?
 |
|  | The Royal College of General Practitioners  | 1 | The statement is too restrictive and should state early support for behaviour that challenges within 4 weeks of identification (or some other measurable time). (JA) |
|  | The Royal College of Psychiatrists | 1 | Most of the evidence is around children with autism. New evidence-based guidance on early support and training for families would improve practice |
|  | The Huntercombe Group  | 1 | There is ample Applied Behaviour Analysis literature and guidance for 0-5 years, and the simplification of this into guidance for practitioners and families/ parents would be most helpful. |
|  | United Response  | 1 | We believe that a pro-active approach to early intervention is vital; not only to proactively reduce the number of people who present behaviour which is challenging but also in the proactive planning of local support and services for children and adults. Evidence based guidance for 0 to 5 years support and training for families is required to improve practice in this area. |
|  | Avenues Group  | 1 | We would agree with the standard that early intervention is vital, with a detailed assessment of the function of behaviours and appropriate support strategies developed. This needs to include a crisis management plan but that should not be the starting point. Everyone involved in the child’s life should be included in the assessment and the training and support that is provided to implement an intervention. Ongoing support and review should be provided as well. |
|  | College of Occupational Therapists  | 1 | COT considers that early intervention is very important but is not clear why the statement specifies 0-5 years and would suggest that is should be considered at any stage that challenging behaviour or the potential for challenging behaviour is first noted. |
|  | Oxfordshire County Council  | 1 | It is not clear which definition of learning disability is being used. For example, assessment of under-fives looks at delay in cognitive development whereas adult assessment looks at degree of functional ability. As the standards cover provision for all age groups, definition must also apply across all ages.  |
|  | Southern Health NHS Foundation Trust  | 1 | Such early years evidence and guidance may be unlikely to impact with current service structures where the only involvement from Health services for children with diagnosed LD and behaviour concerns at 0-5 years may be from Paediatricians who may not be in a position to apply detailed strategies from evidence if they also have to focus on a general paediatric caseload. |
|  | Mencap | 1 | Yes, we believe evidence-based guidance relating to early support and training for families and those who support children with learning disabilities would have the potential to improve practice. |
|  | Hftrust | 1 | **Statement 1**Need to define the role and responsibilities of a placeholder. This role must possess authority to call people to account in all sectors or it will not have impact. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 1 | We believe that there must be evidence from Portage programmes – which are PBS based – e.g. building skills and preventing behaviours. Also is there evidence from Sure Start programmes.  |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 1 | We fully endorse the view that early support and training, but the main issue is funding for early years support. Commissioning should be for ageless service. |
|  | The Royal College of General Practitioners  | 1 | Good resources (besides NICE) are Contact a Family cafamily.org.uk who have a section on Challenging behaviour written by Prof J Turk (last updated 2014) and MindEd, wwwminded.org.uk. The Challenging Behaviour Foundation is recommended on the CaF website although I have no personal knowledge of this. (JA) |
|  | British Institute of Learning Disabilities  | 1 | Don’t know and Yes if the large research base from PBS and PBIS is used to inform it. |
|  | The Royal College of Psychiatrists | 1 | Where ASD contributes to the challenging behaviour, there is evidence-based guidance in the NICE Guidelines on the management and support of children and young people on the autism spectrum (NCG170). There is similar guidance in Attention Deficit Hyperactivity Disorder (NCG72). There is also the guidance in the Briefing Paper on this issue, produced by the Challenging Behaviour foundation in November 2014 |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 1 | For statement one – I am unclear what this looks like. There is good evidence about what helps – see below. I think there is a need for it to be much more specific. There is nothing about the role of positive behaviour support (PBS) – this is very important and should be specified.Evidence based guidance –The learning disabilities public health observatory will shortly be publishing a review of the evidence of the determinants of health inequalities experienced by children with learning disabilitiesThere is also Paving the Way, a resource from the Early Intervention project: <http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/paving-the-way.html> |
|  | The British Psychological Society  | 1 | The Society would welcome new evidence-based guidance relating to early support and training for families and those who support children with learning disabilities; in particular, guidance similar to that which we understand the Department of Health is currently updating on the support of children who engage in challenging behaviours (DH, 2014, p.12, paragraph 6), which focuses on reducing restrictive interventions through psychologically informed assessment and intervention, would be beneficial.  |
|  | Association for Real Change (ARC) | 1 | The majority of our members do not support children so we do not have a view on this question. |
|  | United Response  | 1 | We are not aware of any evidence-based guidance that could be used to develop this statement. |
|  | The Challenging Behaviour Foundation  | 1 | Early years (0-5) support is important. There is no reason children with learning disabilities should be excluded. Consider the Allen reviews of Early Intervention, which make the clear case for intervention in the early years. Would new evidence based guidance improve practice? – Yes. Currently the families who contact the CBF struggle to access information and support – they do not know what to ask for, what would help or where to go for help. In addition, there is wide variation in areas about what is available. Families can clearly articulate what would be helpful see <http://www.challengingbehaviour.org.uk/learning-disability-files/A-Vision-for-our-children.pdf> Existing mechanisms could be used to collect data about intervention with under 5s. For all children accessing free early education, the record of their developmental milestones according to the Early Years Foundation Stage can be used to identify any children with developmental delays not identified at birth. Health Visitor checks and Child Development Centres can also be used. |
|  | National Development Team for Inclusion  |  | Evidence based guidance –The learning disabilities public health observatory will shortly be publishing a review of the evidence of the determinants of health inequalities experienced by children with learning disabilitiesThere is also Paving the Way, a resource from the Early Intervention project: <http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/paving-the-way.html> |
|  | Future Directions CIC  | 1 | Not aware of anything. |
|  | Future Directions CIC  | 2 | * **Statement 2 Initial Assessment:** Other comment: from personal experience I think it’s really important that as part of the initial assessment a communication assessment is also undertaken. As you point out in the consultation many severely and/or profound learning disabled people have communication needs and this communication is not just about expressive communication it is also about comprehension / understanding of language. Maybe included or reference The ‘Five Good Communication Standards:’ developed by the Royal College of S&LTs:

Standard 1: There is a detailed description of how best to communicate with individuals. Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services. Standard 3: Staff value and use competently the best approaches to communication with each individual they support. Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate. Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing |
|  | Avenues Group  | 2 | The assessment needs to be more encompassing – what function does the behaviour serve for the individual, are there any sensory issues, what are the outcomes from the behaviour, are there any health issues that are causing the behaviour. The person undertaking the assessment should be trained in functional assessment and positive behaviour support (PBS). |
|  | UK Society for Behaviour Analysis (UK-SBA) | 2 | The UK-SBA welcomes the inclusion of a quality statement on the assessment of the environmental and personal variables that occasion and maintain behaviour that challenges. In its current form, however, Statement 2 does not adequately capture the recommendations of the guidelines. The word “trigger” is potentially misleading; it suggests that the emphasis of assessment should be directed towards events that immediately precede the behaviour of concern. The guidelines explicitly and repeatedly recommend the use of a functional assessment: “*Carry out a functional assessment identifying and evaluating any factors that may provoke or maintain the behaviour”* (recommendation 1.5.8, see also recommendations 1.5.9-1.5.11). Undertaking a functional assessment necessitates the analysis of events that follow, as well as precede, behaviour of concern, in addition to other factors. To this end, we strongly recommend that the term Functional Assessment be incorporated into Statement 2.We also recommend removing the word “initial” from Statement 2. In accordance with the guidelines, assessment should incorporate measures that are ongoing (“*repeated measurements in order to evaluate change*”; recommendation 1.5.10), and, thus sensitive to changes in behaviour over time “*assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change* ”; recommendation1.5). In light of our comments above, and in order to better reflect the essential components of the guidance, we therefore propose the following revision to quality Statement 2: “***People with learning disabilities and behaviour that challenges have a functional assessment to identify the factors that occasion and maintain the behaviour.”***Later in the section on Statement 2, a summary of the features of assessment is presented as follows: “*People who have learning disabilities have an assessment as soon as there are signs of behaviour that challenges. The assessment includes the following: a description of the behavior; how often it occurs and for how long; how it affects the person; what events or situations make the behaviour happen. This helps to identify what may be causing the behaviour and any changes that might stop or reduce the behaviour*.” It is not clear on what basis the recommendations on functional assessment detailed in guidelines (1.5.9- 1.5.11) have been reduced to these summary statements. Many critical elements of the process have been omitted (see the section above). We recommend that the section entitled ‘Functional Assessment’ (recommendation 1.5.9), or some variant of, be reproduced in full here.  |
|  | College of Occupational Therapists  | 2 | This is very important but COT would suggest that clarification is required as to when a comprehensive MDT assessment occurs as the standards do not make this clear. We would then assume that the MDT assessment would inform the behaviour support plan.COT would suggest that is would be useful to give some indication about what the ‘signs of behaviour that challenges’ might be. |
|  | Oxfordshire County Council  | 2 | We support this.  |
|  | Southern Health NHS Foundation Trust  | 2 | This is very important but I wonder when a comprehensive MDT assessment happens as the standards do not say. I guess this would inform the behaviour support plan.It would be useful to give some indication about what the ‘signs of behaviour that challenges’ might beIn the MDT initial assessment description it did not mention the value of involving the service user and identifying where their behaviours are affecting their quality of life. |
|  | The Challenging Behaviour Foundation  | 2 | Initial assessment of behaviour that challenges to identify triggers – this must be carried out by a suitably qualified person and must result in a support plan that is implemented. Identifying the triggers without any practical suggestions about how to deal with them is no use!There must be on-going assessment and review. Situations and triggers change over time so an initial assessment is not sufficient. People with complex needs may require more in-depth behaviour assessments with several elements, for example a sensory assessment by a specialist Occupational Therapist. The CBF’s experience is that people who display challenging behaviour may have repeated assessments that are not based on enough collected and observed data, or are not analysed by an experienced or specialist professional, so the results are reports and plans that only skim the surface of their needs.Commissioners need to commission services that can conduct more in-depth assessments. |
|  | Mencap | 2 | It would be helpful for this to cover initial assessment and further assessment. These are both referred to in the guidance including the need for those carrying out the assessments to have the necessary skills and competencies. It should be clear that assessment must result in a behaviour support plan, and this must be implemented. It should be clear that behaviour should be considered in context by a multi-disciplinary team. |
|  | Leonard Cheshire Disability  | 2 | This quality statement does not capture that for some people with learning disabilities, challenging behaviour is one of a limited number of ways in which they can effectively communicate. As such, it misses the opportunity to implement effective communication strategies which can reduce incidences of challenging behaviour by supporting communication in other ways.In order to address this, the statement should include a specific requirement to undertaken an assessment of the communication needs of people with challenging behaviours. Only by understanding the communication needs that people with challenging behaviours have can their behaviour be understood, and effectively managed. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 2 | Quality statement 2 is about new episodes of behavioural problems. Denominator should be reflect this – i.e. newly referred episodes of people presenting with behavioural problems. Numerator should be the proportion of these where a satisfactory assessment is completed. It is currently ambiguous. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 2 | P13 – The assessment list is very incomplete, though this is probably not the place for a detailed setting out of the elements of a review. However the most obviously missing perspectives are communication style and capability of the person, when the problem behaviour started, and its relation to the ways the person communicates distress, anxiety, annoyance, pain, fear and boredom. |
|  | SeeAbility | 2 | For the reasons highlighted in the previous section, there is danger that teams who assess the physical health or mental health of individuals who present challenging behaviour will not have expertise on vision and visual assessment, and can overlook the importance of visual problems which may trigger or exacerbate behaviour which challenges. **This statement must encourage the recognition that the possible trigger for challenging behaviour could be a change in what the person can see and a deterioration or disturbance in vision.** As Statement 3 advocates for a comprehensive annual assessment of the person’s health, it would be our contention that an assessment of any underlying health reasons should be specified as part of the initial assessment, with prompts to consider the need to assess for any change in sight or eye health. Otherwise it would appear that the initial assessment would rely on what the individual or those that know them best report – rather than prompts for those undertaking the initial assessment of the triggers to be aware of and potentially sight or life threatening conditions.At SeeAbility we have a range of tools freely available to professionals to help functionally assess vision see: <https://www.seeability.org/sharing-knowledge/?book=functional-vision-assessment> The Standard should be clear that there should not be a protracted approach to assessment for challenging behaviour. For example the initial assessment needs to consider the timescale within which the change of behaviour has occurred, whether this has happened gradually over time or has been a sudden change. The assessment might be the first time underlying health reasons and possible sight/life threatening conditions are considered. In the case of vision, urgent conditions such as corneal ulcers, retinal detachment or acute glaucoma need prompt treatment. If by the time these conditions are considered the situation may be too far advanced for there to be successful treatment.  |
|  | The British Psychological Society  | 2 | The NICE clinical guideline states that initial assessment should lead to a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour, which should be used to develop the behaviour support plan (p.26, section 1.5.6). The Society believes that such formulation is a key part of psychological assessment and intervention (e.g. Royal College of Psychiatry, British Psychological Society & Royal College of Speech and Language Therapy, 2007; British Psychological Society, 2004) and as such that reference to a written statement (formulation) should be included in this quality standard. For example, the quality statement (p.12) could read (addition in italics): **“People with learning disabilities and behaviour that challenges have an initial assessment to identify possible triggers for the behaviour *that leads to a written statement (formulation)*”.** In the definition of terms for the quality statement, under initial assessment (p.13), we think this should include an additional bullet point such as:* The initial assessment should lead to a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour, which should be used to develop the behaviour support plan
 |
|  | The British Psychological Society  | 2 | Initial assessment includes risk assessment, which can play a key role in the decision as to whether further assessment of the behaviour that challenges is indicated. We believe that risk assessment should be included in the definition of initial assessment outlined on pp.13-14 of the draft quality standard.  |
|  | The Huntercombe Group  | 2 | 1. THG agrees with the importance of responding to challenging behaviour in an early and timely manner to reduce the ‘entrenchment’ of such behaviours. The description of the initial assessment is helpful, but seems to be incomplete as it does not mention maintaining factors such as reinforcing consequences for challenging behaviours.
2. It is felt that there should be an emphasis on the importance of a language assessment of both comprehension and expressive skills when using a behavioural management approach. The proposal mentions interpreters but not the role of Speech and Language Therapy (SLT). It is hoped that there can be a mention of it within the document as it features highly in the recently published Prevention and Intervention guidelines.
 |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 2 | The word trigger can be misleading and people often concentrate on immediate (fast) triggers and pay less attention to background (slow) triggers. We feel it would be better to say;Understand factors that contribute to – rather than identify possible triggersNeed to emphasise that we are trying to understand the person – not just the behaviour. To focus on behaviour is to lose the person.A holistic assessment is required. Regarding measures – structures need to be in place. Measurement needs to reflect quality of action but needs to remain person centred. Need to ensure full battery of assessments including risk assessment is included. |
|  | United Response  | 2 | We are concerned that the use of the term “triggers” in this statement will mislead people into only thinking about triggers and not the longer-term factors that make challenging behaviour more likely. A focus on triggers - to the detriment of longer-term factors - is already a substantial and chronic problem in services for people with challenging behaviour in our experience. Such a focus on triggers increases the risk of support for challenging behaviour only being reactive, and therefore ineffective, over the longer term. The rationale and source guidance for this statement refer to “factors”, i.e. not just triggers. We therefore recommend replacing the words “triggers for” with “factors associated with” throughout pages 12-14 in relation to quality statement 2. |
|  | United Response  | 2 | In line with our previous comment and following the same rationale, we recommend that the wording of the fourth bullet point be amended from “what events or situations make the behaviour happen” to “what factors make the behaviour likely to happen”. |
|  | United Response  | 2 | In line with our previous comments around the use of the term “triggers” we recommend that in the second and third bullet points the word be replaced by the word “developing”. This word is used in the source guidance and we believe it to be a more appropriate term. |
|  | Hftrust | 2 | **Statement 2**The Care Act sets out the rights of individuals to an assessment and if necessary provides the support required. This Act should be used to ensure individuals and family carers receive their entitlement.An assessment must take account of all needs. Where this includes challenging behaviour then a functional behavioural assessment should be a natural part of the process.Professionals need to identify the most suitable person to carry out an assessment; this would necessitate better co-operation between health and social care services. There is evidence of where this happens the outcomes for people are better. |
|  | The Huntercombe Group  | 3 | The importance of physical health check-ups, at least annually, is agreed as an important element of care and avoidance of challenging behaviours due to pain and discomfort. For those with more severe intellectual disabilities and greater communication difficulties, an annual check may be insufficient, and check-ups six monthly or when unexplained increases in challenging behaviour occur may be more appropriate. One of our clinicians had worked with a person with a severe intellectual disability and autism whose undiagnosed kidney stones were subsequently recognised as a significant factor in his severe challenging behaviour.We suspect the measure for this quality statement may suffer from definitional difficulties around challenging behaviour, and that a clear definition of challenging behaviour may be difficult. Operationalising this as “the number referred to a secondary or tertiary service for challenging behaviour” may be helpful. |
|  | The Royal College of Psychiatrists | 3 | Although this will vary with locality, the child in special education may be better served by the community child health service which will often have a closer, more continuous and longer contact than the local GP. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 3 | Currently annual health assessment is basic, not comprehensive. Head to Toe type detailed assessment leading to follow on referrals to other agencies is good practice and leads to development of a Health Action Plan and hospital passport.Need to build on link between health issues and behaviours that challenge within services and primary care.Number of health assessments completed is measurable.Link to quality statement 4 designated coordinator could coordinate annual health check with full MDT. |
|  | Royal College of Paediatrics and Child Health  | 3 | Although GP annual health checks are valuable, these are not universally available and, from anecdotal feedback, are not carried out uniformly or always to a sufficiently high standard. |
|  | SeeAbility | 3 | **We believe that this Standard must include a recommendation that the person has a sight test, for the reasons and evidence outlined in below.** Every adult should be accessing a sight test every two years and for some people this may need to be more often. For children this should be every year or more often if clinically justified. The NHS contract for sight testing allows for domiciliary sight testing in residential care settings, so this could be made available to people who would find it difficult or challenging to attend a high street optician, or alternatively examinations can take place in hospital eye clinics. However it will be vital that eye care professionals have the training and understanding on how to undertake a suitable sight test for a person who may not communicate verbally or presents challenges. SeeAbility has a range of tools, materials and training for professionals in assisting people with a learning disability prepare and have a sight test on its website [www.seeability.org](http://www.seeability.org). Regular sight tests will provide a baseline assessment by which it will be possible to monitor vision and detect any possible changes which may alter a person’s behaviour. Specifically in answer to Question 6, the NICE standard should not assume that a comprehensive annual health assessment will cover sight. Page 15 states that “annual health checks are likely to lead to identification and management of underlying physical health problems at an early stage”. We disagree. GPs do not undertake sight tests nor comprehensive eye examinations, and can merely encourage the individual to book a sight test after asking some questions about their vision or making observations. Nor is it the case that a GP would necessarily recognise the importance of a sight test as part of the annual health check. A study of the scheme to provide annual health checks has found many people were not being told about sight tests.[[12]](#footnote-12) In response to Question 7, it is suggested that the annual health assessment is comprehensively commissioned and available to all, and so the statement only needs to target those under 14 who are not covered by the current Direct Enhanced Scheme. However, research has found only 6 out of 10 surgeries take part in the scheme[[13]](#footnote-13), and 40% of patients with learning disabilities still do not receive a health check. Even where health checks are given, individuals also report these can be of poor quality or very short.[[14]](#footnote-14) Therefore while annual health checks have been shown to pick up on more health issues in surgeries that are part of the scheme, they do not capture all people with learning disabilities, nor are they comprehensive. Any eye care actions recommended in the annual health checks can, in our experience, also fall down because, unlike many other annual health check outcomes, they do not generate a hospital referral which is more likely to be followed up. For these reasons we believe it is important that the Quality Standard separately and distinctly includes the need for the individual to have their sight checked and eyes examined by an optometrist so any underlying issues can be identified and any necessary referrals made. |
|  | Future Directions CIC  | 3 | We provided services in Manchester, Stockport, Oldham, Rochdale, Trafford, Warrington, Halton and East Lancashire – all of the people we support in these areas have a Health Action Plan (& Health Support Plans) which are formally reviewed at least once every 6 months. Current health needs and prevention are included within plans but GPs refuse to sign them off. Annual health checks by GPs are monitored and still requested by our Future Directions, they are still not triggered by GP practices. Re a ‘comprehensive annual health assessments’ as there is no standard the checks differ from GP to GP & some GPs still refuse to do them, primarily due to cost. I know that a pilot study was undertaken in the Trafford where some GPs were financial incentivised to undertake health checks.The GM s contract states*: ‘………..enhanced service (ES) is designed to encourage practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check, which will include producing a health action plan*. The NICE Standards need to be stronger and not use words like ‘encourage.’ |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 3 | This depends if the GP practice is signed up to do annual health checks. If GP hasn’t then they won’t happen. |
|  | The Royal College of General Practitioners  | 3 | The Community Paediatrician often does this at the moment, although the services seem overloaded and some families are slipping through the net, or being dealt with by a “LD team” (nurse or HCA led) which does not seem adequate. The GP actions any letters or plans from the MDT and may initiate the review of seeing the child with problems such as behavioural difficulties. (JA) |
|  | Oxfordshire County Council  | 3   | We support this. We know that take-up of annual health checks for people remains patchy across the country with different denominator groups being identified. We know that GPs are not obliged to provide annual health checks and that standards of what is considered and annual health check vary greatly within CCG areas. There is therefore a clear need to ensure that GPs are signed up to deliver this standard. The annual health check tends to focus on physical care needs so there will need to be considerable training rolled out to GP practices. The standard also needs to reflect that health assessments for children can be completed by different people, for example school nurses as well as GPs. This creates potential for duplication or assessments being missed, which needs to be addressed.  |
|  | College of Occupational Therapists  | 3 | COT would suggest that the annual health check should lead to a health action plan which should have specific SMART actions with named people responsible for carrying them out.Part (a) under process suggested data collection of people with LD and ‘behaviour that challenges’ – but does not specify how this will be defined to ensure discriminant validity – for example; ‘those in receipt of care funded via Health for reasons of challenging behaviour’.The definition given for a ‘comprehensive health assessment’ includes ‘review of any known or emerging behaviour’ and ‘other types of treatment (for example psychological therapy)’. COT suggests that it is not correct to assume that GPs have the skill, training or time to conduct a detailed and sufficient review of all these elements. COT strongly recommends that other LD skilled expert staff have a role within this health assessment such as Registered LD Nurses and other professions including Clinical Psychologists specialising in LD.Review of medications should include any known side effects and should involve easy read information about the health action planCOT recommends that discussions with family and carers should always be with the service user’s permission.  |
|  | Southern Health NHS Foundation Trust  | 3 | Part (a) under process suggested data collection of people with LD and ‘behaviour that challenges’ – but does not specify how this will be defined to ensure discriminant validity – for example; ‘those in receipt of care funded via Health for reasons of challenging behaviour’.The definition given for a ‘comprehensive health assessment’ includes ‘review of any known or emerging behaviour’ and ‘other types of treatment (for example psychological therapy)’. I believe it is not correct to assume that GPs have the skill, training or time to conduct a detailed and sufficient review of all these elements. It must be specified that other LD skilled expert staff have a role within this health assessment such as Registered LD Nurses and other professions including Clinical Psychologists specialising in LD. |
|  | Leonard Cheshire Disability  | 3 | This quality statement should be expanded to make explicit reference to effectively managing the mental health needs of people with challenging behaviour. Too often in current service provision, the mental health needs of people with challenging behaviour remain unaddressed. |
|  | Avenues Group  | 3 | The comprehensive health assessment is very important and needs to be coupled with the behaviour assessment and analysis. The assessment should include whether there are any mental health issues that need addressing. There is an issue with GPs undertaking these assessments as there is often limited knowledge of people with learning disabilities and low expectations of people’s capabilities, particularly when people present challenging behaviour. In our experience annual health checks are not happening/available routinely for people with learning disabilities. Mental capacity issues need to be considered - best interest processes will need to be followed in order to undertake some tests (e.g. blood tests) where people are unable to consent.As a starting point, measuring the number of people who have had an annual health assessment would be valuable, longer term it would be good to link this to data on the health of people with learning disabilities. |
|  | Mencap | 3 | It is important people have an annual comprehensive health check. The quality standard states that this should include an ‘agreed and shared care plan for managing any physical health problems (including pain)’. This plan should focus on managing current and potential health issues – for example, it may necessary to start a programme about de-sensitising someone with a learning disability and behaviour that challenges to needles. It is important this plan includes what communication and behaviour support the person may need to access healthcare (eg. if going into hospital – reasonable adjustments that might be needed). It would be helpful to refer explicitly to Health Action Plans and health (hospital) passports. The quality stand should include a focus on ensuring this plan around managing health is implemented and kept up to date and there is an ongoing focus on identifying and managing physical health problems, not just a yearly health check.People with a learning disability are at risk of diagnostic overshadowing – where changes in communication or behaviour are attributed to their learning disability and as a consequence underlying health issues are not identified and treated – so it is crucial there is a focus on identifying and managing physical health needs. |
|  | British Institute of Learning Disabilities  | 3 | Don’t know |
|  | Hftrust | 3 | Hft provide support to individuals across England. Our experience of health support is patchy and reliant on the GP’s understanding and commitment to people with a learning disability.As stated earlier individuals require more time to build relationships and trust the medical practitioner. The changes to GP practice and pressures on primary health care means this important element of support is difficult to maintain. Some GPS and the Medical Practice they are attached to maintain great relationships and go the extra mile to get achieve assessments for people.However as indicated in Death by Indifference health outcomes for people who have a learning disability is poor; add to this challenging behaviour and difficulties increase.Hft is working with each person to develop a Health Equality Plan and signed up to the Health Charter. The consultation period does not allow for collection of data that would inform this question. However we would be willing to do so if asked. |
|  | The Royal College of Psychiatrists | 3 | This varies across the country and dependent on degree of cooperation from person with intellectual disability with physical examination and investigation but also how much primary care makes adjustments to meet needs of those with challenging behaviours |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 3 | Approximately half of people with learning disabilities eligible for an annual health check have one. It isn’t possible to tell if people with learning disabilities who challenge are proportionately represented in this group. There are also issues with the quality of health checks in some areas – they may be far from comprehensive. People with learning disabilities who challenge may get less comprehensive checks due to the difficulties in carrying these out.It is important not to overstate the likely effect of this. These are at best annual. Their effect should preventive rather than remedial – and then only where appropriate health action plans are produced and implemented. The fact that a person has had their annual health check does not remove the need for appropriate physical investigations to look for possible new health problems as a cause of new behavioural issues. I would say that checks are ‘intended to lead to identification …..’ as opposed to ‘likely’ to lead to this.  |
|  | The British Psychological Society  | 3 | Information on the uptake of learning disability health checks in general is provided by Public Health England (e.g. Public Health England, 2014). Key issues that remain in relation to people who engage in behaviours that challenge include: Encouraging all GPs to complete them; getting consistency on what a health check covers; and ensuring the behaviour that challenges does not restrict the comprehensiveness of the check whenever possible (i.e. additional reasonable adjustments may need to be made). |
|  | Association for Real Change (ARC) | 3 | Our experience is that people supported by our members are in the main receiving a comprehensive annual health assessment. We are concerned that such checks are unlikely to cover long-standing hospital prescribed antipsychotic medication and this can mean that such medications are not reviewed as they should be. The importance of the input of community based support needs to be reflected in this standard. |
|  | United Response  | 3 | Our experience is that annual health checks are routinely taking place for a majority of people we support, but not for everybody. Guidance should clarify which health and social care practitioner is responsible for ensuring that these checks are carried out. |
|  | College of Occupational Therapists  | 3 | As NICE will be aware, Public Health England data illustrates that 44.2% of adults with LD accessed an annual GP health check on average across the country (2013-2014). The proportion of adults with LD and challenging behaviour who have an annual GP health check will be markedly lower than this proportion due to issues in accessing these people by GPs to conduct their assessments and also a failure to ensure that physical health needs are recognised and not attributed only to behaviour issues. For example in Portsmouth the annual health check occurs for all service users known to the team and the DES helps achieve this |
|  | Southern Health NHS Foundation Trust  | 3 | As you will be aware, Public Health England data illustrates that 44.2% of adults with LD accessed an annual GP health check on average across the country (2013-2014). The proportion of adults with LD and challenging behaviour who have an annual GP health check will be markedly lower than this proportion due to issues in accessing these people by GPs to conduct their assessments and also a failure to ensure that physical health needs are recognised and not attributed only to behaviour issues. |
|  | The Challenging Behaviour Foundation  | 3 | Health assessments vary in quality and availability. Again, an assessment should result in good health outcomes for the person – e.g. a health action plan that is implemented and the health benefits that result are recorded. Our experience is that often challenging behaviour develops due to an unmet physical health need (e.g. self injury due to pain from an ear infection, or toothache). Diagnostic overshadowing is well documented (e.g. <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>) People with learning disabilities who are admitted to in patient settings due to their behaviour often have unmet health needs even whilst in hospital e.g. <https://www.mencap.org.uk/sites/default/files/documents/Out%20of%20sight_report_0.pdf> Further to an assessment, an agreed and shared care plan for managing physical health is needed. It should include communication and behaviour support that the person may need to access health care, as well as management of current and potential health issues. |
|  | National Development Team for Inclusion  | 3 | Approximately half of people with learning disabilities eligible for an annual health check have one. It isn’t possible to tell if people with learning disabilities who challenge are proportionately represented in this group. There are also issues with the quality of health checks in some areas – they may be far from comprehensive. People with learning disabilities who challenge may get less comprehensive checks due to the difficulties in carrying these out. |
|  | Southern Health NHS Foundation Trust  | 3 | As you will be aware, Public Health England data illustrates that 44.2% of adults with LD accessed an annual GP health check on average across the country (2013-2014). The proportion of adults with LD and challenging behaviour who have an annual GP health check will be markedly lower than this proportion due to issues in accessing these people by GPs to conduct their assessments and also a failure to ensure that physical health needs are recognised and not attributed only to behaviour issues. |
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|  | National Development Team for Inclusion  | 3 | Approximately half of people with learning disabilities eligible for an annual health check have one. It isn’t possible to tell if people with learning disabilities who challenge are proportionately represented in this group. There are also issues with the quality of health checks in some areas – they may be far from comprehensive. People with learning disabilities who challenge may get less comprehensive checks due to the difficulties in carrying these out. |
|  | Southern Health NHS Foundation Trust  | 3 | As you will be aware, Public Health England data illustrates that 44.2% of adults with LD accessed an annual GP health check on average across the country (2013-2014). The proportion of adults with LD and challenging behaviour who have an annual GP health check will be markedly lower than this proportion due to issues in accessing these people by GPs to conduct their assessments and also a failure to ensure that physical health needs are recognised and not attributed only to behaviour issues. |
|  | The Challenging Behaviour Foundation  | 3 | Health assessments vary in quality and availability. Again, an assessment should result in good health outcomes for the person – e.g. a health action plan that is implemented and the health benefits that result are recorded. Our experience is that often challenging behaviour develops due to an unmet physical health need (e.g. self injury due to pain from an ear infection, or toothache). Diagnostic overshadowing is well documented (e.g. <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>) People with learning disabilities who are admitted to in patient settings due to their behaviour often have unmet health needs even whilst in hospital e.g. <https://www.mencap.org.uk/sites/default/files/documents/Out%20of%20sight_report_0.pdf> Further to an assessment, an agreed and shared care plan for managing physical health is needed. It should include communication and behaviour support that the person may need to access health care, as well as management of current and potential health issues. |
|  | British Institute of Learning Disabilities  | 3 | Don’t know |
|  | Future Directions CIC  | 3 | No the Standard should cover 0 to death. |
|  | Surrey and Borders Partnership NHS Foundation Trust  |  | No this should not be targeted just at under 14’s – because there are still lots of adults without them. It also depends on the quality of health needs assessment and who does it. |
|  | The Royal College of General Practitioners  | 3 | Should be under 18s or under 16s as the adult review is not QoF until after this. This would also cover difficult transitions. (JA) |
|  | Hftrust | 3 | **Please see answer to Question 6.**We do not believe people with a learning disability and challenging behaviour are receiving the comprehensive assessment they require, therefore this should be a right for every person irrespective of their age. |
|  | The Royal College of Psychiatrists | 3 | It should be kept focused at adults with Intellectual disability with additional targeted screening at those aged under 14 |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 3 | No – because of the above. Why should its commissioning mechanism be relevant to whether it is good practice? |
|  | The British Psychological Society  | 3 | The Society does not believes that this statement should be targeted just at under 14s, as many people with a learning disability still do not get the Direct Enhanced Service (e.g. Public Health England, 2014). It would, however, be helpful to have an explicit statement saying that the annual health assessment in the quality statement would not be in addition to, or replace, the DES, so as to avoid the potential for confusion. |
|  | Association for Real Change (ARC) | 3 | We do not have a view on this question. |
|  | United Response  | 3 | We believe annual health checks should be provided for all people with learning disabilities who present behaviour described as challenging, including under 14’s. |
|  | College of Occupational Therapists  | 3 | COT feels that it is useful to leave it in for all service users. It also emphasises the need to maintain a focus on this and highlights this important aspect of assessment of challenging behaviour.COT would recommend that statement 3 should not only be targeted at under 14s, but should include those aged over 14 as GPs have difficulty in providing annual health checks to all people with LD and challenging behaviour regardless of age. |
|  | Southern Health NHS Foundation Trust  | 3 | This statement (statement 3) should not only be targeted at under 14s, but should include those aged over 14 as GPs are not good currently at providing annual health checks to all people with LD and challenging behaviour regardless of age. It will also help to emphasise the importance of this assessment as part of the Challenging behaviour assessment |
|  | The Challenging Behaviour Foundation  | 3 | Despite the DES, there are many adults with a learning disability who do not have an annual health check ([https://www.improvinghealthandlives.org.uk/securefiles/150625\_1945//Joint%20Health%20and%20Social%20Care%20Self%20Assessment%20%28Numbers%29.pdf](https://www.improvinghealthandlives.org.uk/securefiles/150625_1945/Joint%20Health%20and%20Social%20Care%20Self%20Assessment%20%28Numbers%29.pdf)) |
|  | National Development Team for Inclusion  | 3 | No – because of the above. |
|  | Hftrust | 3 | **Statement 3** Again individuals have a right to good health care which includes the correct diagnosis of any health needs. Supporting people with a learning disability and challenging behaviour requires a GP, and the Medical Practice team, to understand the person’s communication, including taking time to build a trusting relationship. This needs to happen before a comprehensive assessment can be completed. Ten minute appointments do not allow for this; for some people several visits over several days is required. In the past the longevity of GP’s tenure, and the practice of seeing the same person each visit supported good relationships. This practice is declining; appointments are booked on the same day with whoever is available. There is good practice around and this should be examined with recommendations for all GP Practices developed. We would suggest these would create NICE standards in their own right.The use of technology should be encouraged to enable people to achieve ongoing monitoring of chronic or enduring conditions. The use of media such as Skype can support good communication reducing anxiety when attending Practices. |
|  | The Huntercombe Group  | 4 | 1. While we agree with the intention to have a “designated coordinator” for each person with an intellectual disability and challenging behaviour, our experience is that this is often very difficult, especially at the boundaries of services- when for example there is a transition due to a young person becoming an adult (though recent transition requirements under the new Care Act are noted), when the person has a dual diagnosis, for example intellectual disability and a mental health issue. We think the mechanisms for ensuring this thorny issue is resolved need to be spelled out clearly and measured for effectiveness.
2. Continuity in Professional involvement is key to continuing best practice; ensuring an effective transition for the client; and the development of the guidelines.
 |
|  | Avenues Group  | 4 | In principle the idea of a designated co-ordinator is a good one; some thought needs to be given to how this can be achieved in practice. Ideally the co-ordinator needs to be a PBS specialist – for people receiving health and social care services, some providers have people who undertake this role but others don’t so it would need to be an external professional. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 4 | Would need to be a person who is familiar to the service user and family.Would affect clinical caseloads – high percentage of people would require coordinating Low number currently coordinated under the Care Programme Approach. Would need more people including families trained in positive behaviour support – this isn’t a negative thing but has financial implications. |
|  | Royal College of Paediatrics and Child Health  | 4 | Quite rightly, this consultation asks who will be the dedicated co-ordinator. Experience of families known to the BACD suggests that there often is no co-ordinator, and so it’s uncertain who will perform this role, given resource restrictions in LD (and other) services. Perhaps each patient’s multi-disciplinary team should be required to identify a co-ordinator (so different professionals may undertake this role for different individuals but a challenge will be to find the time to undertake this role properly). |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 4 | Sometimes - depends on the service and service provider. |
|  | The Royal College of General Practitioners  | 4 | As mentioned in 1 challenging behaviour often seems to result in parents being in confrontation with school or the LD team where inadequate. It is not working in some cases. (JA) |
|  | College of Occupational Therapists  | 4 | COT recommends that the standard should make clear if all service users will have a behaviour support plan and also clarify if it is the co-ordinator’s role to ensure this is carried out. If so, is any special training required for the co-ordinator and should this be specified?COT recommends that it would be useful to specify which staff should be involved in writing the behaviour plan and for what purpose e.g. occupational therapy for activity and sensory assessment, speech therapy for communication assessment etc.It would be useful to highlight here that the plan should be based on comprehensive MDT assessment.It is suggested that the plan should state when restrictive practices should be used It is recommended that the plan should state how the service user was involved in developing the support plan and how they have been supported to be involved in management of their own condition. This might include the use of tools such as a wellness recovery action plan.The section starting ‘People with learning disability and behaviour that challenges’ states that service users ‘have one person…’ The College would raise the point that this could be unrealistic given sickness and staff turnover rates among staff in NHS or LA agencies responsible for coordinating the care of this client group. Different ways of working should be considered to establish the same outcome.COT is unconvinced that in practice the presence of such a role would ‘reduce need for transition between services’. It is vital to meet the holistic needs of people with learning disability and there is a marketplace of care providers meaning there are many diverse services involved over the any period of a person’s life (when they have LD and challenging behaviour) and many service changes. It may be more practical to emphasise the importance of communication and integrated working as a way to achieve a better outcome for this service user group.Under heading ‘Behaviour Support Plan’, there is a bullet point stating ‘incorporate risk management and take into account the effect of the behaviour support plan on the level of risk’. The College’s recommends that this bullet point should also refer to the need to specify ‘positive risk-taking’ in particular areas in order to achieve the aims of the behaviour support plan. |
|  | Southern Health NHS Foundation Trust  | 4 | I disagree that the presence of such a role would ‘reduce need for transition between services’. It is vital to meet the holistic needs of people with learning disability and there is a marketplace of care providers meaning there are many diverse services involved over the any period of a person’s life (when they have LD and challenging behaviour) and lots of service changes.It would be useful to specify who should be involved in writing the behaviour plan e.g. Occupational Therapy for sensory assessment and assessment of activity, Speech therapy for communication assessment etc...It would be useful to highlight here that the plan should be based on comprehensive MDT assessmentIt should state when restrictive practices should be used It should state how the person was involved in developing the support plan and how they have been supported to be involved in management of their own condition. This might include the use of tools such as wellness recovery action plan |
|  | Southern Health NHS Foundation Trust  | 4 | The section starting ‘People with learning disability and behaviour that challenges’ states ‘have one person…’ I believe this is unrealistic given sickness and staff turnover rates among staff in NHS or LA agencies responsible for coordinating the care of this client group. Rather than identify the co-ordinator by profession perhaps it is more appropriate to identify who has the appropriate skills base and availability to complete workWill everyone have a behaviour support plan and is it the co-ordinators role to ensure this is done? If so, is any special training required for the co-ordinator? |
|  | Future Directions CIC  | 4 | **Provider Services:** Not a specific role but within our services our local managers, as part of their role are responsible for overseeing what is identified within the Standard; with some limited support in some areas where we provide support from local Health & Social Care Practitioners. In many supported living services they have ‘key worker’ roles which could possibly, with some training take on this role.**Health & Social Care Providers:** CCG support services have been significantly reduced during the past 4 years and we have seen many of the supporting services necessary to oversee this standard i.e. challenging behaviour outreach / support teams, Psychologist’s, Behavioural Nurses, S&LTs, OTs reduced to zero in some cases. Equally, within the LA Social Workers / Care Managers who would have overseen support & care plans have been significantly reduced or their workloads increased which has means that they no longer have time to ensure detailed reviews unless there is something not right. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 4 | This could be a range of people either in health or social care. Should include service providers/care manager. |
|  | The Royal College of General Practitioners  | 4 | The co-ordinator seems to be a parenting adviser (lay) who has insufficient medical knowledge, or inadequately by the LD team who do not always engage well with parents. (JA) |
|  | The British Psychological Society  | 4 | The Society believes that it is important to be clear in the quality statement that the Designated Coordinator would not necessarily be the responsibility of local NHS or Social Services. Although it may be appropriate for members of the local specialist learning disability team to be the coordinator for people they are working with, it would not be possible, without a very significant increase in resources available, for members of local specialist learning disability teams to be the Designated Coordinator for every person with a Behaviour Support Plan in their locality.  |
|  | Oxfordshire County Council  | 4 | This care co-ordinator role is consistent with the Care Programme Approach (CPA) co-ordinator role. We would suggest that CPA is the best way to ensure joined up, multi-disciplinary and multi-agency working. People whose behaviour challenges should meet the criteria for CPA, which would mean that the best co-ordinator is the person who knows the service user best. We think the same principle should be applied here and CPA should be able to deliver the requirements in this standard, as there may be a danger of setting-up separate systems. We also suggest that the care coordinator function should apply holistically across all life areas, not just behaviour support.  |
|  | Southern Health NHS Foundation Trust  | 4 | Under heading ‘Behaviour Support Plan’, there is a bullet point stating ‘incorporate risk management and take into account the effect of the behaviour support plan on the level of risk’. I believe this bullet point should also refer to the need to specify ‘positive risk-taking’ in particular areas in order to achieve the aims of the behaviour support plan. |
|  | Mencap | 4 | It is important that the designated coordinator responsible for the person’s behaviour support plan is suitably skilled. The quality standard must include a focus on not just having a designator but on co-ordination actually happening.  |
|  | The Challenging Behaviour Foundation  | 4 | It is not clear. The question also appears to assume that everyone has a behaviour support plan and this is not the case.Co-ordination of the range of support and services that should be available is a recurrent issue that families identify as an issue. <http://www.challengingbehaviour.org.uk/learning-disability-files/A-Vision-for-our-children.pdf> The quality standard needs to capture that simply assigning a person called a co-ordinator is not enough- they need to deliver some co-ordination! There needs to be a measure of the outcomes for the person as a result of having a co-ordinator. For children, this role could be a key worker and the quality standard needs to be linked to the SEND work and co-ordination of the Education Health and Care Plan.The behaviour support plan must be implemented! |
|  | National Development Team for Inclusion  | 4 | This would vary according to the individual circumstances. It should be someone the person and their family knows and trusts. It might be the social worker or a community nurse – but could be another practitioner |
|  | UK Society for Behaviour Analysis (UK-SBA) | 4 | The document does state that there is scope for recommendations regarding competencies that “exceed standard professional training” (p.8) during quality standard development. Developing and implementing evidence-based behavioural interventions, and conducting the functional assessments from which they are derived, requires a highly specialized set of skills and experience. Behaviour Analysts, in particular those credentialed by the Behaviour Analyst Certification Board (see www.BACB.com), are trained in the competencies necessary to perform this role. Indeed, the guidelines do explicitly reference “behavioural (sic) analysts” (recommendation 1.1.5). |
|  | British Institute of Learning Disabilities  | 4 | Not consistently or with any regard to people’s skill base in a lot of care health and education settings |
|  | Hftrust | 4 | Where individuals are referred to local teams for an assessment a named coordinator is allocated. As stated earlier it is paramount that a person is identified not a role. The person must know the individual, be motivated to support, able to access resources and committed to complete the process. |
|  | The Royal College of Psychiatrists | 4 | This happens where organisations have a CPA process that covers people with behaviour that challenge. So not universal |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 4 | No. An important issue here is the relationship of the behavioural support coordinator to the consultant in charge of the person’s care. The wider context of the presence of a consultant level clinician (of whatever clinical discipline) from the local service to which the person relates taking an active role in overseeing the care is critical here. Without this, the wider care management plan within which a behavioural support programme is a component is likely to drift. |
|  | The British Psychological Society  | 4 | The Society believes that it is not always clear who the designated coordinator for a behaviour support plan is at present.  |
|  | Association for Real Change (ARC) | 4 | Our experience is that there is inconsistency in whether a designated coordinator is identified across multidisciplinary teams. |
|  | United Response  | 4 | In our experience, a key person to co-ordinate and update the behaviour support plan is generally agreed at service level (often the individual’s key worker) but not at professional level. However, we are unsure whether this practice is being followed more widely. It is also important to note that the service level co-ordinator does not have the authority to ensure continuity of care in other service settings or influence transition arrangements. |
|  | College of Occupational Therapists  | 4 | From information from respondents to the consultation COT would suggest that this is variable between services. There are examples of service without designated co-ordinators and if this role is allocated to a community nurse the CPA process for people who are exhibit challenging behaviour is used. Another service report that there is currently a designated coordinator within the service, but this changes when agencies close cases (e.g. NHS teams) so there is no coherence over time. |
|  | Southern Health NHS Foundation Trust  | 4 | Yes there is currently a designated coordinator within our service, but this will change when agencies close cases (e.g. NHS teams) so there is no coherence over time. |
|  | The Challenging Behaviour Foundation  | 4 | Designated co-ordinator: in our experience, no this is not currently happening. |
|  | National Development Team for Inclusion  | 4 | No |
|  | Hftrust | 4 | **Statement 4**This is fundamental to good support.It is important not to identify a set role such as Nurse or Care Manager; the key person that is best placed to co-ordinate will differ for each person as their unique needs require a range of solutions. Often this will be someone who is working to minimise the need that impacts most; such as Autism or physical health problems. This person must be committed to the individual, champion on their behalf and importantly be able to invest in the long term. We believe this should be for a minimum of two years (whilst accepting life events can change this). Far too often we find ourselves introducing co-ordinators or other key roles who are planning to leave within the next three months.The person must be able to influence the support received including fundersThis person should be able to hold any role within the circle of support and as far as possible be chosen by the individual requiring support.  |
|  | British Institute of Learning Disabilities  | 4 | Someone who know the person whose plan it is and has the skills and knowledge to support the planning |
|  | Hftrust | 4 | It is important not to identify a set role such as Nurse or Care Manager; the key person that is best placed to co-ordinate will differ for each person, as their unique needs require a range of solutions. Often this will be someone who is working to minimise the need that impacts most; such as Autism or physical health problems. This person must be committed to the individual, champion on their behalf and importantly be able to invest in the long term. We believe this should be for a minimum of two years (whilst accepting life events can change this). Far too often we find ourselves introducing co-ordinators or other key roles who are planning to leave within the next three months.The person must be able to influence the support received including fundersThis person should be able to hold any role within the circle of support and as far as possible be chosen by the individual requiring support. |
|  | The Royal College of Psychiatrists | 4 | The designated care coordinator should be determined by the team during the multidisciplinary initial assessment and ongoing reviews This should be the individual who is likely to have the longest contact with the individual so that s/he is a link for the individual and the family and is able to deploy other members of the team as appropriate. The coordinator has to focus on coordination and not on direct care provision |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 4 | This would vary according to the individual circumstances. It should be someone the person and their family knows and trusts. It might be the social worker or a community nurse – but could be another practitioner |
|  | The British Psychological Society  | 4 | Please see our earlier comment on this quality statement. We believe that the coordinator could be someone from local community learning disability services if they are actively working with the person, and at vulnerable times (e.g. transition, periods of crisis). Otherwise, however, this role would need to be taken on by others in the person’s support network (e.g. keyworker in a staff team).  |
|  | Association for Real Change (ARC) | 4 | We feel that the designated coordinator should be the primary commissioner of the individuals support. For example if an individual is primarily supported in the community this should be a named social worker. |
|  | United Response  | 4 | We believe that the designated co-ordinator must be someone who is suitably qualified and experienced and who is chosen by the person with learning disabilities and/or family where possible. Given the current funding situation, it is difficult to see how someone working for statutory authorities could carry out such a role in a meaningful way. We would therefore recommend that it be made a requirement for service providers in adult services, and education and health for children, to appoint such a person. |
|  | College of Occupational Therapists  | 4 | COT believes that this is not straightforward as very few professionals will retain involvement over any length of time beyond a few months. Families retain the longest involvement in many cases. In terms of a professional coordinator, the commissioning agent retains longer involvement (i.e. NHS commissioner or LA care manager) however they will usually have exorbitantly high caseloads (e.g. 200+ people allocated to one professional) which prohibit them having a detailed understanding of the person’s needs. A community nurse or social worker could do this however this would be dependent on caseloads. Perhaps matching with those with an appropriate skilled professional rather than a professional group in particular would be a better way of working. |
|  | Southern Health NHS Foundation Trust  | 4 | This is not straightforward as very few professionals will retain involvement over any length of time beyond a few months. Families retain the longest involvement in many cases. In terms of a professional coordinator, the commissioning agent retains longer involvement (i.e. NHS commissioner or LA care manager) however they will usually have exorbitantly high caseloads (e.g. 200+ people allocated to one professional) which prohibit them having a detailed understanding of the person’s needs. |
|  | Oxfordshire County Council  | 4 | We support this.  |
|  | Leonard Cheshire Disability  | 5 | We are very pleased to see this guidance recommend a designated coordinator for creating support plans for people with challenging behaviour. It is our view that this will dramatically improve quality in this area of work. |
|  | Leonard Cheshire Disability  | 5 | This quality statement would benefit from more details and examples of what might be included in the support plan, to provide additional support to those service providers who need it. |
|  | The Royal College of Psychiatrists | 5 | Personalised daily activities: it would help if these were specified as being ‘meaningful’ in order to try to minimise the listing of routine activities that had little significance for that particular person with LD |
|  | The Huntercombe Group  | 5 | This statement seems to confuse a behaviour support plan and the provision of personally relevant daily activities. While someone with intellectual disability and challenging behaviour would no doubt usually benefit from both a behaviour support plan (as in a PBS plan), and a meaningful daily activity schedule (as in Active Support), on some occasions just the behaviour support plan would be needed, and occasionally only the /Active Support plan would be needed. Measures for this statement need to reflect only the provision of daily activities not necessarily behaviour support plans. Likewise, the definition of Behaviour Support Plan would seem to fit better in the following section, and this section would be clarified by a definition of a Personalised Daily Activity Schedule. |
|  | Avenues Group  | 5 | There should be an emphasis on person centred active support (PCAS) as it is closely aligned to positive behaviour support; it focuses on quality of life and there is much evidence to demonstrate that focussing on both PCAS and PBS reduces levels and frequency of challenging behaviour.Success measures need to focus more on outcomes – are levels of challenging behaviour reducing or is the severity of the challenging behaviour reducing; this shows how effective the behaviour support plan is. |
|  | United Response  | 5 | We recommend that this quality statement is reworded to state the use of the practice and principles of Active Support as a recognised approach to ensuring that activities and occupation are meaningful. We would also recommend that the word “documented” is changed to “referred to” because the approach to activity needs to be comprehensive, which would make documenting it in the behaviour support plan unrealistic, and would increase the risk of meaningful activities being seen as “one-off” events – an approach which will have limited impact on engagement levels and challenging behaviour.Taking into account the above, we would suggest that quality statement 5 is reworded to read as follows:“People with learning disabilities and behaviour that challenges have personalised daily activities that will increase their levels of engagement, planned in line with the principles and practice of Active Support, and referred to in their behaviour support plan.”We also recommend that a definition of the terms engagement and active support be included in the definitions listed on p.24 |
|  | College of Occupational Therapists  | 5 | COT would suggest that systems should also be in place to review activitiesThe section on beginning Data source: Local data collection (b) states that data be collected on proportion of people with daily activities ‘planned and documented’. COT would suggest that this appears to be insufficient as it cannot be assumed that what is written down actually takes place for the individual.COT recommends that plans should set out not only how the behaviour will be supported but also how the activity will be supported and how carers will know the person is engaged and finding the activity meaningful.COT would suggest that it would be helpful to specify how the activities will be supported using a framework such as person centred active support. |
|  | United Response  | 5 | In line with previous comment on statement 5, we recommend that the rationale be reworded as follows:“People with learning disabilities and behaviour that challenges often have limited opportunity to engage in meaningful occupation or activity, or may take part in activities that are not meaningful to them. Very high rates of behaviour that challenges have been reported in institutions that typically offer relatively limited opportunities to be involved in everyday activities. Ensuring that people with learning disabilities have planned personalised daily activities should reduce rates of behaviour that challenges. Active support is an effective approach that delivers increased levels of engagement, and enhanced quality of life.” |
|  | Southern Health NHS Foundation Trust  | 5 | The section on beginning Data source: Local data collection (b) states that data be collected on proportion of people with daily activities ‘planned and documented’. This appears to be insufficient as it cannot be assumed that what is written down actually takes place for the individual. There is also no suggested minimum limit for time spent in daily activities. Plans should set out not only how the behaviour will be supported but also how the activity will be supported and how carers will know the person is engaged and finding the activity meaningful. |
|  | The Challenging Behaviour Foundation  | 5 | Activities written in plans do not necessarily mean that the activities take place! There needs to be a measure of whether the person does the activities. It is common for planned activities not to take place due, for example, to staff shortages.For children link to the EHCP process and educational reviews. |
|  | Mencap | 5 | The quality statement and measures must go beyond ensuring activities are planned and documented in their behaviour support plan. They must ensure that activities happen and deliver outcomes for individuals. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 5 | Requires better monitoring day to day and reviews that include the individual their support staff and clinical staff. |
|  | Hftrust | 5 | **Statement 5**Day activities require regulation to ensure that they provide quality support.There is a need to recognise that people who have a range of complex needs and exhibit challenging behaviour require safe spaces for recuperation and safety alongside accessing community resources.  |
|  | United Response  | 6 | We are concerned that this statement may not be achievable for all, particularly reviews that would involve a range of professionals. It may be necessary to prioritise reviewing certain plans this frequently, such as those which include the use of restrictive interventions and/or deprivation of liberty. |
|  | SeeAbility | 6 | Whilst we support the concept of fortnightly reviews of the person’s support plan, with an emphasis on providers to co-ordinate this, it presents a resource challenge, particularly when the healthcare professionals aren’t engaged. Our experience suggests this is a limited resource. |
|  | The British Psychological Society  | 6 | We believe that it is important to be clear in the quality statement that reviewing Behaviour Support Plans on an ongoing monthly basis would not be the responsibility of local NHS or Social Services. Although NHS services may be responsible for the initial reviews it would not be possible, without a very significant increase in resources available, for local specialist learning disability teams to review every Behaviour Support Plan in a locality every month on an ongoing basis.  |
|  | Oxfordshire County Council  | 6 | Although we support this idea, we consider that this may not be appropriate in all cases as it depends on severity level. It is also not clear who would do the reviewing, which could be very resource intensive and costly.  |
|  | The British Psychological Society  | 6 | The Society believes that the quality statement focussing on the quality of a behaviour support plan rather than whether it has been reviewed is not a desirable outcome. We recognise however, that the content of question 10 of this consultation suggests that NICE are already exploring this possibility.  |
|  | College of Occupational Therapists  | 6 | This section is very repetitive. It may be more useful to state how the review will be carried out and what it will involve.This section states that review should ensure behaviour support plans ‘remain current and are adjusted as treatment, behaviours and the person’s preferences change’. This process can only be effective as long as these plans are reviewed objectively and without bias by any reviewer. COT would point out that there are several potential sources of bias exist in this regard, that should be considered; * A care provider may seek to disguise a problem
* The person’s preferences may effectively be ignored or unheard due to communication issues
* Information may not be made available or may be falsified
* There may be an agenda to increase or decrease costs

There may be influence of expectations held by others about the opportunities for a person with LD – this may include the relatives of an adult. Practitioners should be aware of this. |
|  | Southern Health NHS Foundation Trust  | 6 | This section states that review should ensure behaviour support plans ‘remain current and are adjusted as treatment, behaviours and the person’s preferences change’. This process can only be effective as long as these plans are reviewed objectively and without bias by any reviewer. Several potential sources of bias exist in this regard; * A care provider may seek to disguise a problem
* The person’s preferences may effectively be ignored or unheard due to communication issues
* Information may not be made available or may be falsified
* There may be an agenda to increase or decrease costs

There may be influence of expectations held by other about the opportunities for a person with LD – this may include the relatives of an adult. |
|  | The Huntercombe Group  | 6 | We are not sure that regular review of Behaviour Support Plans is as important as constant measuring of the outcome, that is, the challenging behaviour of concern, and/or possibly the more appropriate behaviour being taught or encouraged to replace it. This would allow constant monitoring of progress and requiring formal review when progress falters or reverses. Fixed time periods for reviews across all categories of challenging behaviour and al populations seem arbitrary and unlikely to lead to improvements in practice. Certainly ensuring the means of assessing the progress of behaviour plans is in the hands of the individual, their family or staff, and allowing faltering or decline in effectiveness of such programmes to trigger an automatic formal review would be desirable. |
|  | The Challenging Behaviour Foundation  | 6 | Simply reviewing it is not enough- what are the outcomes of the review? Are any revisions made and implemented? |
|  | Mencap | 6 and 7 | It is not enough to just record that a review has taken place. Reviews must look at purpose of an intervention or treatment and the desired outcomes for individuals and where outcomes are not being met/ poor outcomes, then changes made. We know that too often this isn’t happening, for example, people continuing to be given high levels of medication despite no evidence it is having a positive effect.  |
|  | Hftrust | 6 | **Statement 6**Continual monitoring and reassessment of a positive behavioural support plan, positive behavioural management plan and other guidelines are important to ensure that interventions are having the best effect. However, any standard needs to recognise resource constraints and not set people up to fail. Often teams will collect months or even years of monitoring where people have not returned to review as they have left or picked up another referral.We would suggest that continual monitoring is expected and regular reviews take place at a minimum of four weekly for the first six months. Guidance should state that this can be achieved in the best way possible for the team such as use of media rather than travelling.The agreement for one set of recording amongst all professionals will enable better inputs and greater motivation to achieve. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 6 | Qualitative measures could include – asking the service user if they feel their Positive Behaviour Support plan is working.Quantifying behavioural occurrences within review of PBS plan to check quality. |
|  | UK Society for Behaviour Analysis (UK-SBA) | 6 | To ensure that Statement 6 encourages adherence to the guidelines, we recommend that clarification is provided on what constitutes a ‘review’. In particular, we recommend that a review of a Behaviour Support Plan involves an evaluation process that is reliable, objective, and relatively continuous in nature (“*repeated measurements in order to evaluate change*”; recommendation 1.5.10, and *“monitored using the continuous collection of objective outcome data*”; recommendation 1.6.1), involves both indirect *and* direct measurement of the behaviour in context (“*measurements including direct observations*”; recommendation 1.5.10), and is directly used to adapt intervention strategies (“*Use this to develop a behaviour support plan*”; recommendation 1.6.1). The figures cited in the Statement 6 (i.e., “every other week for the first two months and then every other month”) seem to be entirely arbitrary and not derived from clinical need. |
|  | British Institute of Learning Disabilities  | 6 | Yes the guidance in the back of Ensuring Quality services can be used as a checklist also there are a number of research tool which can be used BILD are developing a user friendly tool which could also be used for reviewing. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 6 | PBS format we are using has quality checking methodology incorporated based on La Vigna PSR. |
|  | Hftrust | 6 | The BILD outline of a PBS plan provides a good overview of contents.Behavioural plans differ for every person; as they should to reflect the persons unique needs and communication style. However the key elements of primary secondary and reactive strategies should have data driven evidence to allow for monitoring and assessment of the plans success. |
|  | The Royal College of Psychiatrists | 6 | The Faculty has developed and evidence outcome framework specifically for the population with learning disability which could be used for people with challenging behaviour. The full report can be found at <http://www.rcpsych.ac.uk/pdf/FRID07.pdf> |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 6 | See PBS literature |
|  | The British Psychological Society  | 6 | Abertawe Bro Morgannwg University Health Board have produced a tool for reviewing Positive Behaviour Support Plans as part of their suite of e-learning qualifications in Positive Behaviour Support. |
|  | Association for Real Change (ARC) | 6 | We feel that tools and methods for assessing the behaviour support plan should be developed through CQC. We would however want to highlight the training in Positive Behaviour Support offered by BILD. <http://www.bild.org.uk/our-services/positive-behaviour-support/> |
|  | Avenues Group  | 6 | Tools that could be used to measure the effectiveness of a behaviour support plan could be quality of life measures such as those developed by the Tizard Centre at the University of Kent and momentary time sampling observations as used to measure the effectiveness of PCAS.In addition it would be good to identify the frequency the reactive strategies are utilised (as you would expect to see this decrease), and where restrictive practices are being used that the level/intensity and frequency of these is reducing over time |
|  | The Challenging Behaviour Foundation  | 6 | The Behaviour Support Plan should result in an improved quality of life – a QoL outcome measure should be used. In addition support staff should be utilising and implementing the plan- this staff performance should be measured also. |
|  | National Development Team for Inclusion  | 6 | See PBS literature |
|  | College of Occupational Therapists  | 6 | A tool used in practice for this purpose is Periodic Service Review (La Vigna et al, 1994). Application in this way is described in this article: Lowe et. Al. (2010) Tizard Learning Disability Review, Vol 15 (3) pp. 17-28 |
|  | Southern Health NHS Foundation Trust  | 6 | A tool used in practice for this purpose is Periodic Service Review (La Vigna et al, 1994). Application in this way is described in this article: Lowe et. Al. (2010) Tizard Learning Disability Review, Vol 15 (3) pp. 17-28.  |
|  | Future Directions CIC  | 6 | Nothing specific but the following are Person Centred ways of working / tools, quality of life measures, |
|  | The Royal College of General Practitioners  | 6 | Tools – as on CaF or MindEd (JA) |
|  | The British Psychological Society  | 7 | The Society believes that, as it stands, this quality statement is not practical, due to the broad nature of the term ‘restrictive practices’, as outlined in the definition included on p.32 of the consultation. For example, it will not always be possible to identify every incident where a locked door has had a direct impact on the person. This could lead to circumstances where a review never happens, as no documented instances of its effects are kept, despite it having an impact on the person. The Society would like to see this accounted for in the quality statement by making adjustments such as:“*People with learning disabilities and behaviour that challenges have a documented review every time a restrictive intervention is actively used with the person (e.g. restraint, medication aimed at this purpose). All restrictive interventions are reviewed on at least an annual basis.”* |
|  | Oxfordshire County Council  | 7 | We support this, but think the standard needs to make clear what is meant by restrictive intervention and who would need to conduct this review. There are different types of restrictive intervention named in the guidance which suggest different types of clinical knowledge and expertise might need to be employed for different practices. There may also be difficulties in terms of the resource implications of who conducts the review, especially if independent scrutiny is required. Without this clarification it is also not possible to specify review intervals.  |
|  | The Challenging Behaviour Foundation  | 7 | Many support staff are unclear about what a restrictive intervention is – if this is the case, it will not be recorded as such. <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf> The review after the use of a restrictive intervention should involve a detailed analysis of what led up to the intervention, why it happened and what can be learned to prevent it / minimise the risk of it happening again. It should result in learning for support staff.The standard must be practical for support staff to implement; some children and adults are experiencing restrictive interventions multiple times a day so the frequency and depth of the review must be realistic.A review of restrictive interventions should also consider the introduction of psychosocial interventions as part of a restrictive intervention reduction plan. |
|  | The Huntercombe Group  | 7 | This statement is welcomed, but we would encourage clearer differentiation between levels of restriction and an understanding of age-appropriateness. For example children are often served in settings where their freedom of movement is restricted (e.g. school boundaries, locked doors in Child Care centres), and there is a significant difference between a full physical restraint on the one hand and a defensive block if the challenging behaviour is physically aggressive to others. |
|  | The Royal College of Psychiatrists | 7 | Because this standard does not make any allowance for age, it places the same constraints on the management of a small child as on that of an adult. Consequently, if followed to the letter, the standard requires that parents who have prevented their child from going out of the room into, say, the kitchen or garden, would have to document and review their action.The standard might recognise that distinctions between early childhood and adulthood is not over-ridden by the presence of learning disabilities. |
|  | SeeAbility | 7 | All restrictive strategies should be carried out in manner that takes into account any known sensory impairment of the individual that may be requiring reactive intervention (such as their visual field, hearing loss, wearing of hearing aids, glasses etc). The NICE guideline, now published, while rightly identifying the need to be aware of sensory sensitivities (see 1.9.3) such as being intolerant to touch, visual clutter, noise etc that will be common in people with autism, for example, should have been clearer for practitioners that this is not the same as taking into account the needs of those with sensory impairments such as those with impaired or damaged sight, or hearing, or both. References –  For example, see Warburg M. Visual impairment in adult people with intellectual disability: literature review. J Intellect Disabil Res 2001 45:424-38. 2 Emerson and Robertson (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disability in the UK.3. Van Splunder et al. Van Splunder et al. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study. Eye (2006) 20, 1004-10104 Royal College of Ophthalmologists. Ophthalmic Services Guideline. The Management of Visual Problems in adult patients who have learning disabilities. 5 Leamon, S. et al (2014). Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. *J. Public Health (Oxf).* 1–7.6 For example, see a case study in SeeAbility’s guidance for GPs, produced with the Royal College of Ophthalmologists and Royal College of GPs [www.seeability.org/uploads/files/PDFs\_Books\_non\_Easy\_Read/RCGP\_Guidance\_for\_GPs.pdf](http://www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/RCGP_Guidance_for_GPs.pdf)7 Newsam, H., Walley, R. M. and McKie, K. (2010), Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers. Journal of Policy and Practice in Intellectual Disabilities, 7: 211–220.8 De Winter C, et al. (2011) Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. See comment in PubMed Commons below [Journal of Intellectual Disability Research, 55: 675–698..](http://www.ncbi.nlm.nih.gov/pubmed/21366751) 2011 Jul;55(7):675-98. 9 Cooper S A, et al. Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. Journal of Intellectual Disability Research. 2009a;53:200-16. 0 Evenhuis H M, Does visual impairment lead to additional disability in adults with intellectual disabilities? Journal of Intellectual Disability Research vo 53 No. 1 pp 19-28, 2009. |
|  | Future Directions CIC  | 7 | Under the DOL legislation and more recently the Cheshire West judgement for supported living surly any restriction will form part of a Court of Protection Authorisation which will then fall to the Local Authority (DOLs team) to monitor with the support of the provider (& other disciplines) delivering and monitoring progress / changes which would be notified to the DOLs team. Would have thought that reviews would be set in any CoP authorisation or a review would be based on a ‘treatment’ outcome date but in any event should be formally reviewed at least once a month.  |
|  | College of Occupational Therapists  | 7 | COT would highlight that perhaps there should there be some mention of DOLs here.The section beginning ‘Commissioners’ states ‘ensure that they commission services that conduct a documented review’. COT would suggest that this statementsis made more robust as there will frequently be a lack of transparency between providers and commissioners, and the statement currently implies that Commissioners do not seek to establish the effectiveness of any review undertaken by the provider.COT asks the development group to consider if the review should involve a statement about how the person will be supported to understand why and when restrictive practices will be used and any alternative.In relation to the section beginning ‘Restrictive intervention’: Deprivation of Liberty Safeguards assessments are already undertaken for several of the restrictive intervention purposes outlined in this paragraph in accordance with the Mental Capacity Act (2005) Code of Practice (Revised Jan 2015) and resources for conducting these assessments are limited and over-stretched.COT would recommend that restrictive practices should always to care planned.COT recommends that the practicalities of conducting a formal review every time restrictive practices are used should be considered. For some people this might be necessary fairly regularly (although you would hope not if proactive strategies are used). It may be preferable to include a review of restrictive practices as a key part of the monthly review of the behaviour support plan. |
|  | Southern Health NHS Foundation Trust  | 7 | In relation to the section beginning ‘Restrictive intervention’: Deprivation of Liberty Safeguards assessments are already undertaken for several of the restrictive intervention purposes outlined in this paragraph in accordance with the Mental Capacity Act (2005) Code of Practice (Revised Jan 2015) and resources for conducting these assessments are limited and over-stretched. |
|  | Surrey and Borders Partnership NHS Foundation Trust  | 7 | The Review timescale shouldn’t be too prescriptive. You might need to review a plan daily if the person has extereme behaviour that challenges.  |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 7 | This needs to be outlined in the behaviour support plan and reviewed by more than people who were involved in the incident.Question does this include as and when required medication.Need more vigilance within services around what restrictive practice actually is. |
|  | United Response  | 7 | We believe that clarification of the term “restrictive intervention” is required in order to determine whether this level of reviewing and recording is realistic.If the definition outlined by the Department of Health (2014) in ‘Positive and Productive Care: reducing the need for restrictive intervention,’ is applied, the frequency of review, level of recording and requirement to involve a range of people including family members every time a restrictive intervention is in use would be unachievable.We feel that it would be more realistic to specify the level of review required e.g. service level – ongoing review of incidents by the manager and staff team. CLDT – ongoing monitoring of the frequency and duration. Specific review triggers should be set, such as when use is outside of the norm, or where injury occurs, for example. We also recommend that this is linked to the reviews outlined in statement 6 and the role of the co-ordinator outlined in statement 4. |
|  | Rotherham Doncaster and South Humber NHS FT | 7 | 7. Review should take place as soon as practicable following an intervention, and in line with NG010 – no later than 72 hrs post incident. The review should be conducted by a senior staff member within the organisation. |
|  | Avenues Group  | 7 | We would like to see the guideline rationale amended to state that ‘restrictive interventions should ONLY be used as a last resort’. Any restrictive intervention should include a restriction reduction plan to maintain the focus on reducing the need for any restrictive practices. A local review should take place (to include debriefing for all involved, including the individual) within 48 hours of the restrictive practice being utilised, a more formal review should take place monthly, 3 monthly or 6 monthly depending on individual circumstances and frequency of interventions being used. |
|  | UK Society for Behaviour Analysis (UK-SBA) | 7 | The UK-SBA strongly supports the principle of least restrictive alternatives. In the exceptional circumstances in which they are deemed necessary, interventions defined as ‘restrictive’ should be subject to systematic, frequent and objective review. The UK-SBA would further recommend that any Behaviour Support Plan that involves the use of restrictive interventions must (a) incorporate reinforcement-based procedures, (b) be derived from a functional behaviour assessment, (c) be carefully monitored on a continuous basis using reliable assessment methodology that enables evaluation of its effects and (d) be consistent with the scientific literature and current best practices. |
|  | The Royal College of General Practitioners  | 7 | The community paediatrician should lead an expert MDT including the GP – including transitional arrangements to adult care. (JA) |
|  | British Institute of Learning Disabilities  | 7 | The service manager or BSP coordinator should be responsible. It should happen within 72 hours (Leitch and Deveau 2014)**Reference:****Leitch S and Deveau R The impact of restraint reduction meetings on the use of restrictive physical interventions in English residential services for children and young people**Child: care, health and development WileyAugust 2014 |
|  | Hftrust | 7 | The named coordinator should be responsible for calling a review.Continual monitoring should be taking place as the intervention is put in place to ensure changes are monitored. There needs to be enough time for interventions to settle and everyone to understand approaches. The complexity of the behaviour plan will influence when review should take place. Any review is if the plan has unforeseen consequences.In our experience most plans need at least one month to embed, where small changes may be noticed. |
|  | The Royal College of Psychiatrists | 7 | The care coordinator should lead on ensuring the review with the active involvement of the individual with intellectual disability, their families, carers, advocates and members of the clinical team involved. This will need to involve a review of why the restrictive intervention took place along with a proactive review of the behaviour support plan in place to look at how to limit the use of restrictive interventions in the future. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 7 | The provider is probably best placed to carry out the review – but needs an outside view as well – perhaps the co-ordinator, depending on their role. This is a problematic standard in some instances as restrictive interventions for a small number of patients can be either extremely frequent (hands on restraint happening several times in a week), or unduly protracted (for example seclusion for extended periods). Thought should be given as to whether the proportion of person days care in which a restricted intervention took place should replace or possibly supplement the first of the two metrics suggested. Restrictive interventions should recorded in the MHLDMDS |
|  | Association for Real Change (ARC) | 7 | Our view is that a first stage review should be carried out by the support provider within a week of the restraint taking place. The documented review should be shared with commissioners and others who are involved in the behaviour support plan. There needs to be a clear process that would identify changes in the nature of the intervention and the number of times restraint is used so that an overall review of the behaviour support plan itself can be instigated. |
|  | United Response  | 7 | We would suggest that the review be carried out by those who are responsible for the use of restrictive intervention and that it take place approximately 3 days after the intervention has occurred. Such a time period would allow time for reflection, whilst ensuring that the review is carried out in a timely manner and while the event/learning is still at the forefront of the minds of those carrying out the intervention. |
|  | The British Psychological Society  | 7 | The Society believes that this review should be carried out in the context of the Behaviour Support Plan, so the review is best led by the person responsible for this, along with the person with a learning disability and other key stakeholders. Please see our earlier comment about the specificity of this quality statement.References

|  |
| --- |
| British Psychological Society (2004). *Psychological Interventions for* *Severely Challenging Behaviours Shown by People with Learning Disabilities:**Clinical Practice Guidelines.* Leicester: British Psychological Society.Department of Health (2014). *Positive and Proactive Care:* *reducing the need for restrictive interventions*. London: Department of Health.  |
| Public Health England (2014). *The Uptake of Learning Disability Health Checks* *2013 to 2014.* London: Public Health England |
| Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007). *Challenging behaviour:* *A unified approach.* London: Royal College of Psychiatrists. |

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|  | College of Occupational Therapists  | 7 | COT suggests that the author of the behaviour support plan should co-ordinate with members of the family/ support team and any other professionals involved.COT considers that the responsibility for reviewing should be with the clinician developing the behaviour support plan initially and then transfer to the Care Provider and / or Commissioner. Frequency of review should be weekly or daily initially and then fortnightly or monthly thereafter.  |
|  | Southern Health NHS Foundation Trust  | 7 | Responsibility for reviewing should be with the clinician developing the behaviour support plan initially and then transfer to the Care Provider and / or Commissioner. Frequency of review should be weekly or daily initially and then fortnightly or monthly thereafter. Pilot study being undertaken in Hampshire and Southampton to handover PSR review tool of bespoke PBS plans to Care Managers and commissioners following closure to Health LD Team. |
|  | National Development Team for Inclusion  | 7 | The provider is probably best placed to carry out the review – but needs an outside view as well – perhaps the co-ordinator, depending on their role. |
|  | Southern Health NHS Foundation Trust  | 7 | The section beginning ‘Commissioners’ states ‘ensure that they commission services that conduct a documented review’. It is believed this is a weak statement as there will frequently be a lack of transparency between providers and commissioners, and this statement implies that Commissioners do not seek to establish the effectiveness of any review undertaken by the provider. What counts as a documented review needs to be specified as well as what counts as restrictive practice. |
|  | Hftrust | 7 | **Statement 7**As stated above the standard needs to reflect the resources available. This requirement to review must be tempered with the level/intensity of the intervention. An increase in the level of intervention can demonstrate both positive and negative outcomes. For example; a plan might call for an increase of community presence, where a person uses a car and requires a mechanical restraint of a harness to facilitates this; if the plan is successful the use of restraint increases. Detailed monitoring should take place and be reviewed by a professional external to the line management of the direct support. When restrictive interventions are prescribed an impact and risk assessment should be completed which assesses the level of restraint and makes a judgement on the level of need for monitoring.To ascertain required level of monitoring, would suggest a matrix similar to that used in risk assessments would be suitable to judge, **alongside,** other measures including the opinions of the professionals.Reviews should be at intervals of no more than monthly. Again guidance should promote best use of technology to achieve this. |
|  | Mencap | 7 | In statement 7 reference should be made to ensuring a review of restrictive interventions includes consideration of the introduction of psychosocial interventions as part of restrictive intervention reduction plan. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 7 | QS 7 indicator a – The denominator is too loose. There will be people with behaviour that challenges where the degree of this is not such as to require any specific intervention. I suggest it should be the number receiving any type of intervention for reasons of behaviour.  |
|  | The British Psychological Society  | 8 & 9 | The Society welcomes the focus of these standards on access to psychosocial interventions and limiting the use of antipsychotic medication for people whose behaviour challenges |
|  | The Huntercombe Group  | 8 | Agree with the quality statement. |
|  | Oxfordshire County Council  | 8 | Overall we are in agreement with this but are concerned that this should be guidance rather than an ‘all or nothing’ approach. It might also be worth considering defining when exceptions might be clinically appropriate.  |
|  | Southern Health NHS Foundation Trust  | 8 | The section beginning ‘Service providers (secondary services) ensure that systems are in place…’ suggests antipsychotic medication only be prescribed as part of treatment including psychosocial interventions. It is believed that this is unlikely to be achieved in services led by Psychiatrists and conforming to a medically-oriented approach to treatment.It may be more appropriate to state that antipsychotic medication should only be used as a treatment relating to a diagnosis of psychosis rather than for medical restraint. In all other cases a medication review and plan should be put in place to withdraw antipsychotics and replace with a more appropriate medication. This should be monitored through the CPA process. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 8 | QS8 needs to be clearer in the metrics about the status of prn prescribing. Is this included or is it more important to know how many people had antipsychotics administered? My view would be that prn medication for control of acute behavioural disturbance needs to be recorded separately from continuous administration intended to prevent behaviours. Possibly also consider an indicator for routine recording of somnolence, weight gain and neurological side effects in people receiving antipsychotics. The Royal College Audit indicated that this is currently poorly done. |
|  | The Royal College of General Practitioners  | 8 | I understand that propranolol or pregabalin in titrated doses are often more effective for anxiety which can precipitate challenging behaviour. These should be mentioned in guidance for parents and GPs. (JA) |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 8 | Education is required for support staff and families around medication strengths, actions, and side effects.Potentially a restrictive intervention when using as and when required medication. |
|  | College of Occupational Therapists  | 8 | COT suggests that this section includes a statement about how medication should be monitored?The section beginning ‘Service providers (secondary services) ensure that systems are in place…’ suggests antipsychotic medication only be prescribed as part of treatment which includes psychosocial interventions. A purely medical approach treatment is to be discouraged.The section beginning ‘People with learning disabilities and behaviour that challenges’ states ‘medication is only used’…’or when the risk to the person or others is very severe’. COT is concerned that this caveat will allow for the justification of using antipsychotic medication due to poor practices which conversely lead to increased risk of harmful behaviours.The College suggests that it would be better to state that antipsychotic medication should only be issued to those with a diagnosis of psychosis rather than as medical restraint. COT would expect that if it was identified an individual has been placed on antipsychotics this should be addressed and reviewed with plans to change this when appropriate. |
|  | Southern Health NHS Foundation Trust  | 8 | The section beginning ‘People with learning disabilities and behaviour that challenges’ states ‘medication is only used’…’or when the risk to the person or others is very severe’. It is believed that this caveat will allow for the justification of using antipsychotic medication due to poor practices which conversely lead to increased risk of harmful behaviours. Use of CPA mechanism for review |
|  | Mencap | 8 and 9 | It is important the rationale for use of medication is sufficiently detailed – so that the thinking behind the decision is really explicit. The quality measure must ensure that the review of medication has looked at purpose and outcomes, and changes are made if it is not having the intended effect. It is not enough just to record that a review of medication has taken place.  |
|  | Avenues Group  | 8 | For people with complex challenging behaviours the proactive use of PRN medication can be a very effective strategy, reducing the need for more restrictive practices. However it is essential to have a clear guideline in place for use, developed jointly by the prescriber and PBS practitioner and for the use to be closely monitored.In our experience some people with learning disabilities have been prescribed antipsychotic medication historically and this has never been fully reviewed. We would welcome better data collection on this area and would hope that with better education for GPs and a more multi-disciplinary review of medication for people with challenging behaviour that levels and quantities of antipsychotic medication reduces over time. |
|  | Hftrust | 8 | **Statement 8**The aspiration must be that antipsychotic medication is only prescribed for challenging behaviour, where this is not caused by a diagnosed mental health or syndrome specific condition, in extreme situations and the individual is presenting extreme danger to themselves and othersTo achieve this there is a need for families and professionals to have an open discussion about the long term effects of medication. Often medical professionals are faced with emergency situations and the assessment process is at the beginning; psychosocial interventions have not been devised. Very quickly the individual, their family and support staff become dependent on the medication and it becomes more difficult to remove. All assessments and support plans need to consider the reduction and removal of antipsychotic medication.Whilst Hft does not work with children we support adults, many older individuals have been subjected to decades of Antipsychotic drug use for challenging behaviour. The individuals are now either unable to be removed totally, or have side effects that impact on their daily lives and require medication to counteract this. We must protect future generations from this situation.There must be greater guidance and more stringent procedures for the administration of antipsychotic medication as a strategy when working with children. This should only occur in a very small number of children and where it does a national overview should be maintained, possibly with the expectation of peer review of plans. |
|  | The Huntercombe Group  | 9 | Agree with the quality statement. |
|  | Improving Health and Lives Learning Disabilities Public Health Observatory | 9 | Quality statement 9 seems to accept chronic use of antipsychotics as a normal treatment approach. This is regrettable. The clear aim and expectation in management of behavioural problems should be resolution. It should always be assumed that behaviours that have started should stop if the causes are properly responded to, although they may need careful work to reduce the likelihood of relapse. There will be exceptions to this, but they should be viewed as exceptions not the expected situation. In the longer term, care reviews should be framed around the circumstances in which NG11 considers antipsychotic use appropriate. With the exceptions of people who have psychotic illnesses, these are spelt out in section 12.3. Reviews should cover the issues raised here. I would change the phrasing of both metrics to refer to ‘a review fully covering the relevant issues set out in NG11 section 12.3’.  |
|  | Avenues Group  | 9 | The review of medication should not be done in isolation; it needs to include a review of the behaviour support plan and other interventions. |
|  | Oxfordshire County Council  | 9 | We support this. This review should be aligned with the social care review for new services, for which the intervals of 6 weeks and 3 months are set out in national guidance. In cases where it is not possible to align the twelve-week medication and 3-monthly social care reviews, both will still need to take place.  |
|  | The Royal College of Psychiatrists | 9 | The multidisciplinary team of staff reviewing the use of antipsychotics specifies the inclusion of nurses and care staff, professions that may not be involved in the management of children in that particular service/locality. People that are more relevant might include parents, teachers and a variety of other staff, depending on local service provision. Therefore, the standard might be less specific about the composition of the multidisciplinary review. |
|  | Leonard Cheshire Disability  | 9 | We are very pleased to see this quality statement included, and are confident that it will help establish what both health and social care professionals must do to manage challenging behaviour. In particular, the role of non-specialist provision (e.g. from GPs) is a vital component of managing challenging behaviour, and it is useful to emphasise that relationship here. |
|  | Southern Health NHS Foundation Trust  | 9 | The section beginning ‘Multidisciplinary review’ states that a review should include: ‘a record of the extent of the response…’It is believed that this quality statement can be improved by specifically stating that such reviews should be ‘data-driven’ or ‘based on evidence from practice’. For example clear data on; behaviour presentations, episodic severity of incidents and the extent to which restrictive interventions are applied.* Review of medication should include other AHP’s if their involvement is relevant.
* Accessible information should be included about the medication, side effect, benefits and any monitoring arrangements.
* This should also be fed in to the review of the behaviour plan.
 |
|  | College of Occupational Therapists  | 9 | COT recommends that the review of medication should include other allied health professionals if their involvement is relevant.Accessible information should be included about the medication, side effect, benefits and any monitoring arrangements.This should also be fed in to the review of the behaviour plan. The section beginning ‘Multidisciplinary review’ states that a review should include: ‘a record of the extent of the response…’COT suggests that this quality statement can be improved by specifically stating that such reviews should be ‘data-driven’ or ‘based on evidence from practice’. For example clear data on; behaviour presentations, episodic severity of incidents and the extent to which restrictive interventions are applied. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 9 | Some logistical challenges - Would need a lot of resources especially around planning – but is agreed very much in principle.GP responsibility open to challenge – not issuing repeat prescriptions without review in presence of individual  |
|  | The Challenging Behaviour Foundation  | 9 | The multidisciplinary review must involve families and advocates. |
|  | Leonard Cheshire Disability  | 9 | It is also our view that this review should encompass all medication, not just antipsychotic medication and should be linked where appropriate with the annual health review. Underlying physical conditions can impact on someone’s behaviour, particularly if they are unable to verbally communicate symptoms and so it is important that other medication (whether this is adequate or appropriate) is taken into account in this review. In particular, depression and anxiety can be a significant stimulus for challenging behaviour. |
|  | The Huntercombe Group  | 10 | We are in support of this statement and recognise the importance this will make to early intervention and reducing the development of challenging behaviour through adolescence and into adulthood. We would encourage the standard to not only specify the initial training, but also ongoing support to implement behavioural principles in the home environment, rather than a simple ‘Train and hope’ approach. |
|  | Royal College of Paediatrics and Child Health  | 10 | It is doubtful that there are sufficient relevant parent training programmes around the country, so these are likely to need to increase. There are some excellent training programmes for parents of young children with autistic spectrum disorders (e.g. the Early Bird programme), but generic parent training programmes are usually not adequate for behaviours that challenge in children with learning disabilities. |
|  | Leonard Cheshire Disability  | 10 | This statement should include a definite timescale, so that parents can know when they will be offered the choice of additional support. In general, we feel this support should be offered as soon as is possible.We also recommend that the statement be reworked so that it ensures no criticism of parents of children with challenging behaviour is implied. We suggest replacing ‘referred to’ with ‘offered’, to ensure that both parents and medical professionals know that attendance at these programmes is voluntary. |
|  | Sheffield Health and Social Care NHS Foundation Trust  | 10 | Statement appears judgemental and not holistic, may need training but also support after.Families require a lot of social support not just training. May be required for children over the age of 12 years also |
|  | The Royal College of Psychiatrists | 10 | This statement appears to promote a very specific form of parent training programme although it is not actually named and it is unclear from the Guidance how its specifications were arrived at. For example, many of the programmes available in England use sessions of 120 minutes or more. The standard might be less specific in its prescription or, if the GDG does wish to endorse a particular programme, it might be given as example. |
|  | College of Occupational Therapists  | 10 | It would be useful to recommend evidence based treatment manuals if that information is available. Courses should be accessible not only from a practical point of view but also an information giving point of view. Some parents may have learning disabilities themselves or be vulnerable adults.This statement describes training provision, however it is believed that providing training with no provision of support in implementing such learned strategies using Positive Behaviour Support will have limited effectiveness. There is a risk that only families with sufficient levels of literacy and with resources to attend such training will benefit from this training, and effectively families with poor literacy (as many families of children with LD may have concurrent learning difficulties) or unable to attend due to personal / financial circumstances will be excluded inadvertently.COT would raise the issue of awareness about these courses and their availability nationwide, as some respondents reported that they were not aware of such courses in their locality.COT suggests that there should there be consideration of a role around ‘assertive outreach’ to hard-to-engage families of children with LD an challenging behaviour within this quality statement. |
|  | Avenues Group  | 10 | The focus of the parent training programme should be positive behaviour support. |
|  | Oxfordshire County Council  | 10 | We are in strong disagreement with the use of the term ‘parent training’ programme, as it implies that parents are at fault. Generic programmes do not work for families with special needs. There is no mention of positive behaviour support for parents and families in this standard, which we view as a significant gap.  |
|  | Southern Health NHS Foundation Trust  | 10 | This statement describes training provision, however it is believed that providing training with no provision of support in implementing such learned strategies using Positive Behaviour Support will have limited effectiveness. There is a risk that only families with sufficient levels of literacy and with resources to attend such training will benefit from this training, and effectively families with poor literacy (as many families of children with LD may have concurrent learning difficulties) or unable to attend due to personal / financial circumstances will be excluded inadvertently.Should there be consideration of a role around ‘assertive outreach’ to hard-to-engage families of children with LD an challenging behaviour within this quality statement?There is also a risk of non individualised training being completed that may lead to inappropriate use of techniques as what works for one person will not be appropriate for the next and can be potentially have a negative impact on the individual |
|  | Hftrust | 10 | **Statement 10**This statement would support parents to receive the help they need as early as possible. The statement needs to signpost how the resources for this could be achieved.We know early intervention can improve outcomes and reduce ongoing support needs, however, the culture of preventative support is often lacking due to access to resources. Without access to ring-fenced funding that lasts for a generation then the circle of reactive rather than proactive intervention will continue. |

## Registered stakeholders who submitted comments at consultation

* Association of Directors of Adult Social Services (ADASS)
* Association for Real Change (ARC)
* Avenues Group
* British Institute of Learning Disabilities
* College of Occupational Therapists
* Department of Health
* Future Directions CIC
* hftrust
* Hearing and learning disabilities special interest group
* Improving Health and Lives Learning Disabilities Public Health Observatory
* Leonard Cheshire Disability
* Mencap
* National Development Team for Inclusion
* NHS England
* NHS Protect
* Oxfordshire County Council
* Rotherham Doncaster and South Humber NHS FT
* Royal College of General Practitioners
* Royal College of Nursing
* Royal College of Paediatrics and Child Health
* Royal College of Psychiatrists
* Royal College of Surgeons of England
* SeeAbility
* Sheffield Health and Social Care NHS Foundation Trust
* Southern Health NHS Foundation Trust
* Swanton Care and Community
* Surrey and Borders Partnership NHS Foundation Trust
* The British Psychological Society
* The Challenging Behaviour Foundation
* The Huntercombe Group
* UK Society for Behaviour Analysis (UK-SBA)
* United Response

# Appendix 2: Quality standard consultation comments table – non-registered stakeholders

| **ID** | **Stakeholder** | **Statement number** | **Comments[[15]](#footnote-15)** |
| --- | --- | --- | --- |
| 1 | Non-registered | General | I am a mum to a boy of 12 who has autism and a learning disability. I am also managing the ABA4All parent campaign, though I seem to have been a registered stakeholder for the Challenging Behaviour guidance but not for the Quality Standard?  Can I submit my thoughts on the QS anyway, on behalf of the 3000 parents/family members/professionals on my campaign?It is very brief. It is basically this: how can it not be an anomaly that the treatment for my son which NICE recommends is different if I say his challenging behaviour is stemming from his autism, than if I say it is coming from his learning disability? As his mum, *I* certainly can't tell you which is making him self injure, punch the side of his own head. The photo and link below illustrate the point. In the (excellent) new QS on challenging behaviour and learning disability, ABA is clearly listed as a 'psychosocial' intervention to try out before resorting to medication (photo).Yet the NICE autism team by contrast pointedly does not name ABA, or indeed any other intervention, but just lists out the steps. This is surely too vague for commissioners. Are we to suppose that any person can just follow these steps and deliver the psychosocial intervention? John from the chip shop? Bert who you just met on the bus?My feeling would be that the autism team, through their circumlocutions, have left both parents and commissioners up the creek with no paddle, in the face of what can be very dangerous challenging behaviours in kids with autism.Can someone with an overarching brief at NICE perhaps examine this anomaly?ABA professionals can help both groups, many of whom are the same children with dual diagnoses. I would also like to recommend, per your request for feedback on placeholder QS1, that you look at the evidence base for EIBI as an early intervention. Since half of children with autism also have a learning disability, the crossover must be huge. I have included just one link to a meta-analysis at the end (you will note that most of the  participants in the included studies had IQs < 70, as well as autism). ABA works well for both groups, please take a view on the evidence? image1.PNG |

# Appendix 3: Quality standard internal checks table

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| --- | --- | --- | --- |
| **Comment number** | **Page number**Or **‘general’** for comments on the whole document | **Statement number**Or **‘general’** for comments on the whole document | **Comments** |
| **QS Team** |
| 1 |  | 2 | Reword statement to use wording from section on what means for service users and carers to make clearer -“have an assessment as soon as there are signs of behaviour that challenges”• |
| 2 |  | 3 | Amend statement to people with learning disabilities, not LD and behaviour that challenges, to reflect issue that assessment can be preventative measure and also amend rationale to reflect this. |
| 3 |  | 5 | Amend statement to place focus on the importance of the personalised daily activities not that they are documented in a plan and emphasise in rationale. Create definition of personalised daily activities. |
| 4 |  | 6 | Amend statement to include phrase ‘the effectiveness of the behaviour support plan’ to show that the review needs to understand how plan is working. |

1. PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees. [↑](#footnote-ref-1)
2. For example, see Warburg M. Visual impairment in adult people with intellectual disability: literature review. J Intellect Disabil Res 2001 45:424-38. [↑](#footnote-ref-2)
3. Emerson and Robertson (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disability in the UK. [↑](#footnote-ref-3)
4. . Van Splunder et al. Van Splunder et al. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study. Eye (2006) 20, 1004-1010 [↑](#footnote-ref-4)
5. Royal College of Ophthalmologists. Ophthalmic Services Guideline. The Management of Visual Problems in adult patients who have learning disabilities. [↑](#footnote-ref-5)
6. Leamon, S. et al (2014). Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. *J. Public Health (Oxf).* 1–7. [↑](#footnote-ref-6)
7. For example, see a case study in SeeAbility’s guidance for GPs, produced with the Royal College of Ophthalmologists and Royal College of GPs [www.seeability.org/uploads/files/PDFs\_Books\_non\_Easy\_Read/RCGP\_Guidance\_for\_GPs.pdf](http://www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/RCGP_Guidance_for_GPs.pdf) [↑](#footnote-ref-7)
8. Newsam, H., Walley, R. M. and McKie, K. (2010), Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers. Journal of Policy and Practice in Intellectual Disabilities, 7: 211–220. [↑](#footnote-ref-8)
9. #  De Winter C, et al. (2011) Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. See comment in PubMed Commons below [Journal of Intellectual Disability Research, 55: 675–698..](http://www.ncbi.nlm.nih.gov/pubmed/21366751) 2011 Jul;55(7):675-98.

 [↑](#footnote-ref-9)
10. Cooper S A, et al. Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. Journal of Intellectual Disability Research. 2009a;53:200-16. [↑](#footnote-ref-10)
11. Evenhuis H M, Does visual impairment lead to additional disability in adults with intellectual disabilities? Journal of Intellectual Disability Research vo 53 No. 1 pp 19-28, 2009. [↑](#footnote-ref-11)
12. [↑](#footnote-ref-12)
13. # xMarta Buszewicz[Search for articles by this author](http://www.thelancet.com/action/doSearch?searchType=authorLookUp&author=Buszewicz,%20Marta&prod=LN)Affiliations

	* Research Department of Primary Care and Population Health, University College London Medical School, Royal Free Campus, London, UK
#### Correspondence

	* Correspondence to: Dr Marta Buszewicz, Research Department of Primary Care and Population Health, University College London Medical School, Royal Free Campus, Rowland Hill Street, London NW3 2PF, UK [↑](#footnote-ref-13)
14. [↑](#footnote-ref-14)
15. PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees. [↑](#footnote-ref-15)