National Institute for Health and Care Excellence

Challenging behaviour and learning disabilities
Guideline Consultation Table
29 December 2014 - 9 February 2015

Stakeholder	Order No	Document	Section No	Page No	Comments	Developer's Response
2gether NHSFT	1	NICE	General	General	Primary goal of intervention should be quality of life of person and those that know them. This is not adequately reflected in the guidance and focus appears to be on reduction in behaviour rather than QoL gain. The importance of person centred planning/approaches are not mentioned anywhere which will lead people to advocate methods limited to narrow Functional assessment.	Thank you for this comment. We have amended our recommendations to include quality of life as an outcome (see revised recommendation numbers 1.1.2 and 1.6.1. It should however be pointed out that for many people a reduction of the behaviour that challenges will promote a significant improvement in quality of life. We disagree regarding person centred assessment, a number of recommendations stress the importance of service user and family and carer involvement in the process (see section 1.3) and require broad range of issues to be considered.
2gether NHSFT	2	NICE	1.6.5	14	(Priorities) Section 1.1.1, p20 states that "a range of evidence-based interventions" should be offered. This is contradicted on P14 which states interventions should be "based on behavioural principles", and an exclusive focus on behavioural principles does not allow sufficient flexibility to address systemic / organisational issues that affect staff's responses to behaviour (without sufficient attention to staff and organisational issues, there is a danger that behavioural work gets focused on whether there's a PBS document or not). Perhaps the phrasing could be changed from "based on" to "incorporating behavioural principles". P14 also refers to psychosocial interventions as "behavioural" – omitting any reference to the relational aspect of a person's life; psychosocial interventions should by definition be about	Thank you for your comment. The GDG does not see any contradiction – the reference to evidence-based interventions refers to the full range of support, interventions and strategies set out in this guideline, not just personalised psychosocial interventions based on behavioural principles. You have made reference to the recommendations in the key priorities section, but if you read the rest of the guideline this should be more evident. The other aspects to which you refer (relational aspects, mental health problems) are covered in the revised recommendation numbers on assessment (revised section number 1.5) and coexisting conditions (revised section number 1.10). Regarding your final point, the terminology relation to psychosocial/psychological interventions has been revised ('psychological' is now used in the

					relationships, not just behaviour. If challenging behaviour is related to mental health problems (as the guidance previously mentions) these need to be addressed with more than "behavioural principles". P14 mentions only offering "medication in combination with psychosocial, psychological or other interventions", yet under the heading in the previous paragraph for "interventions for behaviour that challenges", psychological interventions are not mentioned.	recommendations).
2gether NHSFT	3	NICE	1.1.8	20	Section 1.1.8 talks about pathways and integrated approaches. There should be greater emphasis on equivalent outcomes and the reasonably adjusted services necessary to produce those. Reasonable adjustments will include specialist services not just mainstream If integrated models of delivery were interpreted as mainstream and getting the same as everyone else (which it might be in current financial context) then appropriate services would not be available. Should be noted too that if people with LD to benefit from mainstream services then national targets / monitoring of those mainstream services needs to be looked at. For example pressures to achieve IAPT access and recovery rates do not encourage provision to people with LD who need reasonable adjustments.	Thank you for your comment, it is beyond the remit of this guideline to make specific suggestions as to what might be reasonable adjustments for each service. This is a matter for local implementation.
2gether NHSFT	4	NICE	1.1.2	17	On working with families and carers, there is no mention of work needed to build up relationships with families and carers and addressing organisational issues in teams that may affect their ability to implement appropriate care.	Thank you for your comment. The GDG agrees that this is important, but feels that working with families and carers and building a relationship with them is amply covered in section 1.3 of the NICE guideline. Your concern about organisational issues in teams is addressed in revised recommendation numbers 1.1.4 and 1.1.5 on team working.
2gether NHSFT	5	NICE	1.4	23	(Sections 1.4 and 1.5.8, pages 23 and 27) Section 1.4 talks about early identification and doc seems to be trying for stepped care idea as at 1.5.8 it discusses behaviour that is complex or not	Thank you for your comment, in light of yours and others' comments we have made a number of revisions to recommendations both for identification and assessment which we hope have clarified the

					responsive. . However we see many people where behaviour is established so doc needs to reflect that not all behaviour is 'emerging' but in fact is long-emerged. Principle of 'least intervention, right first time is needed'. Greater clarity between Simple and complex, emerging and established is required	appropriate response to the problem, see sections 1.4 and 1.5.
2gether NHSFT	6	NICE	1.1.7	19	"staff should deliver interventions based on the relevant manuals" – surely practice should be based on thorough assessment, formulation, person centred principles and improving quality of life rather than on manuals.	Thank you for your comment. While the GDG agrees in theory, and has indeed highlighted person centred principles and quality of life throughout the guideline, it is also important that practitioners adhere to intervention manuals for managing behaviour that challenges in order to ensure that the intervention is delivered effectively.
2gether NHSFT	7	NICE	1.5.8	27	(Section 1.5.8 and general) Not enough attention is paid to 'life history, including any history of trauma or abuse' although this is mentioned at 1.5.8. This issue links to point about 1.4 above. Section on emerging issues (1.4.1, p 23) talks about current abusive environments. Where behaviour has emerged already then need to look at impact of past experiences. Interventions do not reflect the strategies appropriate to working with behaviour underpinned by abusive history / life-history. For example, relationships, attachment, sense of security all key issues and behavioural methods are all that really get mentioned. Lack of emphasis in doc on really getting to know the person, person centred thinking and approaches, quality of life as primary outcome needs addressing.	Thank you for your comment. Quality of life has been highlighted throughout the redrafted guideline. Revised recommendation number 1.5.8 and the section on assessment has been revised substantively, however the GDG considers that the guideline adequately covers trauma and abuse in so far as they relate to behaviour that challenges.
2gether NHSFT	8	NICE	1.1.10	20	"promote a range of evidence-based interventions at each step and support people in their choice of interventions" – this is contradicted by the reference to manualised interventions on p19 and on p14 where psychosocial interventions are referred to as	Thank you for this comment. The GDG believe the recommendations are consistent. For example in: a) The active engagement of the service user and family or carer in the assessment

					behavioural.	process b) The consideration of direct (e.g. psychological) and environmental adaptations The use of a manual does not mean reduced choice, rather its purpose is to support the effective implementation of the chosen intervention.
2gether NHSFT	9	Full	General	General	The impact of abusive experience and trauma on thoughts, feelings, behaviours, relationships, interactional style etc would be a useful additional area for review as in our experience much 'complex challenging behaviour' is causally related to this and intervention needs to recognise that.	Thank you for your comment, the GDG agree this is an important issue which is addressed in revised recommendation number 1.5.8 of the NICE guideline.
2gether NHSFT	10	NICE	1.3.3	22	(Pages 22-3) Re supporting family members/carers, there is no mention of the specialist support often needed from MDT professionals to help families understand and change their responses to behaviour, rather than it being limited to giving information and accessing support groups as suggested in the document.	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges. The guideline also makes recommendations for parent training in section 1.6.
2gether NHSFT	11	NICE	General	General	There seems to be little mention of professionals addressing how staff use behavioural principles and guidelines, and how professionals facilitate staff's understanding of a client's behaviour, rather than expecting that if it's written down, then it will change staff's responses. Since the effectiveness of a behavioural approach is as much about how a given staff team use it as the content of the interventions drawn up, greater emphasis on professionals working to address systemic and organisational factors to support behaviour change would prevent a narrow and reductionist approach to behaviour. For behaviour change to be sustained, staff teams also need to address how they work together, how	Thank you for this comment. We agree with you on the importance of staff behaviour in effective implementation and that is why we have placed considerable emphasis on careful monitoring and supervision in a number of our recommendations, a number of which have been revised in light of yours and others' comments.

					they will review their work and how practices are embedded in teams, which professionals should be addressing – none of which is reflected in the guidance as needed to enable behavioural interventions to be implemented.	
2gether NHSFT	12	NICE	General	General	No mention is made of the language or terminology used in PBS plans. The existence of the document of a FA or a PBS plan can become the sole focus in behavioural work, without attention to its accessibility. The use of jargonistic behavioural terms in such documents do not lend themselves to being accessible for clients or staff teams and it would be helpful to reflect this in the guidance so that interventions make sense to all those involved in a clients' care.	Thank you for your comment, we take considerable care to not use jargon in the guideline that would not be understandable by health and social care professionals. The guideline does not specifically recommend PBS plans and therefore it is difficult to make recommendation about the language used in them. NICE will also publish 'Information for the public' alongside this guideline which will set out the recommendations in plain English. An easy read of this document will also be available.
5 Boroughs partnership NHSFT	1	General	General	General	Interventions focused upon staff and carer responses: What to do if interventions stated are not followed or do not work? Role of systemic/family therapy in managing dynamics? How best to monitor adherence? Who are families and direct payments workers accountable to? Training, in my experience, is often necessary but often not sufficient in complex cases.	Thank you for your comment, a number of issues you raise, e.g. non adherence, are a matter for local implementation and governance. The guideline does offer advice in a number of recommendations, e.g. revised recommendation number 1.1.8, about the specific use of supervision in order to promote the best care.
5 Boroughs partnership NHSFT	2	General	General	General	Full/Broader range of possible interventions: (psychosocial interventions only describes behavioural or anger management, when in reality a whole range of interventions are offered according to individual formulation. for example, systemic or family therapy interventions (workshops etc) are often used by psychologists in complex cases and are often necessary when a typical behavioural intervention has not worked due to the dynamics within that system. There are also a wide range of 1:1 interventions that are offered to clients, not only anger management. Eg CBT for anxiety, depression, self-esteem, self-harm (consistent with NICE) where this directly underpins (or is) the challenging behaviour.	Thank you for raising this issue. In the scope, psychosocial interventions covered a broad range of therapies (such as communication interventions, applied behaviour analysis, positive behaviour support and cognitive behavioural therapy) for the short- and long-term reduction and management of behaviour that challenges. What could be recommended depended on the availability and quality of the evidence. With regard to anxiety, depression etc, please see revised recommendation number 1.10.1 in the NICE version of the guideline, which recommends using interventions in line with the relevant NICE guideline for that condition.
5 Boroughs	3	General	General	General	Training and expertise of staff teams:	Thank you for your comment. Revised

partnership NHSFT					what are essential skills required of paid carers, what is most effective way of delivering training. Is this sufficient in changing attributions? What role does stress have in this and how could this be addressed? There is a huge issue of quality of care providers – what is our role within this? What are their duties? -what model of behavioural intervention is most effective?	recommendations 1.1.6 – 1.1.8 make reference to the necessity for staff to be competent and skilled in working with people with a learning disability and behaviour that challenges, with an additional new recommendation about staff stress (1.1.7).
5 Boroughs partnership NHSFT	4	General	General	General	What model of behavioural intervention is most effective?	Thank you for your comment. Based on the evidence and expert opinion of the GDG, no specific model of behavioural intervention is recommended, but rather principles (see revised recommendation 1.7.5 for example, in the NICE version of the guideline).
5 Boroughs partnership NHSFT	5	General	General	General	Clarity on 'specified time to try behavioural intervention' prior to meds needed	Thank you for your comment. In our recommendations for both behavioural and pharmacological interventions we have tried to integrate a set of principles to inform the use of both of these interventions. These include careful monitoring of benefits and harms, use of routine outcome measures and a clear indication of when to stop interventions if ineffective. We think these principles are the most useful approach to dealing with these often difficult problems. Given the variation in individuals' response and other factors the GDG felt it best to avoid specific timescales as this will be decided by healthcare professionals involved in that individual's care.
5 Boroughs partnership NHSFT	6	General	General	General	Additional developmental areas of emergent practice	Thank you for your comment. While we were unsure of the exact reference to the guideline your comment relates to we infer this may be related to training and support for staff. Please see revised recommendation numbers 1.1.6-1.1.8 for amendments on this.
5 Boroughs partnership NHSFT	7	General	General	General	Just a comment/observation that many of these recommendations have been based on very little,	Thank you for this comment. The GDG agree that there was in some reviews little good quality

					low quality evidence, and, where none available, used the 'modified nominal group technique' which may be prone to participant bias. Overall I think there is some good, clear guidance on what to offer as standard, but this does not capture what should be/could be done when these attempts e.g. at behavioural intervention or training etc do not result in change. Does not really help with advising on more complex cases where a broad range of interventions may be required from a psychologist. In reality most complex cases use a range of approaches based on an individual formulation that will often include family or systemic therapy, for which there is no/little reference. Although there is little research in this area this is certainly often used.	evidence, and the strength of the evidence is reflected in the wording of the recommendations.
ABA4All	1	NICE/Full	1.6/11.3.1	260	Why no mention of BCBAs or ABA in this section, given there is much behavioural content? Are you deliberately leaving out the correct professionals, due to cost or vested interests in other courses?	Thank you for your comment, the guideline clearly recommends the behavioural application to the management of behaviour that challenges and are based on a careful review of the available evidence, and where possible the cost effectiveness of interventions, such as parent training. We have not considered the interests of any professional body or training organisation.
ABA4All	2	NICE/ Full	1.1.5/6.4.2.1.1	112	(6.4.2.1.1 (15)) Why no mention of BCBAs or other ABA professionals in this list of specialists?	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has now included them in revised recommendation number 1.1.5.
ABA4All	3	Full	1.1.6/6.4.2.2.2	113	Why is there no mention of ABA in this section, since it is surely relevant?	Thank you for your comment, this recommendation sets out a broad set of objectives for health and social care professionals to adhere to. No specific interventions are mentioned here, although ABA would be covered by the third bullet point, as would a number of other types of intervention. Behavioural applications of interventions are covered in significantly more detail in section 1.6 of the guideline.

ABA4All	4	Full	9.5.1	193	Why is there no mention of ABA or input from BCBAs in this section, since clearly there is a lot of content in this pre-school training which is behavioural? If you cut them out, or just leave it to generalists who have not studied behaviour in depth, are you starting out on the wrong foot with children whose needs are often complex?	Thank you for your comment, the specific evidence on which the GDG based their recommendations drew on a range of theoretical applications, including curriculum design, communication skills training and training for teachers. It was not deemed appropriate by the GDG to include reference to those theoretical models, or ABA.
Abertawe Bro Morgannwg University Health Board	8	Full	General	General	Throughout the document there is no reference to mental capacity of the individual with a learning disability and consent to intervention.	Thank you for your comment. Capacity and consent are mentioned in the 'Person centred care' section of the guideline with links to the relevant documentation provided.
ABMU Health Board	1	NICE	General	General	Useful that the document separates the more severely disabled population from those with milder learning disability in relation to the prevalence of Challenging Behaviour.	Thank you for your comments.
ABMU Health Board	2	NICE	General	General	We note the absence of any reference to Positive Behavioural Support (PBS) as an overarching framework for understanding and managing challenging behaviour. We question whether an RCT is an appropriate method to research PBS outcomes, given it's an 'organising framework' rather than a specific intervention per se.	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended. As you may be aware from reading the full guideline, not only RCT evidence was considered for this guideline but also systematic reviews of single case and small n studies to inform the recommendations, a number of which would be seen as component parts of a PBS approach.
ABMU Health Board	3	NICE	General	General	Even though the recommendations spell out all the key features, it does not name PBS. Without	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching

					reference to this overarching term, we are concerned that PBS will not be acknowledged as the approach that NICE clearly describes in this Guidance. PBS is an important conceptual term. Given the number of documents that places PBS at the core of national strategy across the UK, the absence of this organising term could mitigate against joined up thinking and practice. We consider that adoption of the term PBS will promote more robust and consistent clinical outcomes.	framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
ABMU Health Board	4	NICE	1.5	General	(Assessment) We consider that this under-estimates the skills required to produce the summary statement leading to formulation around appropriate intervention. We would recommend a clear statement about the sheer complexity of this process, the skills required to undertake this and the need for assessment tools to be cross referenced with observational data (i.e., 'triangulation').	Thank you for your comment. The GDG set out a phased approach for assessment, with the requirement that staff are trained (see section 1.1) and have support from specialist services (see revised recommendation number 1.1.5), to enable them to carry out the assessment and subsequent interventions. The use of observational data is highlighted in the recommendations about functional assessment.
ABMU Health Board	5	NICE	0	12	(Pages 12-4) Following from the above point, we would suggest the consideration of an additional tool, the Brief Behavioural Assessment Tool (The BBAT), recently published in the International Journal of Positive Behaviour Support. "The Brief Behavioural Assessment Tool-preliminary findings on reliability and validity". **4,2,**32-40. This tool aims to address some of the inherent weaknesses of earlier tools, with as much reliability and validity as the tools included in the Full Guidance. It would seem appropriate that this tool is considered for inclusion in this guidance.	Thank you for highlighting this tool. The paper was not identified in our search and we do not have access to the full text for this journal. Given that the recommendations do not specify a particular rating scale (other than giving examples), we do not believe that adding the BBAT, with validity and reliability based on one study, would change these recommendations. Therefore, there would be little gained by adding the study at this stage of development.
ABMU Health Board	6	NICE	1.6.6	32	Whilst we appreciate that Anger Management referenced as a psychological treatment is included due to the fact that there is limited RCT evidence on other psychological approaches, we consider that this could reduce scope if read literally. A more	Thank you for your comment, but as you point out the evidence in this area was limited. The GDG hopes that evidence base will expand and has made research recommendations accordingly.

					inclusive statement recognising the role of psychological therapies with this client group is advised.	
ABMU Health Board	7	NICE	1.8	35	(General comment on Reactive strategies) We query why NICE has not stipulated the Regulation of Providers who offer training in Restrictive Practice. We would recommend that we should be looking for consistency in training: a model that all need to sign up to which links in with accreditation. Currently, accreditation is through organisations such as BILD, which is voluntary. Perhaps we need to strive for a National Curriculum.	Thank you for your comment, it is beyond the scope of NICE guidelines to recommend who delivers training.
ABMU Health Board	9	NICE	General	General	There is no reference to the role of acute inpatient psychiatric care facilities in the overall treatment and care of people who present with severe Challenging Behaviour.	Thank you for your comment, the GDG hope that it can be seen from a careful reading of the recommendations that they take into account the environment of people with a learning disability and behaviour that challenges and recommend that adjustments be made to ensure it is a positive one. The recommendations are applicable in any setting and given the wide range of settings people with a learning disability and behaviour that challenges are cared for the GDG felt it most appropriate not to specify setting to ensure all are positive.
ABMU Health Board	10	NICE	General	General	Challenging Behaviour is a social construct (as the Guidance describes) as such, many of the interventions required to respond to such a socially constructed concept cannot be easily condensed into the parameters of an RCT.	Thank you for your comment, the guideline did not only review RCTs but systematic reviews of single case and small n studies, as detailed in the full guideline.
Association for Cognitive Analytic Therapy	1	NICE	General	General	ACAT is keen to put forward a more contextual approach to managing challenging behaviour in people with learning disabilities and sees the current guidance as lacking a relational perspective. CAT, being a relational model of therapy, is well placed to be a therapeutic framework for thinking about challenging behaviour as an interpersonal difficulty- for both carers and people that challenge with their behaviour, that goes beyond just cognitive and behavioural perspectives.	Thank you for raising this issue. The scope did not exclude interventions such as CAT, but certain constraints were placed around the type of evidence included in each review. If the studies of CAT met eligibility criteria, they would have been examined.

					There is much written about using CAT with people with learning disabilities and managing challenging behaviour from a CAT point of view.: Lloyd, J. and Clayton, P. (Eds.) (2014). *Cognitive Analytic Therapy for People with Intellectual Disabilities and their Carers.* Jessica Kingsley, London and Philadelphia. Greenhill, B., 2011. "They have behaviour, we have relationships?". *Reformulation*, Winter, pp.10-15 Available at the following link: "They have behaviour, we have relationships?" (http://www.acat.me.uk/reformulation.php?issue_id=22&article_id=216) ACAT website (LD pages):CAT with people with a learning disability | ACAT (http://www.acat.me.uk/page/cat+and+learning+disability)	
Association for Cognitive Analytic Therapy	2	NICE	1.6.6		Interventions should be based on cognitive - behavioural - relational principles i.e., they should include social and relational factors, not just cognitive and behavioural ones.	Thank you for your comment, however no evidence was found for social and emotional factors, only cognitive and behavioural.
Association for Cognitive Analytic Therapy	3	NICE	1.5.7	13	Risk Assessment. This should include in 'exploitation and abuse by others': exclusion and neglect, including relational and emotional neglect.	Thank you for your comment, neglect has been added to the recommendation.
Association for Cognitive Analytic Therapy	4	NICE	1.1.6	19	(1.1.6-7) on training and supervision. This needs to include: support to help staff and carers recognise and manage better their own stress responses to the impact that client's behaviour has on them.	Thank you for your comment, the GDG agreed that it is important to include support for staff and have added a recommendation to reflect your suggestion, see new revised recommendation number 1.1.7.
Association for Cognitive Analytic Therapy	5	NICE	1.5.10	28	Functional Analysis This should go beyond the ABC linear model described (Antecedents, Behaviour and Consequences) and include how the client's behaviour impacts on staff / carers / families and then how their reaction impacts on the client and how this sets up a fixed and stuck interactional pattern.	Thank you for your comment, but the impact of behaviour that challenges has been covered in the recommendations on initial assessment.
Association for Cognitive Analytic	6	NICE	1.5.13	30	*Behaviour Support Plan As well as identifying strategies that stop conditions that promote*	Thank you for your comment, the suggestions you make would be covered by the first two bullet points

Therapy					*challenging behaviour,* a ***first*** step is to identify constructive opportunities that the client finds positive which include relational opportunities i.e., an awareness and description of the patterns of interaction between the client and those people who get on best / worst with them.	that recommend identifying and adapting the environment of the individual.
Betsi Cadwaladr University Health Board	1	NICE	1.4.1	11	(Consideration of) communication difficulties – effective and functional	Thank you for your comment, however the GDG felt the current terms used to be sufficient.
Betsi Cadwaladr University Health Board	2	NICE	1.6.5	14	(Interventions) to include effective / functional communication strategies	Thank you for your comment. The recommendation to which you refer is specifically about interventions based on behavioural principles, and the points you have raised about communication are more general and sufficiently covered elsewhere in the guideline.
Betsi Cadwaladr University Health Board	3	NICE	0	15	expressive communication – may be non-verbal – use of signs / augmentative systems Receptive language – need to clarify either spoken or written	Thank you for your comment. The definitions have been revised to address your concerns.
Betsi Cadwaladr University Health Board	4	NICE	1.1.1	17	Need to distinguish between appropriate language and language level – clarify as developmental levels of language acquisition / symbolic development needs to be considered when providing pictures / easy read information	Thank you for your comment. The recommendation has been revised to clarify that 'appropriate language' refers to language that is suitable for the person's cognitive ability and developmental level.
Betsi Cadwaladr University Health Board	5	NICE	1.1.2	17	Language skills and development needs to be included when relating to developmental stages	Thank you for your comment. The recommendation has been revised to include communication difficulties. Revised recommendation number 1.1.1 has also been amended to take account of cognitive and developmental levels.
Betsi Cadwaladr University Health Board	6	NICE	1.1.3	18	include relationship between effective communication skills (lack of) and challenging behaviour	Thank you for your comment, the GDG reviewed your comment and decided that the relationship between communication and behaviour that challenges was sufficiently covered in the third bullet point of revised recommendation number 1.1.3.

Betsi Cadwaladr University Health Board	7	NICE	1.1.6	19	include effective communication strategies – under staff training and supervision	Thank you for your comment, however the GDG feels that this is covered by the current wording of the recommendation, and have ensured that effective communication is highlighted throughout the guideline.
Betsi Cadwaladr University Health Board	8	NICE	1.3	22	clarify appropriate language as appropriate language levels	Thank you for your comment. The recommendation has been revised to clarify that 'appropriate language' refers to language that is suitable for the person's cognitive ability and developmental level.
Betsi Cadwaladr University Health Board	9	NICE	1.5.5	25	effective and functional communication – as well as expressive and receptive	Thank you for your comment, however the GDG felt the current terms used to be sufficient.
Betsi Cadwaladr University Health Board	10	NICE	1.5.8	27	again use more effective and functional - difficulties rather than problems	Thank you for your comment, however the GDG felt the current terms used to be sufficient.
Betsi Cadwaladr University Health Board	11	NICE	1.5.12	13	Add in Brief Behaviour Assessment Tool (BBAT) as an example of a brief structured assessment	Thank you for this suggestion. However, the BBAT was not included in the review as no relevant evidence was identified, therefore it would be inappropriate to use it as an example.
Betsi Cadwaladr University Health Board	12	NICE	1.1.3	18	"Behaviour that challenges is communicating an unmet need" does not allow for needs being met through the challenging behaviour, even if this may be maladaptive.	Thank you for this comment. The focus of this guideline is on improving care and the quality of life for people with behaviour which challenges. From this perspective we see 'needs' requirements for personal, psychological and physical care and well-being which can be met by a broad range of formal and informal relationships and related health and social care interventions. Nevertheless, the wording has been revised to add some circumspection ('often indicates an unmet need').
Betsi Cadwaladr University Health Board	13	NICE	1.1.7	19	"deliver interventions based on the relevant manuals" is not helpful	Thank you for your comment. A definition of treatment manuals has been added to the glossary.
Betsi Cadwaladr University Health Board	14	NICE	1.5.4	25	"an explanation of the individual and environmental factors involved in developing or maintaining the behaviour from the person (if possible) and a family member, carer or a member of staff, including a teacher" should include the phrase 'if within an education setting' to place the Teacher reference within context	Thank you for your comment, but the GDG considers the wording to be clear as it stands.

Betsi Cadwaladr University Health Board	15	NICE	General	General	Too much repetition. Try more cross referencing instead	Thank you for your comment. Some recommendations are repeated by necessity. Those recommendations that are 'key priorities for implementation' appear both at the start of the guideline and in the main body of the guideline.
Betsi Cadwaladr University Health Board	16	NICE	1.5.13	30	Add in statements to: include reference to the individual's capacity to understand and consent to intervention State how the individual has contributed to their Behaviour Support Plan	Thank you for your comment. Issues of consent and capacity are covered elsewhere in the guideline, most notably in the 'Person-centred care' section, which applies to the whole guideline.
Betsi Cadwaladr University Health Board	17	NICE	1.8.3	36	Add in that if unpredictable behaviours occur and restrictive interventions are used on an unplanned basis to manage risk, this must then be reviewed, discussed and agreed by the individual and their multidisciplinary team. It is very important that the distinction between planned and unplanned is made.	Thank you for your comment. The recommendation has been revised to say that the delivery and outcome of the restrictive intervention should be documented and reviewed. Regarding your point about planned and unplanned interventions, revised recommendation number 1.9.2 has been amended to cover this.
Betsi Cadwaladr University Health Board	18	NICE	1.8.6	36	Add in duration	Thank you for your comment. Duration has been added to the recommendation.
Betsi Cadwaladr University Health Board	19	NICE	General	General	Positive behaviour support is not a key theme within the document. As this presents as very well evidence-based model that is at the heart of current best practice in most challenging behaviour services (and increasingly being adopted within mental health) I am perplexed at its absence.	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.

Betsi Cadwaladr University Health Board	20	NICE	1.5	General	Add in: Ethical consideration must be given to any form of behavioural assessment that seeks to provoke the challenging behaviour to occur (a feature of functional analysis / analogue assessment). Multidisciplinary discussion and agreement would be expected.	Thank you for your comment. The GDG would expect all interventions to be provided within the same ethical framework for all health and social care interventions
Betsi Cadwaladr University Health Board	21	NICE	1.10	36	Of all the manifestations of challenging behaviour, why are sleep problems singled out for special attention?	Thank you for asking about this. Psychological and pharmacological interventions for the management of sleep problems in children and young people with a learning disability was identified by the GDG as a key issue to be addressed by economic modelling (based on their expert opinion). Therefore, not only were sleep problems considered important, but there was some evidence to base recommendations on.
Betsi Cadwaladr University Health Board	22	NICE	General	General	Multidisciplinary working is at the heart of best practice yet this term features only once in the whole document (in relation to a positive response to antipsychotic medication). This should be a core theme throughout.	Thank you for your comment, the GDG agree that multidisciplinary working is important and think this is reflected in the recommendations, some of which have been revised. These include revised recommendation numbers1.1.4, 1.1.5 and 1.1.14.
Betsi Cadwaladr University Health Board	23	NICE	General	General	The comments I have made are instinctive, based upon my experiences of working with people with learning disabilities in an In-patient Day services setting. I appreciate that the guidance is based upon research evidence and that my comments are often personal reflections but I hope they are of some use. Apologies if they seem out of place for these reasons in which case please discount them, but I felt it important to contribute to this important area of understanding in whatever way I could.	Thank you for your comments.
Betsi Cadwaladr University Health Board	24	NICE	0	3	(Introduction) Paragraph 1. “A broad and detailed assessment is necessary” It would be my view that minimal interference in a persons privacy, a “light touch” approach and carefully targeted appropriate data collection for assessment would be less intrusive. This statement may cause us to intrude. (I understand this is more fully address further on in	Thank you for your comment, this has been amended for clarity.

					the draft guidelines but feel it should be clearer in the introduction and made principal).	
Betsi Cadwaladr University Health Board	25	NICE	0	3	(Introduction) Paragraph 2. It is difficult to understand our cognitions, feelings and emotions at the best of times. It is my experience that key in understanding these difficulties is in seeing them through the lens of social environments - relationships. The paragraph discussed interaction but is less explicit in its understanding of the interpersonal nature of challenging behaviour - it is co-created, that is, for the most part, located within the relationship. I think that we need to be asserting this as a safeguard against punitive approaches and to help us stop blaming and judging people. .	Thank you for your comment, the purpose of the introduction is to give a brief overview and therefore not possible to include the level of detail you request.
Betsi Cadwaladr University Health Board	26	NICE	0	4	(Introduction) I think the word “opportunities” might be added to the sentence “This includes those with limited opportunities for social interaction…..”	Thank you for your comment, this has been amended.
Betsi Cadwaladr University Health Board	27	NICE	General	General	I think the draft guideline is good and as always clearly attempting to focus best practice based on best evidence. I think it is a shame that there is such a reliance on the behavioural interventions and so little focussed on the person in the areas of resilience, therapeutic relationships, narrative therapies and the recovery model as it is in those domains that I have found most the most lasting outcomes for people in my practice. In stripping back, dissembling something in order to understand it, it is not always a working model that gets put back together at the end.	Thank you for your comment, unfortunately the GDG were unable to find any good quality research relating to the interventions you have listed, and therefore unable to recommend them. The GDG do accept that a therapeutic relationship is important in the delivery of interventions and revised recommendation numbers 1.1.1., 1.3.1, 1.3.3. and 1.4.1 outline the factors that should be taken into consideration to contribute to a positive therapeutic alliance.
Betsi Cadwaladr University Health Board	28	NICE	0	4	(Introduction) Regarding assessment, I think there should be a “taxonomy of intrusion”. It is perhaps too heavy handed to include all these assessments and interventions when some clear guidance about the necessity for a light touch approach would seem more respectful. Quality of life I agree is the important factor here but it would be important that	Thank you for your comment, this has been amended.

					this would be defined, wherever possible, by the individuals' values and not by the values of others or of services.	
Betsi Cadwaladr University Health Board	29	NICE	0	6	(Person centred care) Regarding capacity. I think it would be useful to add that where a deficit of capacity is identified, efforts are made to develop understandings and capacity over time with programmes commensurate with assessed communication skills.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Betsi Cadwaladr University Health Board	30	NICE	0	6	(Person centred care) What about service user experience in Learning disabilities? It is increasingly worrying that Mental Health perspectives are applied to Learning Disability Services and thinking.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback. The guideline does make specific recommendations for working with people with learning disabilities and behaviour that challenges to improve their experience of care in section 1.1 of the guideline.
Betsi Cadwaladr University Health Board	31	NICE	0	8	(Strength of recommendations) I think this page is really important. Attempts to hypothesise function are precisely that.	Thank you for your comment.
Betsi Cadwaladr University Health Board	32	NICE	1.1.2	10	(general principles of care) Under general principles of care I think that we should add something about the importance of updating and reviewing plans, of having a responsive," live" plan, as all too often the person needs to become challenging to get their plan changed which defeats the purpose.(I see this is addressed later on)	Thank you for your comment, revised recommendation number 1.1.2 is an overarching recommendation about all care for people with a learning disability and behaviour that challenges. Revised recommendation number 1.5.8 is specifically about behaviour support plans and includes, as you suggest that these plans should be regularly reviewed.
Betsi Cadwaladr University Health Board	33	NICE	1.1.5	11	(general principles of care) I note that this does not include behavioural analysts as distinct from nurses or psychologists. Given the emphasis on behavioualism in the draft guidelines it surprises me. I am however uncomfortable with the rigour of ABC charts and BBATS and the conclusions drawn from them. (1.1.5) and believe broader, more holistic models of understanding are necessary. I think that often the PBS plans masquerade as holistic by	Thank you for your comment. The GDG agrees and has added behavioural analysts to the recommendation. The GDG agree that a support plan should take a broad view and integrate the different elements of assessment and intervention. This is set out in revised recommendation number 1.6.1

					virtue of the numerous parts but as they are considered separately I question the rigour of re-connecting these parts into a holistic view of a whole human being.	
Betsi Cadwaladr University Health Board	34	NICE	1.3.3	11	(support for family members) Regarding support for family members: The list details the importance of advocacy and information but not skills and education. All too often, given the interpersonal nature of behaviours which challenge, families are in need of this too. Nirje Singh work on teaching mindfulness to carers showed greater impact over time teaching family and carers than teaching service users or having a PBS plan.	Thank you for your comment. Following a number of similar comments, the GDG has expanded the recommendation on providing support to family members and carers to include skills training for families and carers.
Betsi Cadwaladr University Health Board	35	NICE	1.4.1	11	(early identification, pages 11-2) Regarding early identification: A recipe for challenging behaviour in my life would be inequality - health inequalities for people with LD persist.	Thank you for your comment, the GDG agree that health inequality is an important issue for people with a learning disability and behaviour that challenges and hope that this guideline will go some way to address these inequalities.
Betsi Cadwaladr University Health Board	36	NICE	1.5.2	12	(assessment) I think this is a good list. It counters the comment in the introduction which gives the impression that broad and detailed assessment is what everyone should have across the board. I do think the word “Skills” should be added by “resources” again as a way of broaching the subject that challenging behaviour is co-created.	Thank you for your comment, the recommendation has been amended in line with your suggestion.
Betsi Cadwaladr University Health Board	37	NICE	1.5.7	12	(Risk Assessment) Regarding Risk Assessment: I think risk of relationship breakdown is so important and this might be added next to the sentence “..breakdown of relationships, family or residential support.”	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
Betsi Cadwaladr University Health Board	38	NICE	1.5.12	13	(functional assessment) Regarding functional assessment: I think something about including the person themselves should rightly be included here. There narratives are most important in this assessment collaboration.	Thank you for your comment, however the GDG feels that revised recommendation 1.5.2 adequately highlights that the person should be fully involved in the assessment process.
Betsi Cadwaladr University Health Board	39	NICE	1.6.5	14	(Psychosocial, psychological and environmental interventions) I would wonder which other approaches may be	Thank you for your comment. The GDG reconsidered this recommendation and have made some changes for clarity. However, the important

					considered? I note the word “consider” has been used - does this suggest there are other approaches or that the behavioural approaches are not entirely “gold standard” perhaps to add other approaches for which there is evidence?	issue is that health care professionals should consider using personalised psychosocial interventions based on behavioural principles and functional assessment of behaviour. This gives some flexibility while remaining evidence based.
Betsi Cadwaladr University Health Board	40	NICE	0	16	(terms used in the guidelines) Regarding terms used in the guidelines: Reinforcer: I have seen examples in practice of this which have been somewhat demeaning and humiliating, Care must be taken to ensure that the person is not perceived as would be one of Skinners Pidgeons to be imprinted but as an equal and whole human being. I do wonder if this system is ever ethical.	Thank you for your comment. The definition has been revised to say ‘Any event or situation that follows a behaviour and increases the likelihood of that behaviour happening again.’
Betsi Cadwaladr University Health Board	41	NICE	1.1	16	(General Principles of Care) Regarding 1.1 General Principles of Care : I really like this section but I think it should be more pre-eminent.	Thank you for your comment. The GDG agrees that this section is important, which is why it is the first section of recommendations in the guideline. The section will be given further pre-eminence in the NICE Pathway.
Betsi Cadwaladr University Health Board	42	NICE	1.1.6	19	(Staff training and supervision) Regarding 1.1.6 : To the sentence “developing personalised daily activities “I think it would be good to add something about opportunities for variety, spontaneous activity or with opportunities to develop resilience in order to cope with variety. Poor active support can fast become a drudge and result in low motivation, lack of self-worth, depression, and low volition to improve things. Whether or not this is borne out by the research, it is certainly my experience.	Thank you for your comment. This recommendation is about what training should cover rather than the components of an intervention, therefore the GDG feels the wording is sufficient.
Betsi Cadwaladr University Health Board	43	NICE	1.3	22	(support and interventions for family members or carers) Regarding support and interventions for family members or carers: I would again like to see something about skills teaching and family counselling even here.	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges.
Betsi Cadwaladr University Health Board	44	NICE	0	General	“Nothing about me without me” and the principles of inclusion are of such importance in respectfully addressing health inequalities that I would be more	Thank you for your comment. The GDG commissioned two expert groups – one of service users, the other of carers of those with profound or

					comfortable with some clear evidence of service user involvement in the building and consultation of this guideline.	severe learning disabilities to input into the guideline – please see chapter 4 of the full guideline for further information.
Birmingham Community Healthcare NHS Trust	1	Full	General	General	**On behalf of the Trust-wide Psychology Services our comments are as follows:** We are impressed by the general breadth and analysis included and the inclusion of qualitative data of people with LD, their parents and carers, views on ABA, medication, the effect of good relationships and even the frequently elusive concept of 'love'. The emphasis on psychosocial models of care before biomedical approaches is encouraging. The document is heading in the right direction towards critical thinking, cogency, and impartial research and against simplistic and spurious reasoning. Encouragingly RCT evidence was also joined by analyses of singe case design methodology From a critical perspective, it is important that key interrelationships between important aspects of understanding and knowledge within the main document, are salient in the abridged document. The key themes here would be: appropriate environments for people with LD and staff/family training before more specific interventions can be considered. The Winterbourne scandal might be used as an example of how the most effective interventions will be hopeless with inept, uncompassionate and ungoverned service contexts.	Thank you for your comment. The NICE guideline does make recommendations for the best ways for staff to work with people with a learning disability and behaviour that challenges, and their environment.
Birmingham Community Healthcare NHS Trust	2	Full	2.5.1	25	(line 47) It is inaccurate to say that the incidence of challenging behaviour is 'unrelated to the degree of mind/brain dysfunction'. Whilst predictions based on assumed causal relationships between neuron and behaviour can be futile, there's so much in-between that suffers from parsimony, i.e. two people with the same neurological profile can behave differently. However, given that the degree	Thank you for your comment, the wording has been amended for clarity.

					of brain dysfunction could give rise to communication, reasoning and emotional regulation deficits resulting in more behavioural challenges, its is therefore a risk factor and therefore related, just not in a linear hypothesis. The degree of brain dysfunction and behaviour may be mediating variables whilst the role of communication, reasoning, staff competency etc could be the moderating variables between brain and behaviours. This exploration must be given some consideration in the document.	
Birmingham Community Healthcare NHS Trust	3	Full	2.5.3	29	(line 4) 'Capable environment' should be part of the introductions about ABA, PBS, medication reactive strategies etc. This is particularly important for the abridged document as the evidence for psychosocial interventions are extremely promising but cannot be separated from the effectiveness of the environment	Thank you for your comment, the guideline did review the evidence for the impact on the environment of behaviour that challenges and made a number of recommendations to take this review into account (see revised recommendations numbers 1.1.3, 1.1.6, 1.1.8, 1.4.1, 1.5.2, 1.5.5, 1.5.9, 1.6.1 and 1.7.5). The review did not identify any evidence relating to 'capable environments' and so the GDG were unable to refer to this in the NICE guideline specifically, however capable environments are discussed in the introduction to chapter 10 relating to environmental interventions.
Birmingham Community Healthcare NHS Trust	4	Full	4.4.2.2	73	(line 42) …physical or mental problem…'. Would be more helpfully described as 'emotional problem' in the context of the supporting qualitative evidence	Many thanks for your comment. From the focus group there was a clear distinction between physical and mental health problems as causes of behaviour that challenges which we felt was important to highlight. This can be viewed in the full report, Appendix U of the Full Guideline. We're not convinced that the qualitative evidence supports characterising their experience as only emotional problems, therefore think the wider terminology is more accurate.
Birmingham Community Healthcare NHS Trust	5	Full	7.2	116	(line 25) Omission of behavioural consequences: inadvertent reinforcement and inappropriate positive and negative punishment may contribute to the development of behavioural problems	Thank you for your comment. This section was based on the synthesis of 20 studies. Omission of behavioural consequences was not clearly demonstrated to be a risk factor.
Birmingham	6	Full	8.3	152	Overemphasis on the psychometrics of proxy-	Thank you for raising these issues. The GDG

Community Healthcare NHS Trust					methods of behaviour assessment that are listed. These measures cannot supplant direction observational methodology. The measures can be in combination with direct assessments but there are often issues of ecological validity with these scales and/or measures when used in isolation. There is also a lack of acknowledgment of carer ratings of behaviour frequency (which have their limitations). There should also be some discussion about the ubiquitous but in practice, somewhat flawed ABC chart. There could be more made on the assessment on severity, frequency and intensity of behaviour in addition to identification of the target behaviour. There may be an overly rash dismissal of observational methods. There was a comment that these have been shown to be lengthy and inconclusive. For example, Hanley et al's (2002) review of functional analyses studies excluded studies not using direct observation. Without it, it's difficult to establish empirical relationships between contingencies and behaviour. Iwata et al"s (1994) experimental epidemiological analysis of 152 functional analyses has not been quoted. With observational methods, only 4.6% of 152 single subject analyses failed to find a function for self-injurious behaviour. There was an interesting part in recommendations on the evaluation of medication effects, which did mention observation techniques. In our experience this has never featured in routine psychiatric practice, nor for that matter have any objective or psychometric techniques recommended. Given the commitment, single case design methodology can be used within routine medication interventions; the proxy psychometric scales will potentially be flawed in these clinical contexts when staff and parents are often happier that a medication is prescribed, regardless of actual	considered carefully the assessment process, deciding on a graduated approach. In recommendation 23 it states that an initial assessment should include a description of the behaviour (including its severity, frequency, duration and impact on the person and others) from the person (if possible) and a family member, carer or a member of staff, including a teacher

					behavioural outcome, hence potentially introducing inflated positive evaluations. Though not expanded upon in NICE or the original paper, this is a possible explanation for the greater effect of placebo over haloperidol and risperidone on aggression in Tyrer et al's (2008) study when as mentioned here on P60 - service users have large gaps in their knowledge of what medication they're on. Therefore, the placebo effect is unlikely to be within the individual treated, more of a proxy effect on staff/parent: perhaps they're more relaxed and positive towards the individual with LD, and therefore trigger fewer difficulties. A related future research recommendation in the full document could be made. The paper which was quoted in the full document - Matson and Neal (2008) -revealed an interesting effect. That is, from their review of the 12 studies of medication effects on challenging behaviour that made their inclusion criteria: 8 found improved effects of medication over placebo, 4 studies found that there was no difference. The 4 studies that found no difference were the only studies that employed direct observations, the other 8, finding improvements, did not use direct observation. The implications give rise for concern regarding how medications are routinely reviewed for effectiveness in clinical practice.	
Birmingham Community Healthcare NHS Trust	7	Full	12	264	The introduction states that the evidence for the efficacy of medication is 'lacking'. Perhaps Tyrer's study indicates that antipsychotics are effective, just less effective than sugar pills. Is there a more accurate way of describing this? e.g. positive benefits may not be due to traditional beliefs about medication's mechanism of action; or should it be said that evidence is that the assumed biochemical processes are not effective in adults with learning disabilities? One of Tyrer et al's recommendations is that antipsychotics should	Thank you for these comments. The GDG reconsidered the recommendations for medication and made a number of changes in response to stakeholder comments. In particular, when to use medication and consideration of the persons preferences has been clarified.

					not be routinely used for challenging behaviour in adults, which is perhaps more or less consistent with the present document, albeit more passively stated in the present document. The greatest concern here is about statements leading to the recommendations: that is that antipsychotics should be considered when behaviour is a) intractable or b) severe c) or presents a severity of risk to others. Routine psychiatric practice could take these statements to include almost all of the challenging behaviour referred, because severity, risk and intractability has not been operationalised within the document. How 'severe' or 'risky' does the behaviour need to be? If, for example, there is no 'capable environment' to live in, how does one evaluate intractability of behaviour? These statements of severity and risk could be conveniently quoted in well meaning, but inappropriate practice where the routine prescribing of antipsychotics continues with ambiguous but authoritative support for the foreseeable future. If it is accepted that there is no evidence for efficacy in adults, how will the severity, risk and intractability be helped by an antipsychotic? Should these issues not be addressed by a higher intensity - albeit more expensive - level of service provision, e.g. within forensic settings? We were interested in the advocating of paediatricians and psychiatrists in the necessary assessment of mental health needs within challenging behaviour. Given the emphasis on establishing environmental and interpersonal contingencies and psychosocial treatments, would communication be enhanced by advocating MDT assessment as in the NICE recommended model for ADHD and medication assessment? If we juxtapose the challenging behaviour assessment results, and there's differences of opinion, can we	

					let the decision maker (i.e. person with LD, parents/service manager) choose? The present document reveals the paradoxical positive findings for medication and challenging behaviour for children? Why is this, and can it be included for research recommendations? Is there, again, an effect of setting and interpersonal relationships that is moderating the medication - behaviour relationship more than adults, or do adults have different chemical imbalances not targeted by the medication?	
Birmingham Community Healthcare NHS Trust	8	Full	General	General	As a research recommendation in the full document, we would like to see some attention being given to potential for clinician biases in assessment and evaluating outcome. We are all potentially prone to confirmation biases when erroneously believing we are 'certain' of the reasons for client difficulties and that treatments 'work'. We are prone to feeling the compulsion to do something, otherwise we may worry that we are being neglectful, or we may be under pressure from parents and colleagues to provide a certain treatment. And whatever we are doing, this might feel better than doing nothing, even if, in reality, the treatment is ineffective or iatrogenic, we can easily convince ourselves otherwise through the process of cognitive dissonance.	Thank you for this comment which the GDG considered. Although an interesting issue the GDG did not think it warranted a recommendation as they were uncertain what impact such a recommendation would have on future NICE guidance in this area.
Black Country Partnership NHSFT	1	NICE	General	General	Considered overall that document is useful , current and positive	Thank you for your comments.
Black Country Partnership NHSFT	2	NICE	General	General	No specific mention of Capacity or consent in a separate / clear format	Thank you for your comment. Capacity and consent are mentioned in the 'Person centred care' section of the guideline with links to the relevant documentation provided.
Black Country Partnership NHSFT	3	NICE	General	General	Some parts of document appear repetitive which may reduce impact and interest for some people	Thank you for your comment. Some recommendations are repeated by necessity. Those recommendations that are 'key priorities for implementation' appear both at the start of the guideline and in the main body of the guideline.
Black Country	4	NICE	General	General	No specific mention of PBS	Thank you for your comment, we acknowledge that

Partnership NHSFT						PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Black Country Partnership NHSFT	5	NICE	0	7	(Person centred care) Closer working? Partnership working between health and social care alluded to although not strongly enough	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Black Country Partnership NHSFT	6	NICE	1.4.1	23	Query why syndromes conditions and behavioural phenotypes , life changes, emotional aspects are not included.	Thank you for your comment. The review of personal risk factors did not identify syndromes conditions and behavioural phenotypes, life changes, emotional aspects and therefore the GDG is unable to include these in the recommendation.
Black Country Partnership NHSFT	7	NICE	1.5.6	26	Too narrow, formulation maybe hypothesised but may not be concrete at this time (eg what has led…/ should be - what is considered to have led…). Need to clarify making plan with the individual after initial assessment	Thank you for your comment. The recommendation says 'sets out an understanding' therefore the GDG thinks it is clear that this is not necessarily concrete. Revised recommendation number 1.5.12 has been revised to make it clear that the written statement (formulation) should be re-evaluated after further assessment.
Black Country Partnership NHSFT	8	NICE	1.5.7	26	(Pages 26-7) Breakdown should include more broadly (eg include other to include day service, loss of placement , job loss etc . Should include offending behaviour	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
Black Country Partnership NHSFT	9	NICE	General	General	Intervention should include an acknowledge person centeredness not solely on outcomes and targets – agreed realistic / achievable goals bearing in mind the individual and those who care/ support the individual	Thank you for your comment, the GDG felt that this is exactly what the guideline aims to do and made recommendations such as revised recommendation numbers 1.1.1 and 1.1.2 to work with the individual to improve their quality of life in trusting and

						supportive way.
British Academy of Childhood Disability	1	NICE	1.2	22	Agree with a need for regular (annual) health checks. This should include regular dental checks from those able to manage children (or adults), with learning difficulties (with or without behaviours that challenge). There has been a useful survey of the challenges associated with dental checks in children and young people with a learning disability (with an emphasis on the use of dental imaging but also covering more general issues regarding dental checks): http://www.pencru.org/evidence/dentistry/	Thank you for your comment. Insofar as this guideline is concerned with behaviour that challenges in the context of learning disabilities, the recommendation makes reference to 'any physical health problems' and a 'physical health' review. The GDG would expect that this would cover pain and discomfort from untreated dental problems. They did not wish to specify individual causes of pain because such a list would be incomplete, but they have added a bullet point about recognising and managing pain.
British Academy of Childhood Disability	2	NICE	1.4.1	23	Agree strongly with the need to comprehensively assess physical health (including a dental check), during the early identification of the emergence of behaviour that challenges (even if annual health checks have been carried out). Importantly, any painful conditions, that may not be immediately obvious, can give rise to behaviour that challenges. It is extremely important when assessing the physical health of people with a learning disability (irrespective of behaviour that challenges, although this tends to make assessment more difficult), that they receive an equitable service with access to the same level of healthcare as those without a learning disability. The MENCAP report – Death by Indifference – tragically revealed the poor standard of healthcare that some people with a learning disability experience within the NHS: http://www.mencap.org.uk/death-by-indifference	Thank you for your comment, the GDG agree that health inequality is an important issue for people with a learning disability and behaviour that challenges and hope that this guideline will go some way to address these inequalities.
British Academy of Childhood Disability	3	NICE	1.5.5	26	(Sections 1.5.5 and 1.5.8, pages 26-7) Again, agree with including a comprehensive physical health check as part of the further assessment of behaviour that challenges when initial behavioural management approaches have not been successful.	Thank you for your comment.
British Academy of Childhood Disability	4	NICE	General	General	(Principles of Care) It is so important, for children and young people with learning disabilities, that there is reasonably	Thank you, the GDG agree that access to support for children and young people with learning disabilities is extremely important. They were

					ready access to CAMHS to help assess and then manage behaviour that challenges. So many parents report very long, frustrating and damaging delays in obtaining access to CAMHS around the UK. Implementing this guideline will be severely compromised where access to CAMHS is limited and/or very delayed. Also good access to other professionals (particularly speech and language therapy but also physiotherapy and occupational therapy), is vital in assessing and, where relevant, helping to manage behaviour that challenges in those with learning disabilities. Community Paediatricians have been a professional group increasingly expected to deal with behaviour that challenges in children and young people (including in children with learning disabilities), and in many cases are not resourced or even fully trained to deal with this properly and, to varying extents in the UK, are becoming overwhelmed with this aspect of their workload, as indicated in a survey covering 2013-14:  pmha submission for HSC.docx.docx.docx	mindful of this when drafting recommendations and believe that if followed, access to services will improve.
British Psychological Society	1	General	General	General	The Society welcomes this guidance as one of a number of documents aimed at promoting positive approaches to the support of people who engage in behaviours that challenge. General areas of the guidance supported by our members include: • The lifespan focus • The consistent message that assessment is a flexible, not fixed, process, depending on a person's needs/complexity • The emphasis on a person-centred approach to assessing and supporting	Thank you for your comments.

					people with learning disability and challenging behaviour, which involves the inclusion of the person and their support network in the assessment process. • Clear guidance on the use of medication with people who engage in behaviours that challenge. We do have some recommendations to further develop the guidance, which are outlined in the remainder of our comments.	
British Psychological Society	2	NICE	General	General	The Society welcomes the strong psychological focus of assessment and intervention in the document. This is consistent with the stated understanding that behaviours that challenge serve a purpose for the person and are the result of interactions between individual and environmental factors. We would, however, like to see a greater use of the term 'formulation' to link evidence from the assessment (including personal beliefs and meanings) with psychological theory and inform the interventions (British Psychological Society, 2011) assessment with interventions. This is included in Section 1.5.6 and 1.5.9, for example, but it would emphasise its importance if it was also used elsewhere. For example: Section 1.5.10 – "The formulation should include a functional assessment of the behaviour that challenges to inform decisions about interventions" Section 1.5.13 – "…develop a behaviour support plan based on a formulation of the behaviour." Section 1.6 – A new first paragraph, such as "All interventions should be clearly linked to the formulation of the person's behaviour".	Thank you for your comment. The GDG considers that it is clear in section 1.5 that assessment should lead to a written statement (formulation), which should lead to a behaviour support plan, but was conscious of the fact that many different professionals and staff will be involved in assessment and providing support and interventions, for whom the term 'formulation' will not be meaningful.
British Psychological Society	3	NICE	General	General	There is a strong focus on behavioural principles and a functional assessment of behaviour, as well as emphasising the need for assessment of a person's environment and other personal factors,	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning

					and maintaining a person-centred philosophy. These would all seem to fit well under the umbrella term of 'Positive Behaviour Support (PBS; Gore et al, 2013), but there is limited reference to PBS in the document. Given this is the term being used in recent DoH policy (2014), we think it would be helpful to include reference to the term PBS in the NICE guidance to explain the term and whether or not a PBS framework is recommended. For example, a paragraph on PBS could be added to the Introduction and / or General Principles of Care section.	disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
British Psychological Society	4	NICE	General	General	Although the guidance states throughout that the environment and other factors are important, our call for responses to the consultation indicates that new readers could get the impression that the document is focusing only on an antecedent-behaviour-consequence approach to assessment. We believe the use of the term PBS, as suggested above, would help to prevent such a misconception.	Thank you for your comment. We acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
British Psychological Society	5	NICE	General	General	The Society strongly recommends that throughout the guidance, it is highlighted explicitly that assessment of other psychological factors that can impact on behaviours that challenge should be considered. For example, a statement such as: "Consider assessing for additional psychological issues that may impact on the behaviours that challenge, such as anger, anxiety, trauma, attachment issues, relational issues or mental health problems" could readily be incorporated into sections 1.5.5 and 1.5.8. Intervention for such issues could be incorporated into 1.5.13, 1.6.5 and 1.9.1.	Thank you for your comment, please see revised recommendation number 1.5.2 which states that "all current and past personal and environmental factors" and revised recommendation numbers 1.5.4, 1.5.5 and 1.5.8 referring to 'coexisting mental health problems'.

British Psychological Society	6	NICE	General	General	The Society believes that the guidance is presently skewed toward adult services, which means that it does not always fit with the family-centred approaches recommended for use in children's services (e.g. Challenging Behaviour Foundation, 2014). For example: • There are very few references to education, no references to siblings, and the suggested measures are mainly for use with adults. • There is limited emphasis on the importance of early intervention despite the strong case made by the CBF and the identified need for screening for risk factors for challenging behaviour in children with LD. • There should be more emphasis on developmentally appropriate general principles (e.g. self- management or independence, which clearly varies depending on the age of a child). • It should be further emphasised that a young person's voice in a complicated system should not be 'drowned out' but is central to any decision making. This may require creative information gathering (e.g. talking mats). • There should be greater emphasis on behaviours that challenge being a difficulty for the whole family system and others who know and support a young person / adult with a learning disability. • It could be made clearer that anyone working with a young person / adult with a learning disability needs to be fully aware of the significance of their specific learning disability and associated needs.	Thank you for your comment, we have revised the recommendations to make it clear that unless specified otherwise they apply to children, young people and adults
British	7	NICE	General	General	As noted in our initial comment, the Society	Thank you for your comment. The guideline has

Psychological Society					welcomes the lifespan approach of the guidance. This does add challenges in terms of organisation of the recommendations, however, particularly with regard to which parts may be more or less pertinent for children, young people and their families. The present structure does not, in our opinion, achieve best clarity, which may cause confusion for professionals, services, service users and carers. We would recommend: • Clearly delineating key recommendations for adults and children, young people and their families. For example, having general recommendations for assessment, then a paragraph stating 'those working with children, young people and their families may need to particularly consider….' • A similar approach could therefore be taken for adults (e.g. considering issues relating to dementia) • Interventions for coexisting physical and mental health problems and sleep problems are currently placed after the 'Reactive strategies' section (1.8). They would appear better placed before this or as part of the 'Psychosocial, psychological and environmental interventions' section (1.6). • The current format of listing the fairly detailed 'Key priorities for implementation' and then the 'Recommendations' makes the guidance quite repetitive. We believe that it would be preferable to list the key priorities briefly at the beginning of a section, then have the detail, and then a summary box at the end.	been revised throughout to make it clear that unless specified otherwise the recommendations apply to children, young people and adults. Regarding your point about coexisting problems and sleep problems, these are not specific to managing behaviour that challenges, which is why they are placed at the end. The listing of key priorities is part of the current NICE template, and therefore cannot be changed.
British Psychological Society	8	NICE	General	General	Some very helpful elements in the Full guideline have not been included into the NICE version, which will be more widely used. For example, the formulation models outlined in Section 2.5 of the Full guideline would be a very helpful addition for	Thank you for these comments. The GDG did consider using the term formulation but decided not to do so as they felt it was possible, and potentially clearer to a wider readership, to explain what is covered by the term in simpler, more direct

					the NICE version.	language. We have revised the recommendations on joint working in light of your and a number of other comments to clarify team membership and competences.
British Psychological Society	9	NICE	General	General	Some assessment tools are recommended throughout the document. The rationale for these seems unclear (e.g. the ABS RC II is recommended but we believe this is now out of print). We are aware of the significant challenges in suggesting outcome measures in this area. We believe that it would be more useful to acknowledge these challenges and include reference to a list of measures that are commonly used, perhaps in an appendix. The Society's Faculty for People with Intellectual Disabilities of our Division of Clinical Psychology completed an evaluation project on outcome measures in this area, which recommended some measures for use based on clinician experience (Morris, Joyce & Bush, 2012), which could also be referenced.	Thank you for your comment. The GDG reflected uncertainty in the evidence by recommending that health care professionals 'consider' using assessment tools. The examples given were based on the GDG's expert opinion of what is commonly used. It should be noted that a new version of the Adaptive Behavior Scale (ABS) will be available this year, therefore the GDG continue to believe that the ABS and the Aberrant Behavior Checklist are appropriate examples. We have checked the reference you provided, but don't believe this would add anything over and above the review presented in the full guideline.
British Psychological Society	10	NICE	General	General	We believe that it would be helpful to have reference to some of the interventions that can be used for people with the greatest degree of intellectual disability, with an acknowledgement that the evidence base for their use is limited. For example, if consistent with a formulation, we would like to see reference to the following being considered: • Intensive interaction • Art and Music therapies • Drama therapy • Adapted communication techniques (e.g. Talking Mats) • Total communication environments • Teaching communication skills	Thank you for your comment, but the GDG believe the evidence supports the revised recommendation number 1.7, which potentially include at least some of the suggestions you make, if they meet the requirements set out in the recommendations.
British Psychological	11	NICE	General	General	The Society would like to highlight that Schuengel et al's (2010) review strongly suggests that	Thank you for your comment. The GDG were mindful of the issues you raise. However, there is a

Society					attachment insecurity, hostility and especially dismissive attachment in the behaviour of care staff is detrimental to the well-being of people with intellectual disabilities. Attachment Theory could be integrated more fully throughout the document in relation to these risks, particularly in relation to: • Attachment insecurity or disorganisation as a risk factor for family / placement breakdown to be assessed as part of the case formulation; • Promotion of positive, significant and enduring bonds with carers and others being a central goal of any intervention because it is such a risk factor for placement breakdown; • The ongoing assessment and promotion of positive personal bonds between family / care staff, professionals and client since the variation in personal qualities of staff; • The adoption of secure attachment as a construct of outcome (i.e. an end in itself).	guideline currently underway (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0675) that will address this specifically.
British Psychological Society	12	NICE	General	General	It would be helpful to emphasise that the guidance is for all people with a learning disability who engage in behaviours that challenge, consistent with the DoH 'Positive and Proactive Care guidance (DoH, 2014). Some parts of the guidance suggest that it is for people with a greater degree of intellectual disability. For example, in the Introduction, line 7, it states that "The amount of support a person with a learning disability receives will depend on the severity of the disability." This is not always the case; some people with the most challenging behaviour have a mild intellectual disability.	Thank you for the comment – line 7 was referring to everyday support for people with a learning disability (and no behaviour that challenges), rather than to people with a learning disability and behaviour that challenges. The wording has been adjusted to make it clearer.
British Psychological Society	13	NICE	0	3	The Society believes that it would be helpful that the guidance has included a clear statement about why the term 'learning disability' is used in preference to 'intellectual disability'. The Society	Thank you for your comment. There is further detail about why the term 'learning disability' is the preferred term in the full guideline (Section 2.1).

					prefers the term 'intellectual disability', as it is accepted internationally as outlined in the guidance. If the term 'learning disability' is kept, we believe that it is important that this is kept under review for any revisions to this document or others focusing on this population, given the developing nature of terminology internationally.	
British Psychological Society	14	NICE	0	3	A list of types of categories of behaviours that can be challenging is included in the second paragraph. We believe that it would be helpful to demonstrate that the list is not finite by including one of the established definitions of challenging behaviour outlined in other guidance. For example: *"Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion"* (Challenging behaviour – a unified approach; RCPsych, BPS, RCSLT, 2007)	Thank you for your comment. The definition of behaviour that challenges from the Royal College of Psychiatrists has been quoted in the introduction to the full guideline. The NICE guideline introduction is intended as a brief overview only.
British Psychological Society	15	NICE	0	3	The Society believes that people who have a diagnosis of dementia should be included in the list of people for whom behaviour that challenges might be more likely (outlined at the end of the third paragraph).	Thank you for your comment. Reference to dementia has been added to this section.
British Psychological Society	16	NICE	0	4	We believe that the importance of physical health support in care environments should be emphasised here, as this can have a key role in behaviours that challenge. This could be achieved by making the following adjustment to the final sentence of the first paragraph (suggested changes in italics): • " ….those that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse *and those that do not pay attention to physical health needs and pain recognition and management"*	Thank you for your comment, this has been amended

British Psychological Society	17	NICE	0	4	The Society strongly recommends that a section on Safeguarding Adults is also included here.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
British Psychological Society	18	NICE	0	6	(Person Centred care) When discussing informed consent, it would be useful to include some consideration of how to manage situations where the individual does not perceive their behaviour as a problem, and chooses not to engage with services, but others involved in their support are concerned about risk to themselves, others or the person concerned.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
British Psychological Society	19	NICE	0	8	(Strength of recommendations) The document suggests discussing interventions with service users. It does not, however, mention situations when meaningful discussion of guidelines with the person is not possible due to their level of understanding. It would be useful to have signposting to relevant guidance as to how such situations should be approached.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. However, the issues you raise are covered in revised recommendation 1.7.5.
British Psychological Society	20	NICE	1.1.2	10	(Key priorities for implementation) We think the following changes in wording would help emphasise: The need to provide support in all the environments in which a person spends time (e.g. school, short breaks service); the need for a consistent formulation across settings; that the person is the focus and not the behaviour; and that skills development for the person is important as well as changes to support (suggested changes in italics): • "- aim to provide support and interventions in the person's home, or as close to their home as possible, and in other environments that they regularly spend time (e.g. school, short breaks service), in the least restrictive setting" • "- aim to reduce the likelihood of the person needing to use their behaviour that	Thank you for your comment. The GDG agrees with your first point and has widened the recommendation to include other settings in which the person regularly spends time. The GDG also agrees with your third point and has revised the bullet point accordingly. Regarding your second point, while the GDG appreciates that it was one factor that might contribute to behaviour that challenges, there might be other mechanisms, therefore the GDG has opted not to include your suggestion because it would lead to too narrow a focus.

					challenges in the future, by supporting them to meet those same needs in more appropriate ways" (rather than "aim to prevent the development of future episodes of behaviour that challenges") • "- Offer support and interventions respectfully, and ensure that the focus is on improving the person's support and developing their skills."	
British Psychological Society	21	NICE	0	10	(General Principles of Care, pages 10-16) It would be helpful to reference key documents from the policy base in the section on General Principles of Care (e.g. Department of Health 2001, 2009, 2012, 2014).	Thank you for your comment. It is not NICE practice to include reference to policy documents in guideline recommendations as these often change and would quickly become obsolete.
British Psychological Society	22	NICE	1.1.5/1.3.3	11	(General Principles of Care) The Society recommends the following changes in wording to better reflect work with children and younger people with learning disabilities (suggested changes in italics): • In the first paragraph - "Occupational therapists, physiotherapists, physicians, paediatricians, pharmacists and Family Support Workers may also be involved" • In the final point in the 'Support and interventions for family members and carers' section - "Consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges. Consider offering short-term direct intervention to the siblings of the person with a learning disability if the difficulties they are facing can be directly linked to their sibling's behaviour that challenges."	Thank you for your comment. Recommendation 1.1.5 has been revised to be more inclusive, and now includes social care staff. Regarding your point about interventions for siblings, unfortunately no evidence was found to support this.
British Psychological Society	23	NICE	1.4.1	11	(Early identification of the emergence of initial behaviour that challenges, pages 11-12) The Society believes that the following changes to the list of personal factors that may increase risk	Thank you for making these suggestions. The GDG reviewed both the recommendation and the evidence, and agreed that some changes should be made, in particular with regard to the

					(listed as bullet points at the bottom of the page 11 and top of page 12) would better highlight risks for people with learning disabilities across the lifespan: • The inclusion of 'sensory sensitivities' and 'gender' as risk factors. • Replacing the term 'visual impairment' with 'sensory impairment'. • Adjusting the following wording (suggested changes in italics) - "Environments with little sensory stimulation and those with low engagement levels, or those with too much stimulation for a person's needs". • Adjusting the following wording (suggested changes in italics) - "Environments where disrespectful social relationships and poor communication are typical, including those that expose someone to lots of unfamiliar people who are unfamiliar with their needs and preferences, neglectful early family environments and those that are characterised by relational and emotional neglect".	environment.
British Psychological Society	24	NICE	0	15	(Terms used in this guideline) We believe that it is very helpful that the definition of 'Functional assessment' differentiates between assessment of the function of the behaviour and functional analysis. It would, however, be helpful to also include a definition of the latter term.	Thank you for your comment. Functional assessment is the preferred term in the guideline and the GDG thinks it is clear from the context what functional analysis means.
British Psychological Society	25	NICE	1.1	16	Many people with a learning disability are supported by paid care staff, and / or advocates, who are valuable stakeholders and key mediators for intervention for behaviours that challenge. We believe that this should be reflected in the title of this section, for example (suggested changes in italics): • "Working with people with a learning disability and behaviour that challenges, and their families, *carers, care staff and / or advocates*."	Thank you for your comment. Paid care staff are addressed by the recommendation, which applies to all professionals and staff working with a person with a learning disability and behaviour that challenges. The role of advocates is covered in other revised recommendation numbers, for example 1.5.4.

British Psychological Society	26	NICE	1.1.1	17	Given the focus on people working in health and social care settings providing compassionate care following the Francis report (2013), we think there should be reference in the guidance to some of the factors that can promote this throughout the guidance. As an example, we suggest the following changes to the first bullet point (suggested changes in italics): • "build and maintain a continuing, trusting and non-judgemental relationship. *Empathy, unconditional regard, and warmth should be enacted, modelled and promoted by all those working with a person whose behaviour challenges*."	Thank you for your comment. The GDG agrees that empathy and warmth are crucial, and are key components of a trusting and non-judgemental relationship.
British Psychological Society	27	NICE	1.1.2	17	We believe that the following changes to the first bullet point in this section would: Help remind readers that the behaviours that challenge are the result of an interaction between psychosocial and personal factors and not a diagnosis; and emphasise the broad nature of developmental stages (suggested changes in italics): • "Take into account the severity of the person's learning disability*, their developmental stage (including their level of cognitive, emotional and moral development), and their current psychological and social situation*".	Thank you for your comment. The recommendation has been revised to say "take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems", which the GDG feels covers the points that you and other stakeholders have raised, while keeping the recommendation as succinct as possible.
British Psychological Society	28	NICE	1.1.3	18	The Society believes that it would be helpful to make the following addition to the first bullet point in this section (suggested changes in italics): "the nature, development and course of learning disabilities *and other co-morbid conditions relevant to an individual (e.g. autism, dementia etc*.)."	Thank you for your comment, this recommendation is about the overall understanding of learning disabilities and behaviour that challenges. Recommendations are made regarding the treatment of coexisting conditions but it would not be practical to ask staff to have an understanding of any possible condition relevant to an individual.

British Psychological Society	29	NICE	1.1.6	19	We believe that the importance of physical health support should be emphasised here, as this can have a key role in behaviours that challenge. This could be achieved by the addition of a bullet point such as: "understanding of physical health issues, including pain recognition and management"	Thank you for your comment. Revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8, 1.8.1, 1.8.2 and 1.9.3 relate to identifying and addressing the physical health needs of people with a learning disability and behaviour that challenges. Recommendation 1.4.1 specifically relates to a physical health problem being a risk factor in the development of behaviour that challenges. In addition, pain management has been added to recommendation 1.2.1.
British Psychological Society	30	NICE	1.1.7	19	To ensure governance of clinical practice, we would recommend that there is an additional bullet point about supervision saying that practitioners engaging in behaviour support who are not regulated by a statutory body should be supervised by someone who is. This will provide additional accountability.	Thank you for your comment. Clinical governance procedures are outside of the scope. However, the GDG have been clear that all staff providing interventions for behaviour that challenges should be supervised irrespective of whether they are GMC or HPC registered.
British Psychological Society	31	NICE	1.1.7	19	We believe that the stress experienced by carers and staff as a result of behaviours that challenge needs to be recognised. For example, an additional bullet point such as: • "support to help staff and carers recognise and manage their own stress responses to the impact of behaviours that challenge."	Thank you for your comment, the GDG agreed that it is important to include support for staff and have added a recommendation to reflect your suggestion, see new recommendation number 1.1.7.
British Psychological Society	32	NICE	1.1.7	19	The Society recommends that the ABC or ABS are used as routine sessional outcome measures. Idiographic measures are mentioned elsewhere in the guidance in Section 1.5.8 and we believe that they should also be recommended here.	Thank you for your comment, the GDG reflected on this but decided that inclusion in revised recommendation number 1.5.8 is sufficient.
British Psychological Society	33	NICE	1.1.9	20	The guidance should specify that Local Authorities should be part of the designated leadership team.	Thank you for your comment. Local authorities have been added to the designated leadership team.
British Psychological Society	34	NICE	1.2.1	22	We believe that pain management should be included here, such as by adding the following bullet point; • *"An agreed plan for recognising and managing when the person is in pain"*	Thank you for your comment. The GDG agrees and has added a bullet point as you have suggested.
British	35	NICE	1.2.1	22	We believe that there should be a clear	Thank you for your comment, the GDG agree about

Psychological Society					recommendation that people with a learning disability should be given advice and guidance about support available to access services required to meet their physical health needs.	the importance of physical health checks but this would be beyond the scope of this guideline.
British Psychological Society	36	NICE	1.3.3	23	We believe that reference to other interventions for families and carers when they do not have an identified mental health problems. For example, additional bullet points could be added into section 1.3.3 including: • *"Consider the use of systemic interventions involving the family as a whole or wider members of the individual's network.* • *Consider direct interventions for carers if they are indicated by the formulation (e.g. stress management interventions)."*	Thank you for your comment. The GDG considered this and have amended other recommendations in section 1.3 to cover related issues they thought most important (e.g., short breaks and respite care; skills training and emotional support).
British Psychological Society	37	NICE	1.4.1	23	We recommend that the identification of attachment insecurity, and especially attachment disorganisation, is included. Attachment disorganisation is a strong risk factor for later mental health problems in the general population and specifically in children with a learning disability (Schuengel & Janssen, 2006). For example, an additional personal factor could be included as follows; "Attachment insecurity and attachment disorganisation"	The review of personal risk factors for the development of behaviour that challenges did not identify attachment difficulties and therefore the GDG is unable to include it in the recommendation.
British Psychological Society	38	NICE	1.4.1	23	The Society believes that dementia should be included in the list of personal factors.	Thank you for your comment; dementia has been added to the list.
British Psychological Society	39	NICE	1.4.1	24	To clarify for readers that 'developmentally inappropriate environments' applies across the lifespan, we would like to see an example for adults as well as for a child or young person.	Thank you for your comment. This is an example only, and the GDG considered that it was important to highlight particular issues for children.
British Psychological Society	40	NICE	1.4.1	24	We would like to see reference to congregant environments, which may not have taken account of compatibility of need. For example, an additional environmental factor could be included as follows: "congregate living environments, which the person hasn't chosen, where other people's behaviour or	Thank you for your comment. The recommendation has been revised to include reference to environments where staff do not have the capacity or resources to respond to people's needs, which the GDG feels captures your point, and points raised by other stakeholders.

					interactions cause the person difficulty (e.g. other people's noise)."	
British Psychological Society	41	NICE	1.5.2	24	We believe that staff and advocates should be included in the first bullet point.	Thank you for your comment. The GDG would expect staff to be fully involved in the assessment process as a matter of course. Advocates would have a particular role to play, that would require a different level of involvement than families and carers.
British Psychological Society	42	NICE	1.5.2	25	We would like to see the following additional detail about what should be assessed with regards to families and carers and to include care staff (suggested changes in italics): "- the resilience and emotional resources of family members, *carers, staff and others to provide a warm, consistent, and engaging social and physical environment* are assessed."	Thank you for your comment, however the GDG feel this is outside the scope of this guideline.
British Psychological Society	43	NICE	1.5.4	25	(1.5.4 page 25 and 1.5.8 page 27) We believe that it would be helpful for the guidance to provide further clarity on the intended difference between initial and further assessment. The overlap, or omission, of some factors in both / either section may cause confusion.	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
British Psychological Society	44	NICE	1.5.5	26	In the third bullet point, we would like to see reference to assessment of the relationships with other people that the person with a learning disability might live with.	Thank you for your comment. Relationships with other people that the person might live with has been added to the recommendation.
British Psychological Society	47	NICE	1.5.7	27	We would recommend greater specification of some of the risks that should be assessed in relation to 'breakdown of family or residential support'. For example: "breakdown of family or residential support, including the psychological processes (e.g. trauma, self-blame, grief etc.) that are associated with this."	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
British Psychological Society	49	NICE	1.5.10	28	We believe that it would be helpful to specify some of the consequences of a behaviour that should be assessed, For example, a fourth bullet point could be added such as: "identifying the impact of the behaviour on families / carers / staff, their behavioural response, and the	Thank you for your comment, but the impact of behaviour that challenges has been covered in the recommendations on initial assessment.

					impact this then has on the person with a learning disability.	
British Psychological Society	50	NICE	1.5.13	30	The wording at the beginning of this section suggests an assessment would be thought likely to change a behaviour that challenges. We think this should be clarified, such as: "Develop a behaviour support plan based on a shared understanding…."	Thank you for your comment, the recommendation has been revised as you have suggested.
British Psychological Society	51	NICE	1.5.13	30	We would recommend additions to the bullet points in the 'Behaviour support plan' section: Identify how the person reports pain and a pain management plan. identify constructive opportunities that the client finds positive which includes relational opportunities i.e., an awareness and description of the patterns of interaction between the client and those people who get on best / worst with them. Consider whether attachment-based interventions (Clegg and Sheard, 2002; Deschipper and Schuengel,, 2008; De Schipper et al., 2006; Sterkenburg et al., 2008; Schuengel et al., 2009;) would provide the conditions for improved attachment security. These could involve: - family sessions, client-specific training for staff (including video feedback) supervision direct psychotherapies organisational work such as provider conferences / workshops.	Thank you for your comment. Many of the points you have listed are covered in the initial assessment. The purpose of the behaviour support plan is to set out strategies to support the person. Regarding your point about attachment, no evidence was identified to show that positive attachments per se impact upon behaviour that challenges.
British Psychological Society	52	NICE	1.6.2	31	The parent training programs in section 1.6.2 should include giving parents information about how to think about/ understand the function of behaviours as well as developing communication and social functioning. We also wondered whether any specific parent training programs could be recommended (e.g. Triple P Parenting Programme).	Thank you for your comment. The GDG reconsidered this recommendation, but felt the focus on developing communication and social functioning was most important – other issues will be picked up by following a manualised parent-training programme. This has been clarified.
British Psychological	53	NICE	1.6.5	32	We would like some specific reference to areas of assessment that are particularly pertinent for	Thank you for your comment. The recommendation to which you refer is specifically about interventions

Society					children and young people. This could be achieved by including some additional bullet points in section 1.6.5, such as: "intervention across the range of settings in which the young person / adult with a learning disability spends time. addressing difficulties within the network that are contributing to stress in the family or for the young person / adult with a learning disability. supporting the emotional well-being of the children / people with LD (e.g. exploring and managing emotions)."	based on behavioural principles, and the points you have raised about difficulties in relationships and emotional regulation are more general and sufficiently covered elsewhere in the guideline. The GDG agrees that the guideline needs to take the needs of children and young people into account and has revised recommendation number 1.1.2 to state the need for interventions to be provided in settings where the person regularly spends time (revised recommendation number 1.1.2), including schools.
British Psychological Society	54	NICE	1.10	36	The interventions for sleep appear limited in their nature. We would like to see an additionally subsection outlining the evidence-based sleep interventions used with the general population.	Thank you for this suggestion, but this would go beyond the scope of the guideline.
British Psychological Society	55	NICE	1.8.2	35	We recommend that the Department of Health's 'Positive and Proactive Care' (2014) guidance is referenced here to link to the policy base for reducing restrictive practices.	Thank you for your comment, NICE guidelines do not reference policy documents in the recommendations as these often become outdated before the guideline is updated.
British Psychological Society	56	NICE	1.8.5	36	It should be clarified in the second bullet point that a planned restrictive intervention being in the person's best interests only applies if they lack capacity to consent.	Thank you for your comment. By referring to the Mental Capacity Act and the Mental Health Act, the GDG feels that this issue has been dealt with.
British Psychological Society	57	NICE	2	37	Our member have suggested other areas for research recommendations, including: • Comparing outcomes in residential care vs supported living for people with behaviour that challenges. • Comparison of the outcome and cost of placements made by LD specialist vs generic care managers for people who engage in behaviours that challenge. • Evaluating the outcome of attachment-based interventions for people with a learning disability who engage in behaviours that challenge who have difficulties relating to a history of attachment issues / trauma / abuse.	Thank you for this comment. The GDG considered that the first two suggestions may well be dealt with in research recommendation 2.4 and that the third suggestion would be better considered as part of work emerging from the NICE guideline on attachment disorders.

British Psychological Society	58	Full	2	18	(Section 2 line 2) To highlight that behaviours that challenge occur across care settings (e.g. DoH, 2014), we would recommend the first sentence in this section to be changed as follows: *"People may display behaviour that challenges in certain circumstances. This includes some people with a learning disability, in certain contexts."*	Thank you for your comment. The GDG reviewed your suggestion but agreed the current wording was sufficient.
British Psychological Society	59	Full	2.5.2	27	(Pages 27-8) We recommend some reference to attachment and trauma here, as this would be consistent with Section 2.4 (lines 33 and 41).	Thank you for your comment, the text has been revised to mention abuse at an earlier point in this section. Attachment is discussed in section 2.4, but is not repeated here as the evidence for its connection to behaviour that challenges is much weaker.
British Psychological Society	60	Full	4.2.1	55	(Pages 55-62) We believe that the inclusion of the service user quotes in this section is a valuable addition to the guidance.	Thank you for your comments.
British Psychological Society	61	NICE/Full	1.1.3/6.4.2	112	We believe that, given the overall strength of evidence being used to develop the recommendations, there is sufficient information for the following change to the second bullet point of Recommendation 13 (suggested changes in italics): "Individual and environmental factors related to the development and maintenance of behaviour that challenges, including the role of histories of abuse and attachment difficulties".	Thank you for your comment, the role of abuse is addressed in recommendation 1.5.8.
British Psychological Society	62	NICE/Full	1.4.3/7.4	148	*(Pages 148-9)* *We believe it should be specifically mentioned in Recommendation 19 that none of the scales reviewed had good psychometric properties.*	Thank you for your comment, but as described in the introduction to the NICE guideline, where the GDG felt that a recommendation was warranted, weaker recommendations were made using the word 'consider'. It is not usual for NICE recommendations to refer to the evidence base.
British Psychological Society	63	NICE/Full	1.5.2/8.5	163	We would recommend the following addition to Recommendation 21 (suggested changes in italics): "…all individual and environmental factors that may lead to behaviour that challenges are taken into account, including historical factors".	Thank you for your comment. The recommendation has been revised to refer to 'current and past personal and environmental factors'.

British Psychological Society	64	NICE/Full	1.5.4 /8.5.1	164	(Section 8.5.1 page 164 and section 8.5.4 section 167) We are unclear as to why the Aberrant Behaviour Checklist is suggested in Recommendations 23 and 27. Although it is suggested, in theory, as an example, repeatedly mentioning it is likely to bias its selection, when the evidence presented does not clearly indicate why this should be.	Thank you for raising this. The GDG discussed again your concern, but did not agree that there was any need to revise the examples given in the recommendation.
British Psychological Society	65	NICE/Full	1.5.12/8 .5.5	168	(Sections 8.3.1.3.1-2) Specifically naming the FAST (Functional Assessment Screening Tool) and MAS (Motivational Assessment Scale) in Recommendation 31 seems incongruous with the evidence presented about them in the evidence section (e.g. p.157), as there does not appear to be significantly more robust evidence for their use compared to the other measures described. We would prefer to see a specific comment highlighting the lack of good psychometric evidence for the measures reviewed and reference to a list of measures that are commonly used, perhaps in an appendix.	Thank you for this suggestion. The GDG discussed this again, but felt that for the recommendation to be useful, examples were appropriate (rather than an appendix).
British Psychological Society	66	NICE/Full	1.5.13/8 .5.5	169	To reinforce the notion that environment does not just refer to someone's physical surroundings, we would like to see reference to the social environment in the examples of proactive environmental strategies in the first paragraph. For example (suggested changes in italics): Identify proactive strategies designed to stop the conditions likely to promote behaviour that challenges, including changing the environment (for example, reducing noise, increasing predictability, promoting positive attachments) and promoting…"	Thank you for your comment, no evidence was found to support your suggested changes and therefore the GDG decided no change should be made.
British Psychological Society	67	General	General	General	**References** British Psychological Society (2011). *Good practice guidance on the use of psychological formulation*. Leicester: British Psychological Society	Thank you for these references. They have been screened for inclusion in the evidence reviews but none were identified that met pre-specified inclusion criteria for the intervention reviews but three have helped inform/shape some of the introductory/background discussion (ie DH

					Challenging Behaviour Foundation (2014). *Early intervention for children with learning disabilities whose behaviour challenges.* Briefing paper Clegg, J. & Sheard (2002). Challenging Behaviour and insecure attachment. *Journal of Intellectual Disability Research*, 46, 503-506. Department of Health (2014). *Positive and Proactive Care: reducing the need for restrictive interventions*. London: Department of Health. Department of Health (2012). *Transforming Care: A National response to Winterbourne View hospital.* London: Department of Health Department of Health (2009). *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: department of Health. Department of Health (2001). *Valuing People: A new Strategy for Learning Disability for the 21st Century*. London; Department of Health De Schipper, J.C. & Schuengel, C. (2008) Less secure attachment behaviour to specific caregivers is associated with maladaptive behaviour in day care. *Journal of Intellectual Disability Research,* 52, 726. De Schipper, J.C., Stolk, J. & Schuengel, C. (2006). Professional caretakers as attachment figures in day care centers for children with intellectual disabilityt and behaviour problems*. Research in Developmental Disabilities*, 27, 203-216. Francis, R. (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: The Stationary Office	2001, DH 2012, and RCPsych 2007). Please note that Department of Health documents are not routinely used as evidence and so tend to be picked up during the scoping search only.

					Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, J.C., Baker, P., Hastings, R.P., Noone, S.J. & Denne, L.D. (2013). Definition and scope for positive behavioural support. *The International Journal of Positive Behavioural Support*, 3 (2), 14-23. Morris, J., Bush, A, & Joyce, T. (2012). *Outcome measures for challenging behaviour interventions*. Leicester: British Psychological Society. 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. Sanders, M.R. (1999). Triple P-Positive Parenting Program: Towards an Empirically Validated Multilevel Parenting and Family Support Strategy for the Prevention of Behavior and Emotional Problems in Children. *Clinical Child & Family Psychology Review*, 2(2): 71-90. Schuengel, C. and Janssen, C.G.C. (2006). People with mental retardation and psychopathology; stress, affect regulation, and attachment: a review*. International Review of Research in Mental Retardation*, 32, 229-260. Schuengel, C., Sterkenburg, P.S., Jeczynski, P. & Jongbloed, G. (2009). Supporting affect regulation in children with multiple disabilities during psychotherapy: a multiple case design study of therapeutic attachment*. Journal of Consulting and Clinical Psychology,* 77, 291-301. Schuengel, C., Kef, S., Damen, S. and Worm, M.	

					(2010). 'People who need people': attachment and professional caregiving. *Journal of Intellectual Disability Research*, 54:38-47 Sterkenburg, P., Schuengel, C. & Janssen, C. (2008). Developing a therapeutic relationship with a blind client with a severe intellectual disability and persistent challenging behaviour. *Disability and Rehabilitation*, 30, 1318-1327. Schuengel, C., Sterkenburg, P.S., Jeczynski, P. & Jongbloed, G. (2009). Supporting affect regulation in children with multiple disabilities during psychotherapy: a multiple case design study of therapeutic attachment. *Journal of Consulting and Clinical Psychology,* **77**, 291-301.	
Calderstones Partnership NHS Trust	1	NICE	1.1.5	18	The importance of case management and a named care co-ordinator is not highlighted, particularly in reference to Team Working. The co-ordination and communication around the complex, inter-related factors is as important a contribution as the factors themselves. This is especially important for better supporting carers also. A number of services in our experience have moved away from case management models. We would suggest this is a must do for severe cases and ought to do for moderate.	Thank you for your comment, revised recommendation number 1.6.1 has been amended to state that there should be a specified care coordinator.
Calderstones Partnership NHS Trust	2	NICE	General	General	A group from Calderstones looked at this and felt they could otherwise support what was contained in this draft.	Thank you for your comments.
CALM	1	NICE	General	4	Guidance notes '*that child maltreatment is common'* CALM would suggest that the evidence indicates that the mistreatment of vulnerable adults should be regarded as common.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
CALM	2	NICE	General	6	The guidance notes that *'People who use health services and healthcare professionals have rights and responsibilities as set out in the NHS Constitution for England'.* Does this guidance incorporate UN charter on rights of individuals with	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it.

					disabilities and EC Human rights?	
CALM	3	NICE	1.6.5	14	CALM would support the guidance suggestion that interventions should be based on behavioural principles but would argue that an integrated approach which incorporates an awareness of the significance of attachment and of the potential for trauma to act as a causal factor in the development of challenging behaviour should be made explicit.	Thank you for your comment, but the GDG did not find any evidence to support the claim that attachment difficulties are a factor in the development of behaviour that challenges.
CALM	4	NICE	1.7.1	14	CALM strongly welcome the proposal that medication should only be offered in medication in combination with psychosocial, psychological or other interventions. The misuse of poorly evidence pharmacological interventions with the associated implications for morbidity and mortality is a national scandal. CALM would however express concerns about how this aspect of the guidance will be policed?	Thank you for your comment, the implementation of NICE guidelines is a local matter, however quality standards will be developed for this guideline which may inform the monitoring of the use of medication.
CALM	5	NICE	1.1.2	17	CALM welcomes explicit reference to the need for services to *'ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion'* Many parents and carers can feel very disempowered in their interactions with agencies and professional.	Thank you for comments.
CALM	6	NICE	1.3.4	23	CALM Believes that where appropriate and necessary, parents and carers should be provided with opportunities to access formal training.	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges. The guideline also makes recommendations for parent training in section 1.6.
CALM	7	NICE	1.5	24	(Pages 24-6) CALM welcome the stress on the early identification of the emergence of initial behaviour that challenges and early intervention but would suggest that a risk factor not identified which may be highly significant is the individuals pattern of attachment. Successful attachment to an attuned adult is	Thank you for your comment. The review of personal risk factors did not identify attachment difficulties and therefore the GDG is unable to include it in the recommendation.

					central to the development of both emotional regulation and empathy.	
CALM	8	NICE	1.5.2	25	CALM welcome the suggestion that the 'the capacity, sustainability and commitment of the staff delivering the behaviour support plan be assessed' but would express some anxiety regarding how this will be undertaken, using what methods and by whom?	Thank for your comment, please see the recommendations in the section on delivering effective care (revised recommendation numbers 1.1.4-1.1.8).
CALM	9	NICE	1.5.12	29	The Motivation Assessment Scale is a commercial product and while it offers many advantages has also been shown to suffer from poor reliability and thus potentially validity?	Thank you for raising this, however, in the full guideline it is acknowledged that the evidence is poor quality. However, the GDG felt it justified to give examples. The cost of any scales used is a matter for those funding the recommendations.
CALM	10	NICE	1.8.3	35	Reference to the need to assess for any known biomechanical risks, such as cardiovascular and musculoskeletal risks should also make reference to psychological risk s such as a history of abuse and trauma/	Thank you for your comment, abuse has been added as an example of a psychological risk.
CALM	11	NICE	1.8.5	36	CALM would suggest that NICE should make reference to ensure that training in reactive interventions is delivered in accordance with the British Institute of Learning Disabilities code of practice and preferably by a BILD accredited provider.	Thank you for your comment, it is beyond the scope of NICE guidelines to recommend who delivers training.
CALM	12	NICE	2	37	(Pages 37-40) CALM welcome the suggested areas for research but would argue that there is an urgent need for a review of the relative safety of restrictive physical intervention procedures and models. There is strong evidence of fatal outcomes linked to the misapplication of some procedures but also strong evidence that the risk of injury to service users may vary significantly depending on the model used. A robust investigation could therefore do much to significantly improve service user safety.	Thank you for this comment. The GDG considered the issue of safety during the review of reactive strategies (please see section 11.3 of the full guideline). They decided to set out a series of key principles to guide the use of reactive strategies including using the least restrictive and safest methods (please see section 1.9 of the NICE guideline), rather than recommend additional research be done as a priority.
CALM	13	NICE	General	General	Although CALM believe there is much to be supported throughout the guidance, we remain concerned to note that the guidance did not address the repeated illustrations of organisational	Thank you for your comment, the GDG agree these are important topics, however as you suggest they are outside the scope of a clinical guideline. The guideline does make some recommendations about

					failure and corruption that have characterised the provision of services to people with a learning disability (its not just Winterbourne!) and challenging behaviour. We would acknowledge that this was beyond the scope of the guidance but a failure to reference or suggest best practice guidance in more detail was an opportunity missed?	delivering effective care, see revised recommendation numbers 1.1.8-1.1.14.
Certitude	1	NICE	1.1.6	19	Teaching skills to reduce challenging behaviours shouldn't just about helping the person develop an alternative behaviour. Teaching skills that increase independence and self esteem that can increase quality of life. A higher quality of life is a setting event/establishing operation for the lower likelihood of challenging behaviours.	Thank you for your comment, the GDG agree that quality of life is of great importance and this has been added to revised recommendation number 1.1.2, and is also included as an outcome in revised recommendation number 1.5.10.
Certitude	2	NICE	General	General	The advice given for proactive strategies – physical environment considerations, adjusting task demand teaching coping and tolerance skills etc. may be useful for a range of challenging behaviour, it may not have much effect on sexually inappropriate behaviour. There seems to be a paucity of guidance on how to deal with challenging sexual behaviours – a section similar to the one of dealing with sleep problems may be useful	Thank you for your comment, sexually inappropriate behaviour is included under the broad heading of behaviour that challenges. The GDG did look for evidence specifically relating to sexually inappropriate behaviour, but was unable to identify any evidence that would have enabled us take up your suggestion.
Certitude	3	NICE	General	General	Advice and training for staff, carers and families working with people at risk of developing dementia to ensure the right support is provided. Ageing and dementia are not mentioned in the guidelines even though challenging behaviour is very common with people with dementia.	Thank you for your comment. The GDG agree that it is important to be aware of dementia, but as a coexisting condition readers should see the NICE guideline for *Dementia* for recommendations about this condition.
Certitude	4	NICE	1.5.5	26	A consequence analysis would be useful, even at the initial stage, to try and establish if a functionally equivalent skill could be taught. It would be a shame if someone had to wait until a functional analysis to have a specific need met.	Thank you for your comment, the recommendation has been amended to take account of yours and others' comments.
Certitude	5	NICE	General	6	Person Centred Care: This section does not sufficiently describe what person centred care (the term support would be preferable) is. A clear statement on what it is, looks like would be helpful.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Certitude	6	NICE	1.1.2	10	The statement that support should be provided in	Thank you for your comment. This recommendation

					the persons home or as close to as possible is arguably one of the most important points of the document. It would be great to have it reiterated within the general principles of care.	is a key priority and is included in the main body of the guideline in the section 'Principles of care'. However it should be noted that following several other comments from stakeholders, the recommendation has been widened to include other settings in which the person regularly spends time.
Certitude	7	NICE	1.1.2	10	Within the general principles of care, it would be helpful for additional statements about support to families to be included as well as skilling up / training family members. The advocacy statement does not feel sufficient.	Thank you for your comment. The GDG would like to draw your attention to section 1.3 which is specifically about support and interventions for families and carers.
Certitude	8	NICE	1.3.3	11	In providing support and intervention to family members or carers, training / skilling up of family members as well as sufficient access to respite / short breaks could be stated.	Thank you for your comment. The GDG agrees and has revised the recommendation 1.3.2 to include access to respite care. Skills training for families and carers is recommended in 1.3.3.
Certitude	9	NICE	1.1.2	17	Training / skill teaching for family members should be included.	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended revised recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges.
Certitude	10	NICE	1.1.8	20	(Sections 1.1.8-13, pages 20-1) Consideration should be given to including individuals and family members / carers alongside the other stakeholders in the actions stated.	Thank you for your comment. The recommendations in this section are about development of care pathways at the organisational level and therefore the GDG did not consider that individuals and their families and carers would be formally involved in this process. Other areas of the guideline do however emphasise the importance of their involvement (see section 1.1 and 1.3).
Certitude	11	NICE	1.3.3	23	Training / skills teaching for family members / carers should be included within the support provision	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges.
Certitude	12	NICE	1.6.2	31	The term "parent- training" is potentially offensive to family members and an alternative should be	Thank you for your comment. The term 'parent training' is universally understood and used in other

					sought. The training isn't about being a parent. There should be reference to any training being personalised to the family circumstances.	NICE guidelines, therefore the GDG prefer to use this term for consistency. It is implicit that any parent training programme will be personalised to family circumstances.
Certitude	13	NICE	1.6.4	32	Pre-classroom interventions should be aligned with home interventions. Care should be given not silo support to the "setting"	Thank you for your comment, however there was no clinical or health economic evidence that pre-school classroom based interventions should be aligned with 'home interventions'.
Certitude	14	NICE	1.6.8	33	Being meaningfully active is an essential part of providing effective support and should be highlighted throughout as a major factor.	Thank you for your comment, but the GDG feels that the current wording ("reflects the person's interests and capacity") is sufficient and clear.
Challenging Behaviour Foundation	1	NICE	1.6.1	31	(NICE version – 1.6.1 page 31 & Full version 4.5 and 5,4 pages 77-9 and 91-3) Family carers whom the Challenging Behaviour Foundation consulted felt that the recommendations to *consider* supporting families with information and training are not strong enough. Family carers felt that offering training and information to families should be a requirement (not optional as is implied by the word consider). Families felt that if the recommendation stayed as "consider" then the recommendation would be unlikely to make any difference to the support they received as carers. This was felt to be the case as the country is entering a further period of economic austerity so they felt that any "optional" recommendations are unlikely to receive funding. Families felt it was essential for the recommendations to be concrete and specific if they were to make a difference. The Challenging Behaviour Foundation acknowledges the explanation in p.8 of the NICE version. If this wording has been used because of the lack of evidence we recommend that this issue is clearly included in the research recommendations as it is very important to family carers.	Thank you for this comment. The GDG understand your concern, and although the evidence base for these interventions is relatively strong, the evidence for cost-effectiveness was weaker and this was one of the reasons why the GDG did not feel able to make a stronger recommendation. This is described in section 11.3 (Trade-off between net health benefits and resource use). With regard to research recommendations, the GDG had to prioritise what it felt was most important, and having reflected on this, still think what is presented in the NICE version of the guideline should have priority for funding.
Challenging	2	NICE	1.1.7	19	The guidance mentions that interventions should be	Thank you for your comment, revised

Behaviour Foundation					delivered by “competent staff”. The most common feedback that the Challenging Behaviour Foundation received on this consultation from family carers was the guidance should give details about experience and/or qualifications needed to carry out the assessments and interventions such a functional analysis and positive behaviour support planning. Families felt that the lack of detail around the qualifications needed in order to carry out these interventions undermined the strength of the guidance significantly.	recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.
Challenging Behaviour Foundation	3	Full	General	General	Family carers provide feedback to the Challenging Behaviour Foundation (CBF) that the guidance should not use the language ‘medication for challenging behaviour’ as this promotes a medical model of challenging behaviour.	Thank you for your comment. While the GDG is concerned that the language employed by the guideline is not stigmatising, nevertheless this is a guideline about behaviour that challenges, and it is important that it is understood that when ‘medication’ is discussed that it is clear which indication it is for (behaviour that challenges or for other conditions).
Challenging Behaviour Foundation	4	NICE	1.7	33	(NICE section 1/7 page 33-5 & full version section 12 pages 264-315) Family carers expressed concern about the medication recommendations which were described as “weak”. In particular families felt they should be much more specific. For example 1.7.1 (NICE version) could state what a “specified” timescale is and provide a definition of “very severe”. There was concern that these recommendations would be open to interpretation and that one practitioner’s view of severe challenging behaviour could vary greatly to another leading to people being inappropriately prescribed antipsychotic medication.	Thank you for your comment. The section on medication has been revised substantively. In particular, the wording has been clarified to say that the timescale should be ‘agreed’ rather than ‘specified’ and examples of ‘very severe’ have been added.
Challenging Behaviour Foundation	5	Full	General	General	Family carers provided feedback to the Challenging Behaviour Foundation that they would like to see a co-ordinated approach across settings and details of who should do this and how	Thank you for your comment, revised recommendation number 1.6.1 has been amended to state that there should be a specified care coordinator.
Challenging Behaviour Foundation	6	Full	General	General	Family carers fed back to the Challenging Behaviour Foundation that they would like to see greater acknowledgment of sensory issues as a	Thank you for raising this. Sensory interventions were reviewed in Section 10.2, and 10.3 provides the rationale for the recommendations, including

					function of challenging behaviour and the need for sensory assessments and sensory diets. Was the literature on this area full reviewed? If there is a lack of evidence could this be included in the research recommendations? We acknowledge that there is reference to sensory profile and sensory interventions in the NICE version (1.6.7) but family carers experiences as reported to the Challenging Behaviour Foundation are that a sensory profile is not routinely conducted as part of a functional assessment.	acknowledgement of the paucity of evidence. The GDG felt there were many important areas needing further research, but did not believe this to be a priority.
Challenging Behaviour Foundation	7	General	General	General	Two different family carers fed back to the Challenging Behaviour Foundation that the guidance contained no mention of consent or the Mental Capacity Act including the importance of assessing capacity and best interest's decision making. The Challenging Behaviour Foundation acknowledges that these issues are covered on pg. 6 of the NICE version. Nevertheless we feel it would be helpful to refer back to this section at relevant points throughout the recommendations in the document as consent and capacity are such key issues to achieving good support for people with learning disabilities who display challenging behaviour and we are aware that there is poor implementation of the Mental Capacity Act (MCA). Poor implementation of the MCA was evidenced by the House of Lords Select Committee on the Mental Capacity Act 2005 published in 2014 which found that "the Act, in the main, continues to be held in high regard. However, its implementation has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives." *Full version available from http://www.publications.parliament.uk/pa/ld201314/l*	Thank you for your comment, as you point out there is a statement about the Mental Capacity Act at the beginning of the guideline and healthcare professionals have a legal obligation to implement this act in their practice. Also, revised recommendation number 1.9.1 makes reference to the MCA, an addition to the recommendations that was added after seeking legal advice on these issues. :

					dselect/ldmentalcap/139/139.pdf	
Challenging Behaviour Foundation	8	NICE/Full	1.5.2/8.5	163	Family carers expressed concern at the use of phrase "their family members or carers" because this could mean in practice paid carers were consulted instead of family carers. It was suggested by family carers that this should be re-worded. It would be helpful to reference the need to consult family carers in line with the Mental Capacity Act over best interest decisions when an adult lacks capacity to consent to assessment or interventions.	Thank you for your comment. The term 'family members or carers' is NICE's preferred terminology and is used throughout NICE guidance. However the definition of carers has been revised to make it clear that it does not refer to paid care staff. The definition of carer will be hyperlinked in the final document the first time the word is used in a section. The GDG feels that the person-centred care section covers the issue of capacity by linking to the code of practice that accompanies the Mental Capacity Act.
Challenging Behaviour Foundation	9	Nice	1.3	22	The Challenging Behaviour Foundation welcomes the inclusion of the recommendation to "Advise family members or carers about their right to a formal carer's assessment of their own needs (including their physical and mental health) and explain how to obtain it". Family carers fed back to the CBF that they would like to see the Carers Assessment conducted at the same time as the needs assessment of the person with a learning disability to ensure a co-ordinated approach. Families lived experience is that too many carers' assessments are carried out much later.	Thank you for your comment. The guideline emphasises prompt and integrated support and interventions for families and carers, but given that assessment for the person with a learning disability and behaviour that challenges may be a process rather than a single event, the GDG were not able to say that assessments should be conducted at the same time.
Challenging Behaviour Foundation	10	Full	General	General	Concern was raised that the full guidance was too long to be a useful to people with learning disabilities, family carers and practitioners.	Thank you for your comment. It is unavoidable that the full guideline is a long document as it details all the evidence reviewed to make the recommendations. However, NICE will also publish a document for the public and service users, with an easy read version available.
Challenging Behaviour Foundation	11	Full	General	General	The studies rarely specify the level of learning disability; this should be an important consideration relating to the guideline recommendations and research recommendations.	Thank you for raising this. The GDG agree and highlighted this issue in several revised recommendation numbers (e.g., 1.1.2, 1.5.8)
Challenging Behaviour Foundation	12	Full	2.2	22	The Challenging Behaviour Foundation would like to query the prevalence figure of 12,000 – 30,000 as we believe this is too low.	Thank you for the comment. The reference was to Emerson, the figures have been checked with him and the text amended to include them.

					The Learning disability Census 2013 showed that there were 3,250 in inpatient settings and therefore if there were only 12,000 people in total that would leave less than 9,000 children, young people and adults living in the community. Additionally we would like to ask for the number of children and young people to be included as this is important for commissioners in planning services. Eric Emerson has estimated this to be in the region of 40,000.You will note this figure is higher in itself than the 12,000-30,000 figure quoted in the NICE guidelines. Please see the following 2 reference documents for details: "Children with learning disabilities whose behaviours challenge What do we know from national data? Data Supplement" by Anne Pinney. Published by the Challenging Behaviour Foundation in 2014 http://www.challengingbehaviour.org.uk/learning-disability-files/EIP-Data-Supplement.pdf and "Estimating the number of children in England with learning disabilities and whose behaviour challenge"" by Eric Emerson (2014) http://www.challengingbehaviour.org.uk/learning-disability-files/Estimating-the-Number-of-Children-with-LD-and-CB-in-England.pdf	
Challenging Behaviour Foundation	13	NICE	0	4	(Introduction) Family carers who the CBF consulted felt the wording "Be aware of or **suspect** abuse as a contributory factor to or cause of challenging behaviour in children with a learning disability." would lead to families feeling that they were always to be viewed with suspicion until proved innocent which would be unfair. The Challenging Behaviour Foundation recognises the importance of safeguarding children and suggests that changing the wording to "Be aware of and **consider** abuse"	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.

					would strike the correct balance between the very important task of safeguarding children and avoiding the vast majority of family carers (who in the main provide a loving family home) feeling stigmatised.	
Challenging Behaviour Foundation	14	NICE	0	4	(Introduction) The introduction highlights the importance of safeguarding children. The Challenging Behaviour Foundation considers that it would also be helpful to highlight the importance of safeguarding vulnerable adults in the introduction. This guidance came about because of the abuse of vulnerable adults at Winterbourne View.	Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.
Challenging Behaviour Foundation	15	Full	4.2.1	55	Line 8/9 states that 21% of participants had a severe learning disability, yet all the statements included in the service user experience (bar line 1-4, page 56) are quotes from those who have a higher levels of communication. Do you think is representative? Additionally you have considered how many 'people' were children and young people? Should children and young people be consulted separately?	Thank you for your comments. The GDG acknowledged from the outset that it may be difficult to get representative views from published qualitative research. Thus, the expert advisory group validation was commissioned. As part of this process, families of children with LD aged 7 to 21 were consulted.
Challenging Behaviour Foundation	16	Full	4.4.3	75	This currently reads 'The Challenging Behaviour Foundation invited 18 family members'. This is inaccurate. The Challenging Behaviour Foundation sent out an open invitation to our networks (500 + family carers) and from the responses we received, we then invited 18 family carers, of which 17 were able to attend and contribute.	Thank you for clarifying this information. We have updated the guideline.
Challenging Behaviour Foundation	17	Full	4.4.3	76	The misuse of medication was a very important issue raised in the focus group conducted by the Challenging Behaviour Foundation. In particular that it should always be linked to outcomes and monitored "Families are concerned that no one knows how to effectively measure the outcomes of medication… *'My daughter was given three medications changes in one month so it is difficult to separate out what effect they had on her'.* Additionally families highlighted the importance of	Thank you for your comment. The GDG were mindful of issues related to medication and working in partnership. We believe the recommendations reflect this.

					partnership working between professionals and themselves & the importance of physical health interventions – these points should be included in any other business or throughout the other sections.	
Challenging Behaviour Foundation	18	NICE/Full	1.1.1/4.5	78	Currently reads 'Provide information… in an appropriate language or format (including…). This could be re-worded as 'in an appropriate language or format for the individual (including but not limited to…'. This is important as providing an easy-read document to all service-users is not sufficient to meet the needs of all people with a learning disability.	Thank you for your comment. The recommendation has been revised to clarify that 'appropriate language' refers to language that is suitable for the person's cognitive ability and developmental level.
Challenging Behaviour Foundation	19	NICE/Full	1.1.6/6.4.2	113	Currently reads 'Training should also include delivering reactive strategies to manage behaviour that is not preventable'. It is suggested that non-preventable behaviour could be explained with an example or re-worded as this could be mis-interpreted.	Thank you for your comment. The phrase 'manage behaviour that is not preventable' has been removed.
Challenging Behaviour Foundation	20	Full	9.3.1	183	Use of 'learning difficulty' not learning disability. Suggest changed to disability so consist with terminology in rest of document.	Thank you for your comment, this has been amended.
Challenging Behaviour Foundation	21	Full	11.2.2.3.4	230	Other results such as increased parental ability to cope and prevention of home breakdown are important outcomes that have a significant effect on intervention effectiveness and economic value.	Thank you for your comment. We agree that these are important outcomes, however they could not be considered in the economic model as no appropriate data on those outcomes were available in the systematic review of clinical evidence. Moreover, it would not be possible to estimate the economic value of such outcomes, due to lack of any relevant data in the literature. In the discussion section of the economic model (11.2.2.3.11) we do acknowledge that parent training offers additional benefits beyond those considered in the economic analysis: "this analysis did not consider other benefits to the family and carers associated with group parent training, arising from meeting with other carers with similar experiences, sharing ideas and receiving peer support" These considerations have been taken into account when making

						recommendations (see Section 11.3, “Trade-off between clinical benefits and harms” & “Trade-off between net health benefits and resource use”).
Challenging Behaviour Foundation	22	NICE	0	5	(Introduction) The paragraph on medication was felt to be unclear and it was suggested this was reworded in plain English. It was suggested that this paragraph could include a brief reference to consent and the Mental Capacity Act or a reference to the more detailed guidance listed on page 6 which should be followed.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Challenging Behaviour Foundation	23	NICE	1	15	The definition of expressive communication was felt to exclude non-verbal communication as it says “using words and sentences”. It was felt that this definition should encompass people with learning disabilities who communicate using augmentative communication such as sign language or PECS. Expressive communication was felt to be any way in which a person makes requests, gives information etc. This does not have to be just verbally. It is important to be inclusive of people with all levels of learning disability and additional needs. Many people with severe learning disabilities whom the Challenging Behaviour Foundation represents use augmentative communication.	Thank you for your comment. The definitions have been revised to address your concerns.
Challenging Behaviour Foundation	24	NICE	1	15	The definition of receptive communication was felt to exclude non-verbal communication as it says “the ability to understand or comprehend language (heard or read)”. Other forms of communication to language can be receptive communication too, e.g. sign language can be ‘received’ and understood but is neither “heard or read”. It is important to be inclusive of people with all levels of learning disability and additional needs. Many people with severe learning disabilities whom the Challenging Behaviour Foundation represents use augmentative communication.	Thank you for your comment. The definition has been revised to address your concerns.

Challenging Behaviour Foundation	25	NICE		16	It was felt that the definition of reinforcer was misleading. A reinforcer is not always a reward.	Thank you for your comment. The definition for reinforcer has been revised, taking into account your comments and comments from other stakeholders.
Challenging Behaviour Foundation	26	NICE	1.6.6	32	Would benefit from a definition of who can be classed as having an 'anger management problem'. In our experience people with profound and severe learning disabilities are not described as having anger management problems.	Thank you for your comment. The points you have raised would have been part of the assessment process (see section 1.5) and the behaviour support plan (see revised recommendation number 1.6.1).
Challenging Behaviour Foundation	27	Full	5.1	80	Incorrect to say 'systematic review of family carers'- should read 'systematic review of research about family carers'	Thank you for your comment, this has been amended.
Challenging Behaviour Foundation	28	Full	5.1	80	Add that distress/trauma is likely to be experienced by all the immediate family when their family member is moved suddenly.	Many thanks for your comment. We have addressed the issue of transition in chapters 4 and 6.
Challenging Behaviour Foundation	29	NICE/Full	1.3.3/5.4	91	Suggest wording is changed to "offer family advocacy". The current wording of explain how to access family advocacy is problematic as in some parts of the country nothing is available for some family carers of people with learning disabilities and behaviour described as challenging.	Thank you for your comment. The GDG acknowledges the concerns you raise, however the purpose of guidelines is to set national standards regardless of the availability of services locally.
Challenging Behaviour Foundation	30	Full	*6.1.1*	94	*Line 17* 'are brought a sudden' doesn't make sense – amend to say 'are brought on by a sudden'.	Thank you for your comment, this has been amended.
Challenging Behaviour Foundation	31	Full	6.1.1	94	*Line 30- 38* Add that a difficult transition is likely to increase challenging behaviour or if no evidence for that, add that incidence of challenging behaviour is higher during adolescence when child-adult service transition takes place.	Thanks you for your comment. We have amended the text accordingly.
Challenging Behaviour Foundation	32	Full	6.1.2	95	*line 11-16* Very long sentence, suggest amend.	Thank you for highlighting this. The sentence has been amended.
Challenging Behaviour Foundation	33	NICE/Full	1.5.2/8.5	163	'Assessments are repeated after any change in behaviour' is not clear enough. Suggest change to 'any significant change'.	Thank you for your comment. The change you have suggested has been made.
Challenging Behaviour Foundation	34	Full	2.6	29	(Pages 29 and 357, line 16) In the main document the Out of Sight report is referenced as Mencap 2013. Please change this to	Thank you for your comment, this has been amended.

					Mencap and the Challenging Behaviour Foundation. This was a joint publication by both charities	
Challenging Behaviour Foundation	35	Full	2.6	30	The Charter was developed by the “Challenging Behaviour – National Strategy Group” rather than the Challenging Behaviour Foundation. The Challenging Behaviour Foundation formed and Chairs the group but it has many members whom contributed to the development of the charter.	Thank you for your comment, this has been amended.
Challenging Behaviour Foundation	36	Full	4.1	52	The Charter was developed by the “Challenging Behaviour – National Strategy Group” rather than the Challenging Behaviour Foundation. The Challenging Behaviour Foundation formed and Chairs the group but it has many members whom contributed to the development of the charter.	Thank you for pointing this out, it has been amended.
College of Mental Health Pharmacy	1	NICE/Full	1.7.1/12.3	312	“Consider medication for people with a learning disability and behaviour that challenges if: - the person has a coexisting mental or physical health problem” I appreciate that this probably means that the behaviour that challenges might be because of a co-existing physical or mental health condition- and therefore symptoms such as unmanaged pain or anxiety may present as, for example, aggressive behaviour- however this isn’t clear the way it is currently written. For example: “46a. Consider medication (or optimise existing medication) for people with a learning disability and behaviour that challenges to adequately manage coexisting mental or physical health problems. 46b. Consider medication for people with a learning disability and behaviour that challenges if: □ psychosocial, psychological or other interventions alone do not produce change within the specified time or □ the risk to the person or others is very severe. Only offer medication in combination with …….” It is important that the focus is not on initiating an	Thank you for your comment. The recommendations have been redrafted to make it clear that medication for coexisting problems needs to be considered to help in the management of the behaviour that challenges.

					antipsychotic to manage aggressive behaviour, without first optimising physical meds to ensure that an individual is not in pain, or not constipated.	
College of Mental Health Pharmacy	2	NICE/Full	1.7.2/12 .3	312	47. When prescribing medication for behaviour that challenges, take into account side effects and develop a care plan that includes: □ a rationale for medication, explained to the individual (where possible), family members and carers Earlier in the document it stated that not everyone had been told why they were prescribed medication for behaviours that challenge- therefore vital that information about medication prescribed is shared with the person it is prescribed for (provided in a format/ easy read info that they can understand)- "nothing about me without me" It may be that medication is prescribed 'off-label' for the management of behaviours that challenge- and this should also be explained to the individual (where possible) and/ or family/ carers- and what this means in practice. □ how long the medication should be taken for □ a strategy for reviewing the prescription and stopping the medication. Although side effects are mentioned at the top- I think that the care plan should also include information about possible side effects and what to do about them (for the individual and/ or family/ carers) AND It should include any recommended monitoring that should be carried out prior to and during treatment with medication (where indicated) and how this will be achieved (i.e. invasive monitoring such as blood tests may be very distressing for some individuals and a specific approach may be necessary to ensure monitoring can be completed- in order to ensure medication can be prescribed safely.	Thank you for your comment. A statement about off-label prescribing has been added to the start of the guideline. Otherwise, the section on medication has been substantively revised. 'Explained to the person with a learning disability' has been added to bullet 1. The section also now includes reference to the psychosis and schizophrenia guidelines for the monitoring of side effects. The point you raise about blood tests needs to be borne in mind, but as this is a guideline specifically about behaviour the challenges, and not about learning disabilities more generally, this level of detail would not be appropriate.
College of Mental	3	NICE/Full	1.7.3/12	312	(Pages 312-3)	Thank you for your comment.

Health Pharmacy			.3		Recommendation no. 48- excellent to see so much detail included. In my experience- when reviewing the notes- it is not always clear when and why a specific medication has been initiated- and entries in the notes such as 'behaviour improved' are too vague to be able to interpret and fully evaluate how beneficial a medication has been and whether benefits still outweigh the risks.	
College of Mental Health Pharmacy	4	NICE/Full	1.7.4/12 .3	313	Recommendation No. 49 Just a very minor point- but in my opinion the order to things to be taken into account when prescribing medication should be in a different order, for example Change from current wording: "When choosing which antipsychotic medication to offer, take into account side effects, acquisition costs, the person's preference (or that of their family member or carer, if appropriate) and response to previous antipsychotic medication. " TO: "When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), the side effect profile, response to previous antipsychotic medication and potential interactions with other medication". In other NICE guidance I think the 'standard phrase is something like "where more than one medication is appropriate, prescribe the medication with the lowest acquisition cost". I think this just sends a better message in saying 'consider personal preference and appropriateness first- and then all things being equal- then consider cost…….	Thank you for your comment. On reflection based on this comment, and a review of the Psychosis and schizophrenia guideline, the GDG did not think that acquisition costs should be a consideration when choosing an antipsychotic.
College of Mental Health Pharmacy	5	NICE/Full	1.7.5/12 .3	313	Recommendation No. 50 With respect to the 'full multidisciplinary' team review- consider stating that this should include a pharmacist/ pharmacist feedback. It states that this review covers ALL prescribed medication (and	Thank you for your comment. Revised recommendation number 1.1.5 lists the professionals who should be involved as part of specialist assessment, support and interventions services, which includes pharmacists,, and

					should take into account any other medication, i.e. over-the-counter, supplements, possibly illicit drugs/ alcohol- and a pharmacist is ideally suited to advise on side effects/ potential interactions- and, where necessary, how medication can be administered (to prevent a change in bioavailability) where an individual struggle to swallow tablets. Medication- especially antipsychotics- may also affect swallowing and increase the risk of choking- therefore to have the input from a pharmacist- combined with SaLT to ensure optimal and safe use of medication is invaluable.	therefore the GDG does not feel that this needs reiterating here.
College of Mental Health Pharmacy	6	NICE/Full	1.7.6/12 .3	313	Recommendation No. 51 "When prescribing is transferred to primary or community care, or between services, the specialist should give clear guidance to the practitioner responsible for continued prescribing about: …" As well as giving clear guidance to the practitioner responsible for continued prescribing- the same advice needs to be shared with the family/ carers that will be supporting the individual- so that they are aware of what to look out for (i.e. side effects)- and what changes might indicate a review is needed. This could also consider including the community pharmacist- and potentially requesting a 'targeted review of medication on discharge' (introduced Dec 2014)- this could be done together with the carer.	Thank you for your comment. The point you have raised about communication with carers is covered by revised recommendation 1.8.5.
College of Mental Health Pharmacy	7	NICE/Full	1.7/12.3	312	(Pages 312-3) Whilst 'capacity' is referred to in other sections of the document- I think that the section referring to the use of medication as an intervention should refer to/ cross reference the issue of capacity. In my experience- people's capacity and understanding of their care and treatment can vary- and they may not be able to understand and retain information given to them about prescribed medication- although might willingly accept and take any medication that is offered to them. Where	Thank you for your comment. As you point out, capacity is covered elsewhere in the guideline, most notably in the 'Person-centred care' section, which applies to the whole guideline, not just the section on medication. The use of covert medication in people with a learning disability and behaviour that challenges was outside of the scope of this guideline.

					medication is prescribed/ administered in this situation- the care plan around medication has to take into account that this is a 'best interest' decision- I think it is important to highlight this here. Likewise- because I am sure it is a scenario that occurs in practice- I think there should be reference to/ guidance on the administration of covert medication. There is clear guidance in professional standards/ codes (i.e. NMC) regarding this- but trained non-registered staff are also involved in supporting people with their medication- and I think it is important that there is clear guidance around this issue- to support staff- but also ensure that medication is always prescribed in the persons best interests where they have no capacity to be able to make an informed decision themselves.	
College of Mental Health Pharmacy	8	NICE	1.4.1	11	("Early identification" section) Consider adding " side effects of medication" to the list of factors that may increase risk	Thank you for making this suggestion. The GDG reviewed both the recommendation and the evidence, and decided that some changes should be made, in particular with regard to the environment.
College of Mental Health Pharmacy	9	NICE	1.7.1	14	('Medication') See comment No. 1 re. full guidance	Thank you for your comment. The recommendations have been redrafted to make it clear that medication for coexisting problems needs to be considered to help in the management of the behaviour that challenges.
College of Mental Health Pharmacy	10	NICE	1.1.5	18	(Pages 18-9) "Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved". *Please consider change of wording to:* *"Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists should be available to support the core multidisciplinary team in delivering specialist interventions and treatment reviews when indicated".* *This recognises that not everyone will need specialist intervention from e.g. a pharmacist- but for those that do- these healthcare professionals*	Thank you for your comment. The recommendation has been revised to be more inclusive.

					should be available as opposed to 'may also be involved' Consider specifying a 'dietician' –nutritional advice may also be an important intervention- especially as lifestyle and prescribed medication may increase the individual's risk of developing metabolic syndrome.	
College of Mental Health Pharmacy	11	NICE	1.2.1	22	a review of all current health interventions, including medication and any side effects ***and recommended monitoring*** Good practice would be to access/ take into account any medication reviews that have been completed by a pharmacist to inform the annual physical health check (secondary care or community pharmacist) e.g. a medication usage review. (This could also include how the medication is take rather than just indication/ side effects & monitoring- and may highlight a need to consider a different medication and/ or formulation depending on practical issues the individual is experiencing (e.g. from swallowing tablets, to inhaler technique).	Thank you for your comment, monitoring of medication and side effects would be as part of the shared care management plan as recommended in the final bullet point.
College of Mental Health Pharmacy	12	NICE	1.5.5	26	6th bullet point "any physical or mental health problems, and the effect of prescribed and other medication " Assume that 'other medication' is referring to non-prescribed 'over-the-counter medication and supplements……but could also include illicit substances- is it worth elaborating on 'other' to ensure clarity?	Thank you for your comment. The recommendation has been simplified to just 'medication'.
College of Mental Health Pharmacy	13	NICE	1.7.1	33	Please see comment No. 1 in this feedback (on full guidance)	Thank you for your comment. The recommendations have been redrafted to make it clear that medication for coexisting problems needs to be considered to help in the management of the behaviour that challenges
College of Mental Health Pharmacy	14	NICE	1.7.2	33	Please see comment number 2 in this feedback (on full guidance	Thank you for your comment. A statement about off-label prescribing has been added to the start of the guideline. Otherwise, the section on medication has been substantively revised. 'Explained to the person with a learning disability' has been added to

						bullet 1. The section also now includes reference to the psychosis and schizophrenia guidelines for the monitoring of side effects. The point you raise about blood tests needs to be borne in mind, but as this is a guideline specifically about behaviour the challenges, and not about learning disabilities more generally, this level of detail would not be appropriate.
College of Mental Health Pharmacy	15	NICE	1.7.4	34	Please see comment No. 4 in this feedback (on full guidance)	Thank you for your comment. On reflection based on this comment, and a review of the Psychosis and schizophrenia guideline, the GDG did not think that acquisition costs should be a consideration when choosing an antipsychotic.
College of Mental Health Pharmacy	16	NICE	1.7.5	34	Please see comment No. 5 in this feedback (on full guidance)	Thank you for your comment. Revised recommendation number 1.1.5 lists the professionals who should be involved as part of specialist assessment, support and interventions services, which includes pharmacists,, and therefore the GDG does not feel that this needs reiterating here.
College of Occupational Therapists	1	Full	2.1.2	20	There is reference to not all behaviours being dealt with by the criminal justice service; there needs to be an explanation about why. The terms ‘actus’ and ‘mens rea’ are used, these may need defining for some readers.	Thank you for your comment, this has been amended.
College of Occupational Therapists	2	Full	2.4	24	There is reference to sensory impairment; we would suggest this also includes sensory integration dysfunction.	Thank you for your comment, it was the consensus of the GDG that this term is not in widespread use in services and therefore this has not been added to the introduction.
College of Occupational Therapists	3	Full	3.3	34	Occupational therapy was also represented on the GDG; this should be included here.	Thank you for your comment, this was an oversight that has now been rectified.
College of Occupational Therapists	4	Full	7.3.2.6	144	The SIPT tool is referenced here. Were the Sensory Integration Inventory and Sensory Profile also considered?	Thank you for your comment. We included only methods and tools for which there were studies that reported sensitivity, specificity, reliability and validity. We did not find evidence for the tools you mentioned.
College of Occupational	5	Full	7.4	148	The table makes no reference to the tools discussed in the text. There is no explanation about	Thank you for this comment. Recommendation 19 makes reference formal rating scales and gives two

Therapists					when you might use the AMPS or the SIPT to assist in assessing challenging behaviour.	examples (the ABS, which is reviewed in section 7.3.2.7.10; and the Aberrant Behaviour Checklist, which is reviewed in Chapter 8). The other scales included in section 7.3 could also be considered, and this includes AMPS and SIPT.
College of Occupational Therapists	6	NICE/Full	1.5.8/8.5.2	166	We strongly believe that further assessment should include an assessment of the impact of occupation/activity.	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
College of Occupational Therapists	7	Full	11.1	207	(Pages 207-263) Should sensory integration be discussed somewhere in this section?	Thank you for your comment. We found no evidence for sensory integration and it will not be discussed in this section.
College of Occupational Therapists	8	NICE	1.1.1	17	Line 4 – range of interventions. We suggest that 'sensory' and 'occupational' interventions are added to this list.	Thank you for your comment. The guideline does not recommend any specific occupational interventions, so is unable add this to the list. 'Sensory interventions' were considered to be a component of environmental interventions – see revised recommendation number 1.7.5, which has been expanded in the light of your and other comments.
College of Occupational Therapists	9	NICE	1.1.5	19	Line 3 – We suggest that occupational therapists should be involved in services rather than 'may' be involved.	Thank you for your comment. The recommendation has been revised to be more inclusive.
College of Occupational Therapists	10	NICE	1.4.1	23	While environments with *little* sensory stimulation are a problem, our members tell us that over stimulation is a greater problem and this should be recognised here.	Thank you for your comment. Following a number of similar comments, the GDG has expanded the recommendation to include environments with too much sensory stimulation.
College of Occupational Therapists	11	NICE	1.4.2	24	'Consider changing the physical and social environment…' we suggest that 'sensory' and 'occupational' are included here.	Thank you for your comment. This recommendation has been deleted..
College of Occupational Therapists	12	NICE	1.5.5	26	The assessment needs to include the person's independent living skill level; their occupational abilities and needs.	Thank you for your comment, the recommendation has been amended in line with your suggestion.
College of Occupational Therapists	13	NICE	1.5.8	28	Line 6 – Changes to routine – should also include Changes to routine, activities and occupations.	Thank you for your comment. This recommendation has been redrafted following consultation, and all areas of assessment are now listed in revised recommendation number 1.5.5. The GDG

						nevertheless considers that activities and occupations would be covered by 'routine or personal circumstances'.
College of Occupational Therapists	14	NICE	1.5.13	30	It is important, whilst calming the person, to maintain an alert level of arousal to allow engagement in meaningful activity and occupation.	Thank you for your comment, the GDG felt that the point you raised is covered in the second bullet point to this recommendation (revised recommendation number 1.6.1).
College of Occupational Therapists	15	NICE	1.5.13	30	Whilst activities can be used for 'distraction and diversion', they also have an inherent therapeutic value in the management of challenging behaviour and this is not recognised in this statement.	Thank you for your comment. The GDG agrees, and feels this point is adequately covered by the second bullet point of this recommendation.
College of Occupational Therapists	16	NICE	1.6.7	32	We support the statement that sensory interventions, such as Snoezelen rooms, should not be used without first carrying out an assessment. However, our members advise us that a person's sensory profile is not established by a function assessment but by the sensory screening section of an occupational therapy assessment.	Thank you for your comment. Occupational therapists are part of the specialist service (set out in revised recommendation number 1.1.5), and therefore may be involved in the assessment (see revised section number 1.5).
College of Occupational Therapists	17	NICE	2	37	We would query why these four topics in particular have been identified as research recommendations. Re: section 2.2 on p38 - while there is limited evidence for the effectiveness of '*applied behavioural analysis or antipsychotic medication'*, there is also limited evidence for the use of sensory integration and occupational interventions. We would, therefore, like to see these topics included in the research recommendations.	The GDG developed this recommendation because the two interventions are the most commonly used interventions and around which considerably uncertainty exists. This is not the case with sensory or occupational interventions in this area where their use is significantly more limited
Contact a Family	1	NICE	0	6	(Person centred care) Best interest decisions. Can you add sentence regarding situation where young adult does not have mental capacity – and good practice of consulting with those involved with their care, including families, to see if they have any information about the person's wishes and feelings, beliefs and values You might also want to highlight the situations regarding children aged 16,17. It is in the code of practice re mental capacity – but would be useful to reinforce it by mentioning it here.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Contact a Family	2	NICE	0	6	(Good practice of patient experience for adults)	Thank you for your comment. This is standard text

					Could you mention importance of considering children and young people experience - not just adults or those in transition?	common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback. The guideline as a whole does apply to children and young people, as well as adults and all recommendations will be relevant to them.
Contact a Family	3	NICE	0	7	(Transition) Needs to take into account Children and Young People Act – 2014 – and where young person has an EHC plan – the transition plan **must** be integrated with this process.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Contact a Family	4	NICE	1.1.5	11	(Top of page) This only mentions health professionals – needs to include those in education who will also be involved in supporting the young person e.g. educational psychologist, SENCO,	Thank you for your comment. The GDG agrees and has added educational staff to the recommendation.
Contact a Family	5	NICE	0	16	(Staff) Should include SENCO and teaching assistants as well as teachers	Thank you for your comment. The definition has been revised to say 'educational staff' which is broader than 'teachers'.
Contact a Family	6	NICE	1.6.1	31	It says training for parent of children aged under 12 – however some families find problems get worse when their child approaches adolescent. Supporting young people at this time around understanding what is acceptable behaviour – might prevent some very challenging situations. Have you searched for the evidence of these interventions?	Thank you for your comment. The GDG reconsidered this issue and felt that they could make a new recommendation for changing the physical and social environment (see revised recommendation number 1.7.5).
Contact a Family	7	NICE	1.6.2	31	I have searched for the research in the full guidelines to support this statement – and cannot find any. We welcome consdieration of parent training to prevent or minimise problems occurring, but disagree with elements of this statement . 1) Please make clear training need to be parent training programs specifically for families of children with learning disabilities – delivered by trainers who also families with working with people with learning disability . We hear (and research has shown – ref SPRU behaviour and sleep	Thank you for your comments. In the full guideline, the review of parent-training can be found in Section 11.2, with justification for the recommendations in 11.3. The GDG considered the recommendation again, and made two changes to improve clarity. The number of sessions and duration was based on the evidence.

					research) that sending families on general parenting training programs are not helpful – and in fact can increase feelings of isolation and hopelessness 2) Timing of training - At Contact a Family we find most parents prefer day time course, not during of school holiday, ideally 10am-2 30 pm - as it is easy to attend while their children are at school, Evening course can be impossible for many to attend – especially if parent often has no one they can leave their child with as they have challenging behaviour. If possible offer training both daytime and evening – but we find daytime works best for most. 3) Challenge statement they 'typically consist of 8 to 12 sessions lasting 90minutes'. Talking to providers such as National autist society (Early Bird and Early bird plus), Triple P, Cerebra, Challenging Behaviour Foundation)– none of these are only 90 minutes long. Also suggest you look at research on this topic – mentioned in Cerebra briefing paper - http://www.cerebra.org.uk/English/getinformation/researchpapers/Documents/behaviourbriefingweb.pdf and SPRU - http://php.york.ac.uk/inst/spru/research/sums/c4eo.php	
Contact a Family	8	NICE	1.10.2	37	(Sleep issues) Could you mention advising families of other strategies that can also help making the bedroom more relaxing, and equipment such as weighted blankets http://www.cafamily.org.uk/media/389272/papt_english_sleeping.pdf and http://www.ncb.org.uk/media/875230/earlysupportsleepfinal2.pdf	Thank you for your comment. The GDG based this recommendation on the evidence reviewed in the full guideline. A functional analysis of the problem sleep behaviour as recommended in revised recommendation number 1.11.1 in the subsection was thought to be the most appropriate method to inform the interventions used.
Department of	1	General	General	General	Thank you for the opportunity to comment on the	Thank you for your comments.

Health					draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	
Department of Health, Social Services and Public Safety - Northern Ireland	1	NICE	General	General	The separation of and requirement for both assessment and risk assessment is helpful. Likewise, the use of medication in conjunction with psychological and psycho-social interventions rather than an intervention in isolation is essential.	Thank you for your comments.
Department of Health, Social Services and Public Safety - Northern Ireland	2	NICE	General	General	The emphasis throughout of the importance of patient inclusion in all planning is supported and welcomed, as is the inclusion of families and carers in the assessment and planning process if we are to acknowledge their expertise and knowledge of the person and the behaviour, in helping us arrive at an agreed understanding of what is going on for the person with learning disabilities.	Thank you for your comments.
Department of Health, Social Services and Public Safety - Northern Ireland	3	NICE	General	General	The focus on providing support at home or as near to home as possible will also be supported by families, carers and the professionals working with the person and their community.	Thank you for your comments.
Department of Health, Social Services and Public Safety - Northern Ireland	4	NICE	General	General	We would like to lend support for the emphasis on supervision, advocacy, audit and service reviews to safeguard good practice. However, some recommendation on governance arrangements would be helpful.	Thank you for your comment, the GDG recognise there are a range of individuals and organisations included in the management of service delivery. These issues are dealt with in the 'Delivering effective care' section of the guideline.
Department of Health, Social Services and Public Safety - Northern Ireland	5	NICE	General	General	It was felt that whilst a rationale for the terminology used had been given (i.e.: learning disability) this, and the use of the term "challenging behaviour" do not reflect the direction of travel in the area and have the potential to "date" the document quickly.	Thank you for your comment, the 'long title' for this guideline includes 'behaviour that challenges' and the guideline uses this term throughout. However the 'short title' has retained the phrase 'challenging behaviour' as it is anticipated that people searching the NICE website for this guidance will use this term.
Department of Health, Social Services and Public Safety - Northern Ireland	6	NICE	General	General	Emphasis on supervision, advocacy, audit and research is welcomed. Resources are however crucial to the delivery of all of the above. The issues of governance and governance frameworks, particularly in relation to Behaviour Support are not	Thank you for your comment, such a recommendation is outside the scope of the guideline and a matter for local implementation.

					addressed and comment would be helpful.	
Department of Health, Social Services and Public Safety - Northern Ireland	7	NICE	0	3	(Introduction) A definition of challenging behaviour should be given at the start of the report.	Thank you for your comment. A definition of behaviour that challenges is provided in the second paragraph of the introduction to the NICE guideline.
Department of Health, Social Services and Public Safety - Northern Ireland	8	NICE	0	3	(Introduction) Usefully includes forensic behaviours and presentations as part of continuum of behaviours, and the importance of similar approaches to manage such behaviours, and adequate resources to do so. The emphasis on importance of environmental factors and sensory considerations useful.	Thank you for your comment.
Department of Health, Social Services and Public Safety - Northern Ireland	9	NICE	0	6	(Person-centred care, pages 6-7) The use of the Transition process to support young people whose behaviour challenges, their families and carers, as they move to less structured Adult services, is a very useful role which will help address the very real anxieties of families. However, more support should be put in place to ease this transition. Child and adult services need to communicate more effectively with each other, service-users and their families. Therefore, a more holistic person-centred approach is needed that allows service-users and their families to make clear informed decisions about their future care and treatment.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Department of Health, Social Services and Public Safety - Northern Ireland	10	NICE	0	6	(Person-centred care, pages 6-7) There is generally limited reference to the key area of consent and its relationship with assessment and the intervention process. Human rights considerations and implications are not well addressed and have significant impact of daily delivery of care. This whole area needs expanding re consent, capacity and impact of legislation versus ethical and clinical issues.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Department of	11	NICE	1.1.2	10	(General principles of care)	Thank you for your comment, we acknowledge that

Health, Social Services and Public Safety - Northern Ireland					The general principles of care should have at their heart a Positive Behaviour Support approach to managing behaviour that challenges – this should be the cornerstone of the guidelines.	PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Department of Health, Social Services and Public Safety - Northern Ireland	12	NICE	1.1.5	11	(Support and interventions for family members or carers) Occupational Therapy should be included in the core team for specialist support and intervention. Evidence and practice would indicate that they have significant roles in this area with regards to issues such as sensory diets/ alert programmes/environmental recommendations / ADL recommendations / education and training and direct therapy.	Thank you for your comment. The recommendation has been revised to be more inclusive.
Department of Health, Social Services and Public Safety - Northern Ireland	13	NICE	1.5.2	12	(The assessment process) Appreciate thorough approach to consideration of all factors in assessment process. Good depth described and importance of ongoing assessment within Behaviour Plans etc. Need to use consistent language with regards to proactive/reactive interventions – title of section should reflect this i.e.: Proactive interventions will include psycho-social, psychological and environmental.	The GDG reviewed and revised the guideline to ensure that the terminology has been used consistently.
Department of Health, Social Services and Public Safety - Northern Ireland	14	NICE	1	15	In the Terms Used in this Guideline, Proactive strategies or Preventive strategies are not mentioned although Reactive strategies are. Positive Behaviour Support approaches view these as primary if the focus is to be on preventing the behaviours arising or being needed in the first	Thank you for your comment, the term 'prevention' is no longer used in the NICE guideline. The GDG felt that proactive strategies did not need defining because its meaning was clear from the context. We acknowledge that PBS is increasingly used as

					place and to minimise restrictive practice. There is an opportunity to better integrate and promote a model of Positive Behaviour Support within the document. This would reflect current work and give clear direction as to where the emphasis should be placed for service providers. This is seen when Proactive strategies are termed "psychosocial, psychological and environmental interventions" (page 14&31). It is important that a clear and consistent language is established and modelled in the document. Personal local experience of using an over-arching PBS policy which is then operationalised via PBS Plans, alongside clear governance structures and audit protocols has been invaluable.	an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Department of Health, Social Services and Public Safety - Northern Ireland	15	NICE		16	The guideline classifies a reinforcer as "a reward that follows a behaviour and increases the likelihood of that behaviour happening again". This does not apply to negative reinforcers when a certain stimulus/item is removed after a particular behavior is exhibited. (The likelihood of the particular behavior occurring again in the future is increased because of removing/avoiding the negative stimuli).	Thank you for your comment. The definition for reinforcer has been revised, taking into account your comments and comments from other stakeholders.
Department of Health, Social Services and Public Safety - Northern Ireland	16	NICE	1.1.2	17	It is important that a person-centred approach should be used when developing an intervention. However, in addition there is a need for more consideration for individual needs and preferences to enable service-users and families to make informed decisions about their care and treatment. Individual differences along with background information need to be taken into consideration when developing an intervention. We need to be wary of a 'one size fits all approach'. Individual needs need to be at the forefront.	Thank you for your comment. The GDG feels that the guideline has highlighted the importance of person-centred care, notably in revised recommendation numbers 1.1.1, 1.1.8 and 1.5.5, and in 1.1.2 by emphasising that the focus of support and interventions should not be changing the person but improving their care. The GDG has added to this that it is also important to increase the person's skills.
Department of Health, Social Services and Public Safety - Northern	17	NICE	1.1.6	19	(Sections 1.1.6-7 pages 19-20) Fully support emphasis on staff training and supervision – important that this includes health & social care professionals, parents & carers and	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills

Ireland					educational staff also.	and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges. As this is a clinical guideline, it is unable to make direct recommendations to educational staff.
Department of Health, Social Services and Public Safety - Northern Ireland	18	NICE	1.1.12	21	To ensure effective communication regarding the functioning of care pathways it is crucial that primary and secondary care professionals, managers and commissioners all work together.	Thank you for your comment, the GDG agree this is crucial.
Department of Health, Social Services and Public Safety - Northern Ireland	19	NICE	1.2.1	22	Recommendation re annual physical health check in all settings is very welcome. This is an ongoing challenge for people with LD admitted to hospital with poor access to Primary care. This is an ongoing resource issue. Also important that GPs not seen as those who are just informed but are integrated into the assessment of the clients and family. The role of dentists also important to note.	Thank you for your comments. The recommendation has been revised to state that GPs are responsible for carrying out the annual physical check. Dentists are not specified because the recommendation makes reference to 'any physical health problems' and a 'physical health' review. The GDG would expect that this would cover pain and discomfort from untreated dental problems.
Department of Health, Social Services and Public Safety - Northern Ireland	20	NICE	1.4	23	(Section 1.4-5 pages 23-31) There is a welcome focus on the importance and scope of assessment and this section is well developed and detailed.	Thank you for your comments.
Department of Health, Social Services and Public Safety - Northern Ireland	21	NICE	1.4.1	23	In addition to personal and environmental risk factors that can influence the challenging behaviour a person may present in their interaction with services – staff working with people with learning disabilities should have enough background information on each person so as to be able to recognise any early warning signs or triggers that could increase the risk of them displaying challenging behaviour. Background data should be collected for all service–users at point of entry and all staff working closely with them should be briefed.	Thank you for your comment, the GDG agrees this is an important issue and has revised the recommendation to say that personal and environmental risk factors should be recorded.
Department of Health, Social Services and Public Safety - Northern	22	NICE	1.5.2	25	The emphasis on an outcome approach and use of standardised assessments of change is appreciated and there is value in expanding the resources noted in this section – possibly considering developing a	Thank you for your comment, the assessment tools recommended is based on a review of the evidence of those tools and therefore we are unable to recommendation a wider range of options.

Ireland					toolkit or wider menu of available options.	
Department of Health, Social Services and Public Safety - Northern Ireland	23	NICE	1.6.7	32	Also welcome the emphasis on appropriate assessment in areas such as sensory profiles prior to any intervention being offered. However Snoezelen rooms seem a limited example to give re such interventions and a wider focus here would be useful.	Thank you for your comment, but the GDG believe that sensory interventions with the example of Snoezelen rooms will be understood by health care professionals working with people with learning disabilities.
Department of Health, Social Services and Public Safety - Northern Ireland	24	NICE	1.7	33	The role of pain relief as appropriate needs noted. The emphasis on use of medication only in conjunction with psychological and psycho-social interventions rather than an intervention in isolation is very welcome and supported.	Thank you for your comment and helpful suggestion. Pain management has been added to revised recommendation number 1.2.1.
Department of Health, Social Services and Public Safety - Northern Ireland	25	NICE	1.7	33	Document talks about antipsychotic medication – possibly better referenced as psychotropic medication as other groups of medicines other than anti-psychotics can be useful e.g.: antidepressants and anxiolytics.	Thank you for your comment, however there was no evidence for the use of psychotropic medication other than antipsychotics for behaviour that challenges in this population.
Department of Health, Social Services and Public Safety - Northern Ireland	26	NICE	1.7	33	Document recommends only prescribing single drug – however sometimes combinations are most effective and clinically relevant. To note that all p.r.n. should be stopped in 4 weeks is possibly optimistic. May be better stated as “all p.r.n. should be used for as short a time as possible, in conjunction with other therapies, and with strict documentation and review processes.”	Thank you for your comment. There is no evidence base for the medications being added in combinations. The GDG felt strongly that drugs should only be prescribed one at a time and each drug properly evaluated before considering prescribing a second either as an alternative, or in the case of a partial response, in addition. However the GDG agreed with your point about p.r.n medication and has adjusted the recommendation accordingly.
Department of Health, Social Services and Public Safety - Northern Ireland	27	NICE	1.7.3	34	Antipsychotic medication should only be considered if all other interventions are inadequate. Medication should be reviewed regularly for effectiveness and side effects. The service user and family members’ preferences should be taken into consideration before prescribing any medication unless in an emergency situation.	Thank you for your comment, revised recommendation numbers 1.8.1, 1.8.2 and 1.8.5 directly address your concerns.
Department of Health, Social Services and Public Safety - Northern	28	NICE	1.8	35	More work needed on whole area of restrictive practices. There is not enough detail.	Thank you for your comment. Restrictive interventions are covered in more detail in the guideline on violence and aggression – a cross-reference to this guideline has been added to the

Ireland						section on reactive strategies.
Department of Health, Social Services and Public Safety - Northern Ireland	29	NICE	1.8.3	35	This version mentions high/low thresholds of pain. GAIN guidelines on caring for people with a learning disability in general hospital settings (June 2010) advises that there is no evidence base for the suggestion that this population have higher thresholds for pain (http://gain-ni.org/images/Uploads/Guidelines/Gain%20learning.pdf)	Thank you for your comment. Reference to pain has been removed from this recommendation.
Department of Health, Social Services and Public Safety - Northern Ireland	30	NICE	2.1	38	Local accessible residential placements have been proved to be beneficial. A high proportion of people with learning disabilities have been placed in residential facilities/supported living schemes as a result of challenging behaviour. However, early intervention to promote positive behaviour change may lead to less people having to be placed in residential facilities as a result of challenging behaviour. Positive behaviour support that aims to reduce behaviour that challenges and increases quality of life through teaching new skills needs to be highlighted and made a priority. Early intervention with children at risk of developing behaviour that challenges is very beneficial and offers an opportunity to significantly enhance their life and that of their family members or carers. There is a need for early interventions to be developed and their feasibility and cost-effectiveness along with the benefits for young people with learning disabilities and their families/carers taken into account and further assessed.	Thank you for the comment and its endorsement of our research recommendation.
Department of Health, Social Services and Public Safety - Northern Ireland	31	NICE	2.3	39	All areas of research interest are supported and emphasis on research to provide directions re service development is very welcome. In particular reference to importance of support at home or near to home will be supported by families and carers and professionals working in community settings. However the use of term residential care should be exchanged for “care settings” to reflect the growing	Thank you for this comment, the terminology has been changed to ‘care settings’.

					variety of options and the hope to expand these over time.	
Department of Health, Social Services and Public Safety - Northern Ireland	32	Full	7.3.2.5	144	It is felt that this section could benefit from an expansion as to the range of sensory assessments that are in use by a wide range of staff.	Thank you for your comment. We searched for studies that reported sensitivity, specificity, reliability and validity. The only sensory assessment tool for which we found evidence was the Sensory Integration and Praxis Test (SIPT).
Department of Health, Social Services and Public Safety - Northern Ireland	33	Full	7.3.2.7.3	145	Issue of statement that no available data on reliability of AMPS – this is felt to not be an accurate reflection of evidence base. Studies noted by Fisher & Bray Jones 2012, Buchan 2002, Dickerson & Fisher 1997, Kottorp 2008 and Mesa et al 2014 all are quoted as demonstrating its reliability and validity internationally across groups.	Thank you for your comment. We have checked the references you cited, and apart from Kottorp 2008 (which is cited in the guideline), there was no other psychometric data that met eligibility criteria.
Derbyshire Healthcare NHSFT	1	NICE	General	General	Accessible structure with clearly presented information	Thank you for your comments.
Derbyshire Healthcare NHSFT	2	NICE	General	General	The reframing of 'challenging behaviour' to 'behaviour that challenges' is appreciated. However the content of the document almost exclusively focuses on modifying the behaviour of the individual rather than improving quality of life. No reference was made to how people with learning disabilities could experience belonging. Further there is almost no reference to people with learning disabilities' personhood and emotional experiences. The few times references to emotional states were mentioned included references to 'depression' and 'anger management'; terms that pathologise distress and do little to challenge the tendency of people with learning disabilities emotional lives to be denied by services (members of our team also subscribe to the DCP's 'Position statement on the classification of psychiatric disorders' and as such don't think such terminology is particularly helpful). 'Challenging behaviour' tends to be referenced as a means of getting needs met, rather than also being a sign of distress.	Thank you for this comment. We have amended our recommendations to include quality of life as an outcome (see revised recommendation numbers 1.1.2, 1.5.2, 1.5.5 and 1.6.1). It should however be pointed out that for many people a reduction of the behaviour that challenges will promote a significant improvement in quality of life. We disagree regarding person centred assessment, a number of recommendations stress the importance of service user and family and carer involvement in the process (see section 1.3) and require broad range of issues to be considered. No evidence of a sufficient quality was found relating to attachment theory.

					The focus of functional assessments, which look for specific triggers and reinforcers of challenging behaviour in terms of what can directly be observed means that factors relating to the individual's inner-world, their difficulties securing interaction with others and how this is *experienced,* their psychological word can get neglected. How staff and relatives experience the person with learning disabilities is also neglected within a functional analysis paradigm. An implication such a focus is that interventions may be directed to altering responses to the person in ways that deny or neglect the person with learning disabilities difficulties with being with others and how belonging might be facilitated. There was a notable absence of research and evidence that has been developed in areas such as attachment theory, psychodynamically informed work and Intensive Interaction that consider ways in which we might build relationships and connect with the inner-lives of people with learning disabilities. I recognise these comments could be interpreted as lacking an appreciation of the ways in which behavioural interventions could potentially be implemented. However the guidance reads as neglecting the interpersonal and inner emotional worlds of these clients.	
Derbyshire Healthcare NHSFT	3	NICE	General	General	Recognition is given to challenging behaviour as a contested construct. However there seems to be an absence of reference to this with regards assessment and intervention. Often work with staff teams or relatives has involved reconstructing behaviour that was previously deemed as 'challenging' such that this behaviour is no longer experienced as such (and thus is no longer a source of distress). It would seem important that people intervening took a critical stance to how the	Thank you for your comment, whilst the points you raise are too detailed for the introduction to the NICE version of the guideline, further discussion of them has been added to the introduction in the full guideline.

					behaviour was being constructed prior to developing and implementing an intervention. Is it necessarily the behaviour that needs to be altered? It is also important to consider sexuality and cultural contexts when critically examining if a behaviour ought to be deemed 'challenging'.	
Derbyshire Healthcare NHSFT	4	NICE	General	General	Choice of the person with learning disabilities was promoted at various stages in the document. At the same time the choice of intervention available seemed to be limited to behavioural interventions or CBT for 'anger management'. There are also difficulties in assuming people are in good positions to make decisions about the interventions they receive, and these challenges can be more pronounced for people with learning disabilities. We agree that people should be empowered and supported to make decisions about the interventions they receive, but it should also be recognised that choice has been shown to be a source of stress for people with learning disabilities. There also seemed to be potential conflict between the recommendations for 'choice' and interventions that might involve withholding a reinforce for the individual: what if the individual chooses that they do not want this reinforce to be withheld?	Thank you for raising this, the GDG agree that the interplay between choice and use of some interventions will be difficult. Guidelines cannot replace clinical judgement, and we believe that this is a situation where clinical judgement is extremely important.
Derbyshire Healthcare NHSFT	5	NICE	General	General	That the choice of the person with learning disabilities is mentioned various times in the document seems in conflict with the behavioural bias in which the inner lives and experiences of the person with learning disabilities is denied.	Thank you for this comment but the GDG were careful in the assessment recommendations to ensure that a person's experience and the impact and relationship of the behaviour that challenges are related to their mental health and well-being.
Derbyshire Healthcare NHSFT	6	NICE	General	General	The document called for a Person Centred approach and argued interventions should always be carried out in the person's home or as close to the person's home as possible. This recommendation seems to fit with recent challenges to the appropriateness of out of county placements for people with LD. Whilst such a recommendation would likely benefit a significant number of people the guidance might apply to, some people might	Thank you. In light of your comments, and the comments of other stakeholders, the recommendation that states that interventions should take place in the person's home has been widened out to include other settings in which the person regularly spends time.

					benefit from a residential/hospital environment: such contexts could suit some individuals needs better, especially if the home is one that is committed to developing environments to meet the needs of people with learning disabilities. The notion of a service closer to home is important but that an individual's concept of their community may involve immediate relationships rather than geography and should not be assumed to fit with broad political pressures.	
Derbyshire Healthcare NHSFT	7	NICE	General	General	Whilst recognising that environments can cause distress and problems, the guidance describes interventions targeted at the behaviour shown by *individuals,* and thus risks placing the difficulties 'within' the individual. The nature of individually tailored 'functional analyses' acts as a barrier to thinking about the development of services that would support the needs of people with learning disabilities	Thank you for this comment. Functional analysis does not focus on the individual alone but crucially also on a range of other factors in the social and physical environment that might lead to the development and maintenance of behaviour that challenges. We think this is reflected in a number of recommendations which focus on the assessment of and intervention at an environmental level, such as revised recommendation numbers 1.4.1, 1.5.2, 1.5.5 and 1.5.8.
Derbyshire Healthcare NHSFT	8	NICE	General	General	Intervention research for people with intellectual disabilities is in its infancy due to various barriers to conducting research with this population and problems associated with the dominant positivist orientation to notions of 'effectiveness'. Restricting the range of interventions offered to those offered in this document precludes developments of new ways of working with this client group and restricts use of effecting interventions that have yet to develop an evidence base, or whose epistemological orientation does not fit with dominant understandings of what constitutes 'evidence' (absence of evidence is not evidence of absence).	Thank you for raising this issue. We do not believe that the recommendations set out in this guideline will preclude the development of new ways of working. The full guideline included a number of research orientations, but nevertheless had to set out in advance methods that meet NICE standards as set out in the guidelines manual (2012).
Derbyshire Healthcare NHSFT	9	NICE	0	4	(Safeguarding children) Positive that information about safeguarding children is added. Perhaps a section on safeguarding vulnerable adults could also be added?	Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.

Derbyshire Healthcare NHSFT	10	Full	3.4	36	The guidance reads that RCTs are to be taken as the main source of evidence of effectiveness, with other sources of evidence only to be considered in the absence of RCTs. This seems problematic because there are barriers to undertaking RCTs with people with learning disabilities meaning certain promising interventions can not be researched in this way. The following paper gives an oversight of the significant barriers that exist to undertaking RCTs with this population: Oliver, P. *et al.* (2002). Difficulties in conducting a randomized controlled trial of health service interventions in intellectual disability: implications for evidence-based practice. *Journal of Intellectual Disability Research, 46*(4), 340-345. The privileging of RCTs also is biased towards those interventions that are more easily operationalised and controlled for (a problem that is also relevant for the second tier of evidence specified in the document). This excludes various therapies that might privilege relational interventions or systemically informed interventions that centre on supporting staff to deconstruct 'problems'. The trend to privilege RCTs as 'gold standard' on the other hand will inevitably result in studies based on behaviourism (an approach which is readily operationalised) being regarded as having a better outcome. That many of the operationalized interventions studied will likely involve interventions delivered to individuals displaying 'challenging behaviour' is also likely to lead to recommendations that promote interventions to individuals, rather than a focus on thinking about how staff and can foster environments that promote inclusion and quality of life for people with learning disabilities.	Thank you for raising this issue. The GDG acknowledge there are barriers to undertaking RCTs. There are also considerable difficulties reviewing other types of evidence in the context of a guideline, therefore the GDG utilised existing systematic reviews, including those of single case and small n research. This approach was agreed a priori, and we believe was the appropriate thing to do.

					Please consider reading the following for a critique of the frameworks by which the quality of outcome evidence is assessed: Larner, G. (2004). Family Therapy and the politics of evidence. *Journal of Family Therapy, 26*, 17-39. Laska, K., Gurman, A. & Wampold, B. (2013). Expanding the Lens of Evidence-Based Practice in Psychotherapy:A Common Factors Perspective. *Psychotherapy*	
Derbyshire Healthcare NHSFT	11	Full	3.5.3	40	As the guidance identifies, a meta-analysis of single case studies overcomes obstacles to conducting RCTs as mentioned above. Such meta-analyses and the single case studies they amalgamate are still reliant upon interventions that are easily operationalised.	Thank you for identifying this issue, the GDG agree, and were cognisant of this when developing recommendations.
Havencare	1	NICE	0	3	Description could include resulting exclusion/discrimination from community and neighbourhood	Thank you for your comment, unfortunately we were unable to identify which section you were referring to.
Havencare	2	NICE	0	8	Can guidance provide best practice examples	Thank you for your comment. NICE will provide best practice examples as part of the implementation resources.
Havencare	3	NICE	0	14	Guidance required on mentoring from preferred person to colleagues to promote positive relationships across the team.	Thank you for your comment, the GDG were unable to find any good quality evidence on mentoring such that would warrant a recommendation so we are unable to take up your suggestion.
Havencare	4	NICE	1.4.1	23	Develop guidance for where responsibility for augmentative communication systems – communication boards, tablet computers etc. should lay. These are currently excluded from commissioning – Reduced funding means social care providers cannot afford the specialised equipment or staff training.	Thank you for your comment, no evidence was found for the systems you mention and therefore the GDG were unable to make recommendations about them.
Havencare	5	NICE	1.7.3	34	Limiting PRN prescriptions to four weeks – concerns this could leave a gap for people who present severe challenging behaviour that is resistant to change over time.	Thank you for your comment. The GDG has revised the recommendation to say that p.r.n.medication should be used for as short a time as possible.
Havencare	6	NICE	1.8.5	36	Guidance does not include significant damage to property and associated risks.	Thank you for your comment. The recommendation is about setting out the legal and ethical framework

						for restrictive interventions, therefore we are unable to include the points raised as this is outside of our remit.
HQT Diagnostics	1	General	General	General	Chemical imbalances in Fatty Acids play a significant part in behavioural and mental disorders, such as ADHD, Depression, Autism, Bipolar Disorder, Borderline Personality, Substance Abuse and Psychotic Disorders More at: www.expertomega3.com/omega-3-study.asp?id=38 Suggest test and correct for: • Omega-3 Index >8% • Omega-6/3 ratio <3:1 and re-evaluate after 3 months More at: www.hqt-diagnostics.com This should be done by General Practitioners before referral for Behavioural Therapies	Thank you for your comment. We reviewed biomedical interventions in Chapter 12 of the Full guideline. There was very little evidence that met inclusion criteria, and what was included was of very low quality. Therefore, the GDG felt there was insufficient evidence to make recommendations at this time.
HQT Diagnostics	2	General	General	General	Chemical deficiencies in Vitamin D play a significant part in behavioural and mental disorders, such as ADHD, Depression, Autism, Bipolar Disorder, Borderline Personality, Substance Abuse and Psychotic Disorders Suggest test and supplement so that 25(OH)D is between 100-150nmol/L and re-evaluate after 3 months More at: www.vitamindwiki.com/Depression This should be done by General Practitioners before referral for Behavioural Therapies	Thank you for your comment. We reviewed biomedical interventions in Chapter 12 of the Full guideline. There was very little evidence that met inclusion criteria, and what was included was of very low quality. Therefore, the GDG felt there was insufficient evidence to make recommendations at this time.
Kent and Medway NHS Trust	1	NICE	General	General	I think that the guidelines are pretty good, and only have one technical ***'Reinforcer A reward that follows a behaviour and increases the likelihood of that behaviour happening again.' (p.16***). A reinforcer is **not** a reward. In fact a reward is a specific type of reinforcer. Equally there are situations where a reinforcer does not 'follow' a behaviour. This sentence would be more accurately written as: Reinforcer: Any event that is contingent on a	Thank you for the comment – we have made an amendment in line with your suggestion.

					behaviour and increases the likelihood of the behaviour occurring again	
Kent Community Health NHS Trust	1	NICE	General	2	There was mention of child abuse and this being contributory to behaviours that challenge, but no discussion in a similar vein with regards abuse and vulnerable adults and the relationship that has with challenging behaviour	Thank you for your comment, this is an important point which is addressed in revised recommendation numbers 1.5.7 and 1.5.8.
Kent Community Health NHS Trust	2	General	General	General	The current guidance does not make mention of pre-screening specifically relating to physical health that could then lead to an individual challenging a service as a way of communication their distress (diagnostic over shadowing) e.g. untreated dental issue, urine infection etc.	Thank you for your comment. Revised recommendation number 1.1.13, 1.2.1, 1.4.1, 1.5.8, 1.8.1, 1.8.2 and 1.9.3 relate to identifying and addressing the physical health needs of people with a learning disability and behaviour that challenges. Recommendation 1.4.1 specifically relates to a physical health problem being a risk factor in the development of behaviour that challenges. The GDG believe these recommendations address the issues you have raised, and it would be beyond the scope of the guideline to recommend anything further.
Kent Community Health NHS Trust	3	General	General	General	The issue of sexuality in pre-screening that could also lead a person to challenge e.g. identity issues, Klinefelter's syndrome etc. is absent from the guidance	Thank you for your comment, however the review undertaken for the guideline did not identify sexuality as a risk factor for the development of behaviour that challenges in people with learning disabilities.
Kent Community Health NHS Trust	4	General	General	General	Older persons conditions that could present in earlier life for individuals that have an intellectual disability e.g. dementia etc. not just for individuals with down's syndrome that could then lead to an individual presenting a challenge to the services they are supported by, such as distressed reaction for individuals who have dementia	Thank you for this comment. We have amended revised recommendation number 1.4.1 to include dementia.
Kent Community Health NHS Trust	5	General	General	General	There is mention of sensory issues but only in relation to self-injurious behaviours. No reference for management of specific sensory impairments such as visual or auditory that could then lead to further challenge for services if reasonable adjustments are not considered and made.	Thank you for this comment. Revised recommendation number 1.4.1 specifically identifies visual impairment as a factor that may increase the risk of self-injury and stereotypy. There was insufficient evidence identified to suggest that people with learning disabilities and auditory impairments were at an increased risk of behaviour that challenges (see Chapter 7 of the full guideline).

Kent Community Health NHS Trust	6	General	General	General	Though epilepsy is mentioned in the data of the main report, there is no consideration that sometimes seizure activity can present as behaviours that challenge services e.g. temporal lobe epilepsy leading to fluctuations in mood and poor impulse control (aggression) etc.	Thank you for this comment. We provide clear guidance on the need for proper assessment and treatment of physical health problems as they are clearly implicated in the development and maintenance of behaviour that challenges for some people. When we reviewed specific risk factors we did not identify epilepsy as a major risk factor and therefore did not identify it as such.
Kent Community Health NHS Trust	7	General	General	General	There are many mentions throughout of involving the family, family therapy, family advocacy etc. these services don't exist nationally for adults in the same way as they do for children we are unsure how this could be achieved	Thank you for this comment – we agree the implications of wider services for families will need to be carefully considered by service managers and commissioners. It is the role of NICE guidelines to review the evidence and identify the most effective and cost-effective interventions and services for the treatment of specific conditions.
Kent Community Health NHS Trust	8	General	General	General	There is mention of all care staff to receive regular training on the management of behavioural issues in all setting, though this would be excellent practice, could services afford this kind of training, who would carry out (over 800 companies in England offer this kind of training only 4 have BILD accredited trainers and there is currently no accreditation for courses) how would this be managed?	Thank you for this comment – we agree this will need to be carefully considered by service managers and commissioners. It is the role of NICE guidelines to set the standard of what should be available nationally, and for the NHS to ensure these services are delivered.
Lancashire Care NHSFT	1	NICE	General	General	We welcome the context and consideration of the document in emphasising the need of people with learning disability across all health and social care providers.	Thank you for your comments.
Lancashire Care NHSFT	2	NICE	General	General	Limited focus on specialist learning disability nursing involvement within the guidance development group or role of their role/function in supporting people with a learning disability/challenging behaviour.	Thank you for your comment, the role of nursing is included in revised recommendation number 1.1.5, however as different teams will be used by different services this has been kept as a broad recommendation – the exact professions will be a matter for local implementation.
Lancashire Care NHSFT	3	NICE	General	General	No explicit reference to Positive & Proactive Care (DH, April 2014).	Thank you for your comment. It is not NICE practice to include reference to policy documents in clinical guideline recommendations as these often change and would quickly become obsolete.
Lancashire Care	4	NICE	General	General	No explicit reference to what constitutes Positive	Thank you for your comment, we acknowledge that

NHSFT					Behavioural Support (PBS).	PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Lancashire Care NHSFT	5	NICE	General	General	Greater clarity required as to what constitutes 'Commissioning; Primary; Secondary Care.	Thank you for your comment. Use of these terms has been reviewed and changed where appropriate, specifically in revised recommendation numbers 1.1.9-1.1.14.
Lancashire Care NHSFT	6	NICE	General	General	Greater clarity required as to the competency and infrastructure required to deliver/meet what is detailed within the document.	Thank you for your comment. This is a clinical guideline and makes recommendations for clinical practice. The infrastructure of how this is delivered in a matter for local implementation.
Lancashire Care NHSFT	7	NICE	General	General	Not enough reference within the document to any design/re-design of service delivery to the inclusion of service users/unpaid carers/advocates.	Thank you for your comment, such a recommendation is outside the scope of the guideline. However, it may be of value to support implementation of the guideline, and we will draw it to the attention of the NICE implementation team. It should also be noted that NICE are currently developing a guideline on the service models for people with a learning disability and behaviour that challenges, see https://www.nice.org.uk/guidance/indevelopment/gid-scwave0770.
Lancashire Care NHSFT	8	NICE	General	General	Structure and flow of the document doesn't promote/reflect fluency, therefore creating confusion and a times repeating information.	Thank you for your comment. Some recommendations are repeated by necessity. Those recommendations that are 'key priorities for implementation' appear both at the start of the guideline and in the main body of the guideline.

Lancashire Care NHSFT	9	NICE	General	General	Insufficient consideration within assessment section of mediator analysis and impact on resources for carers / family	Thank you for your comment. The GDG were mindful of these issues, and feel that mediators are addressed in the recommendations in several places, including the sections about risk assessment (1.5.7), further assessment of behaviour that challenges (1.5.8) and functional assessment of behaviour (1.5.9-1.5.11). Impact on resources for carers/family is addressed in section 1.3.
Lancashire Care NHSFT	10	NICE	1.6.5	General	Questionable whether sufficient attention is paid to systems of reinforcing desired behaviour – non aversive approach to behaviour change (is reference on P32 1.6.5 to "a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly" yet considered insufficient in detail). Would consider more information in the Support plan section (i.e. targeted support strategies, direct treatment plans – DRL / DRO / Alt R etc)	Thank you for your comment. The recommendation explicitly states that the intervention should be based on behavioural principles, which the GDG considers is sufficient.
Lancashire Care NHSFT	11	NICE	0	2	No reference to Human Rights Act or Equality Duty.	Thank you for your comment, recommendation 1.8.5 refers to the Human Rights Act. As a public body, NICE has an obligation to have due regard for the public sector Equality Duty, and consideration or people with protected characteristics has been integral to this guideline.
Lancashire Care NHSFT	12	NICE	0	3	(Introduction, pages 3-5) The introduction doesn't emphasise enough the context of the main content of the document.	Thank you for your comment, the purpose of the introduction is to set the scene of current practice.
Lancashire Care NHSFT	13	NICE	0	4	(Introduction) Safeguarding Adults and Children (No reference to adults in the introduction, therefore not reflecting adult safeguarding considerations equally).	Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.
Lancashire Care NHSFT	14	NICE	0	4	(Introduction) Multi elemental approach to early interventions is not explicit enough within the introduction section.	Thank you for your comment, as this introduction is a brief overview the point you raise is not included here, however it is discussed in the introduction to the full guideline.
Lancashire Care NHSFT	15	NICE	0	4	(Introduction) "*Interventions dependent on the specifics triggers for each person and may need to be [**delivered]** at*	Thank you for your comment. The change you have suggested has been made.

					multiple levels"	
Lancashire Care NHSFT	16	NICE	0	4	(Introduction) Use of the word "*The*" guideline – inconsistence use page 6 "*This*" guideline	Thank you for your comment. The change you have suggested has been made.
Lancashire Care NHSFT	17	NICE	0	4	(Introduction) A section needs to be included clarifying any intervention should be based upon an individually focused (person-centred) multi-element behavioural assessment.	Thank you for your comment, as this introduction is a brief overview the point you raise is not included here, however it is discussed in the introduction the full guideline.
Lancashire Care NHSFT	18	NICE	0	5	(Introduction) No reference to the Birmingham guidance on use of medication for challenging behaviour. Why medication is an explicit sub heading in the introduction? We feel it is inappropriate. http://www.birmingham.ac.uk/Documents/college-les/psych/ld/LDQuickReferenceGuide.pdf	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Lancashire Care NHSFT	19	NICE	0	6	(Person centred care) Would this section be better titled 'Legal frameworks'?	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Lancashire Care NHSFT	20	NICE	0	6	(Person centred care) Paragraph 2: no explicit reference to application related to those age 16+ yrs. Emphasis on ✓age 16yrs within the narrative, however reference to adult only within MCA. Therefore could reinforce confusion.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Lancashire Care NHSFT	21	NICE	0	6	(Person centred care) No direct reference to Health Action Plans, Essential Lifestyle Planning, Hospital Passports which would be keystones to Person Centred Planning. No explicit reference to the philosophy of person centred care for people with a learning disability.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Lancashire Care NHSFT	22	NICE	1.1.5	10	(Key priorities for implementation) No distinction articulated to reflect the difference between specialist 'community' & 'in patient' teams.	Thank you for your comment, but, due to the often complex and varied needs of people with a learning disability and behaviour that challenges, the recommendations apply to all teams, therefore no distinction is needed.
Lancashire Care	23	NICE	1.1.7	19	What is meant by 'manuals'	Thank you for your comment. A definition of

NHSFT						treatment manuals has been added to the glossary.
Lancashire Care NHSFT	24	NICE	1.5.5	26	(Sections 1.5.5-6) Greater clarity/consistency as to what constitutes sensory sensitivities/sensory needs/visual impairment.	Thank you for your comment, the terminology has been changed for consistency to 'sensory profile'.
Lancashire Care NHSFT	25	NICE	1.5.12	29	Concerns as to what is included/excluded within the list are not current (e.g. Mini pass-add/pass-add etc.)	Thank you for your comment. The GDG reconsidered this recommendation, but felt that apart from varying the order of one point, everything in the list was justified, and will be familiar to professionals.
Lancashire Care NHSFT	26	NICE	1.5.13	30	1st sentence could be misconstrued, is misleading.	Thank you for your comment, the recommendation has been revised.
Lancashire Care NHSFT	27	NICE	1.6	31	Primary & secondary prevention needs to include explicit reference to adults as it does for children. No explicit reference to the considerations required for parents with a learning disability who have children with a learning disability.	Thank you for your comment. The evidence reviewed for parent training and classroom-based interventions was for children under 12 only.
Lancashire Care NHSFT	28	NICE	1.6.6	32	Doesn't reflect person centred considerations.	Thank you for your comment, but the GDG feels that the wording (for example, 'personalised') does reflect a person-centred approach.
Lancashire Care NHSFT	29	NICE	1.8	35	Need to differentiate clearly between reatice & restrictive strategies	Thank you for your comment. These terms are both defined in the 'Terms used' section, which the GDG feels is clear.
Lancashire Care NHSFT	30	NICE	1.10.2	37	No reference to the needs of adults pertaining to interventions for sleep problems.	Thank you for your comment. The recommendation has been revised to clarify that it applies to adults, children and young people.
Lancashire Care NHSFT	31	NICE	2.2	38	Content contradicts the assertions made within the guidelines/document.	Thank you for your comment. We are not entirely clear what assertions you are referring to but assume it is to recommendations on the use of both medication and behavioural interventions. The purpose of the recommendation is to provide better evidence on the relative efficacy of the two, direct comparison of the two or use in combination is very limited.
Leeds & York Partnership NHS Trust	1	Full	1.1.6/6.4.2.2	113	You include recommendations that all staff working with people with a learning disability and behaviour that challenges should be trained to deliver proactive strategies to reduce the risk of behaviour that challenges, including:	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.

					‘developing strategies to help the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication, emotional regulation or social interaction). But you do this without saying what such training in proactive strategies might consist of to help service users develop new skills in ‘social interaction’. Don’t you think this is all a bit too vague to be of any real help? Should you not more clearly identify specific types of training in specific skills sets that can help staff actually implement the recommendation?	
Leeds & York Partnership NHS Trust	2	NICE/Full	1.5.13/8.5.5	169	You include recommendations that support plans should identify: ‘adaptations to a person’s environment and routine, and strategies to help them develop an alternative behaviour to achieve the function of the behaviour that challenges by developing a new skill (for example, improved communication, emotional regulation or social interaction)’ But you do this without saying what these adaptations might consist of, or what ‘social interaction’ strategies might be useful to consider for people with a learning disability who have a communication and/or social impairment. Don’t you think this is all a bit too vague to be of any real help? Should you not more clearly identify specific adaptations or particular ‘social interaction’ strategies that can help staff actually implement this recommendation?	Thank you for your comment, it is the GDG’s consensus that the terms used are sufficient for the purposes of the guideline. The evidence did not allow for more specific examples to be included.
National Family Carer Network	1	Full	1.2.2	16	It may be worth noting that those ‘in direct contact’ may include staff who have infrequent contact with people with learning disabilities, such as NHS Continuing Healthcare assessors and co-ordinators, Liaison & Diversion team members, and healthcare staff in police custody suites and prisons. Some such staff may be responsible for advising others (e.g. police, courts, probation) to improve their	Thank you for comment, the GDG felt that ‘healthcare professionals’ was broad enough to encompass those people suggested – it would not be possible to list all those who might come into contact with people with a learning disability and behaviour that challenges.

					understanding of and response to an individual with learning disabilities.	
National Family Carer Network	2	Full	1.2.2	16	The guideline may also be relevant to the work of those in the criminal justice system (see point 1 above).	Thank you for your comment. Criminal justice settings are outside the scope of this guideline, however the *Mental health of adults in contact with the criminal justice system* guideline is currently under development which will address these issues.
National Family Carer Network	3	Full	1.2.2	16	Line 7 lists the 'independent sector' among those whose practice is not covered. I am puzzled and very concerned about this if the term includes independent providers of healthcare, such as voluntary and private sector hospitals. These are amongst the organisations that are in particular need of the guidelines!	Thank you for your comment. NICE guidelines make recommendations for the NHS and are not able to make direct recommendations to the independent sector. However, the guideline does recognise that the recommendations will be relevant to them.
National Family Carer Network	4	Full	4	52	(Et seq, general) It seems to be at this point that the term 'families and carers' starts being used. This is usually regarded as unhelpful by family carers. Government policy uses 'carers' to mean family and friends. We would prefer alternative wording, such as 'family carers and paid staff'.	Thank you for your comments. The guideline uses the term 'family members and carers' to refer to those people who provide informal and unpaid care, which is consistent with NICE terminology and other mental health and behavioural guidelines. Paid carers are defined as 'staff', which has now been clarified.
National Family Carer Network	5	Full	4.1	52	Lines 22/23: it isn't quite clear who is ignoring or not recognising early warning signs? Many families would say that they do recognise signs and ask for help, but don't get it.	Thank you for your comment. This has now been amended so it is clear that it is healthcare professionals who often ignore or do not recognise families' insights into early warning signs.
National Family Carer Network	6	Full	4.1	52	Line 26, lack of training: there is also anecdotal evidence from adult services that, due to lack of support or lack of foresight by children's services, families can develop responses that will not work or will not be acceptable when their son or daughter becomes an adult. This is alluded to on p.95, line 24.	Thank you for your comments. We are aware that the lack of support and early intervention services for families is problematic. As a consequence we have developed specific guidance for parent training in Chapter 11 and recommendation 40-41 (page 261).
National Family Carer Network	7	Full	4.3	62	(Pages 62 et seq) There is evidence (e.g. from the 'Recognising Fathers' research from the Foundation for People with Learning Disabilities) that fathers of people with learning disabilities often fulfil important caring roles, yet often feel excluded by services. There is	Thank you for your comments. We understand that it is important to highlight aspects of diversity in the guideline, however this section has been extracted from an existing review (Griffith 2013a) in which evidence from fathers and minority ethnic groups did not emerge.

					evidence from other research that families from minority ethnic communities experience particular difficulties in engaging with services and finding services that are responsive to their and their relatives' cultural needs. Both these aspects of diversity could usefully be highlighted in this and following sections.	We did not search for surveys as the review of qualitative research was thought to be the most appropriate method of answering the review question.
National Family Carer Network	8	Full	4.3	62	(Page 62 et seq) Another relevant issue to note in relation to families' experiences and circumstances is that family carers are still less likely than the rest of the population to be internet users. This affects their access to information.	Many thanks for your comment. Families' difficulty in accessing online information did not emerge as a theme in the evidence reviewed in this section and therefore is not mentioned. Nevertheless, the GDG recognised that information should be provided in an appropriate format, and this part of revised recommendation number 1.3.1 (in the NICE version of the guideline).
National Family Carer Network	9	Full	5.4.1	91	Opportunity in the recommendations to encourage specific attention to groups at risk of exclusion (e.g. fathers, BME families – see point 7 above) and consideration of non-internet based methods of delivering information (see point 8 above).	Thank you for your comment, the intention of the guideline is that all relevant family groups are involved as set out in revised recommendation number 1.1.1.
National Family Carer Network	10	Full	6.2.1	102	(Page 102 et seq) Table 26: references to primary and secondary care professionals, managers and commissioners should include social care (and education for young people up to age 25, in line with the Children & Families Act).	Thank you for this suggestion. After reconsidering the recommendation related to this section, the GDG specified the designated leadership team as 'health, educational and social care professionals, practitioners, managers and health and local authority commissioners'.
National Family Carer Network	11	Full	6.2.1	102	(Sections 6.2.1 and 6.4.1, page 102 et seq and page 110 et seq) Table 26: advice on care pathways for transitions could usefully include the point that transition from one source of funding to another (e.g. social care to NHS Continuing Healthcare, or children's to adult, or change of responsible commissioner due to a move) should not cause a change in a package of support that is working. It may of course offer an opportunity for review and adjustment to meet the person's needs and preferences better. This is already stated in the NHS CHC practice guidance but could be reinforced here.	Thank you for your comment. The NICE guideline includes standard text in the introduction under 'Person-centred care' that addresses your point: If a young person is moving between paediatric and adult services, care should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people.

National Family Carer Network	12	Full	6.2.1	102	(Sections 6.2.1 and 6.4.1, page 102 et seq and page 110 et seq) Re-statement of Mental Capacity Act principles (such as 'least restrictive option') and a reminder of the MCA meaning of 'best interests' and Article 8 of the Human Rights Act (right to privacy and family life) may be helpful in this section or in the recommendations on p.110.	Thank you for this suggestion. Recommendation 11 does include 'least restrictive' option.
National Family Carer Network	13	Full	13.1	317	(Sections 13.1 and 13.3, pages 317 and 320) Some people with learning disabilities may have capacity to discuss and agree advance plans for reactive strategies.	Thank you for raising this issue. The GDG felt it more appropriate to cover this in the recommendations (please see Section 13.3).
National Family Carer Network	14	NICE/Full	1.8.6/13.3	321	Recommendation 59: it would be good practice to include the person themselves and family carers in debriefing where possible.	Thank you for your comment. An addition has been made to revised recommendation 1.9.3 to address your point.
National Family Carer Network	15	Full	General	General	There is reference early on in the document to the risk that certain behaviours may lead to contact with the criminal justice system. There is also reference to the evidence for some relevant interventions, e.g. anger management. However, I could not see specific consideration of multi-agency (including health) interventions to promote desistance. Now that the NHS is responsible for healthcare in prisons, and is taking over responsibility for healthcare in police custody suites, it may be useful to refer to any specific considerations for health staff in those settings.	Thank you for your comment. Interventions in a criminal justice setting are outside the scope of this guideline, however the *Mental health of adults in contact with the criminal justice system* guideline is currently under development which will address these issues.
NHS Protect	1	General	General	General	NHS Protect leads on work to tackle crime against the NHS that would otherwise undermine the effectiveness and ability of the health service to meet the needs of patients and professionals. It has responsibility for tackling fraud, corruption, bribery, violence and aggression, criminal damage, theft and other unlawful action such as market-fixing. We welcome the opportunity to respond to this consultation and are happy to provide further assistance when appropriate.	Thank you for your comments. NICE and the GDG were aware of the important role which NHS Protect plays in ensuring the safety of NHS staff and are pleased that you find the guideline complements this work. However NICE guidelines do not reference policy documents in the recommendations as these often become outdated before the guideline is updated.

					NHS Protect recently launched guidance, a dedicated website and training videos for the NHS: *Meeting needs and reducing distress: Guidance for the prevention and management of clinically related challenging behaviour in NHS settings.* I attach a link to these resources: http://www.reducingdistress.co.uk/reducingdistress/ Clinically related challenging behaviour by patients and service users makes it difficult for staff to deliver good care safely. It can take many forms, from mildly uncooperative to highly disruptive and potentially dangerous behaviours. Such behaviour is often related to a clinical condition and/or a breakdown in the delivery of care, and is a sign of distress and unmet needs rather than any intent to be challenging on behalf of the patient and service user. The guidance, which I attach, has been developed by an expert group of leading doctors, nurses, trainers and security specialists. It is supported and endorsed by a number of other leading organisations, including NHS England and the Royal College of Nursing. This guidance is designed to assist NHS professionals understand the causes of clinically related challenging behaviour, and to prevent it from occurring by implementing models of care to minimise a patient's distress and meet their needs. It also provides staff with practical strategies to minimise the risks when things go wrong and respond to an individual's anxiety and distress calmly, by non-confrontation and de-escalation. It makes it clear that restrictive interventions should be used as a last resort, in line with the DH's *Positive and Safe programme*. The guidance aims to provide strategies for organisations to:	

					• Improve the assessment, diagnosis and management of those individuals who are at risk of challenging behaviour, so that such behaviour might be prevented • Improve understanding of how such behaviour relates to specific clinical conditions and unmet needs • Improve the approach, skills and attitudes that minimise distress through personalised compassionate care • Assess risk and managing challenging behaviour • Ensure that staff have appropriate training and sufficient resources are available to prevent and manage challenging behaviour. Our guidance is in line with your proposed guidelines and we would be grateful when finalising your guidelines that reference is made to our work.	
Nottinghamshire Healthcare NHS Trust	1	Full	2.5.2	27	(Pages 27-8) It would be helpful to make some reference to attachment and abuse here, linking back to the 'associated characteristics' section. Although the causal links are not proven, the functional links currently referred to in the 'psychosocial causes' section are not proven either, as evidenced by the frequent use of the phrase 'it appears' in the current section.	Thank you for your comment, the text has been revised to mention abuse at an earlier point in this section. Attachment is discussed in section 2.4, but is not repeated here as the evidence for its connection to behaviour that challenges is much weaker.
Nottinghamshire Healthcare NHS Trust	2	NICE/Full	1.1.3/6.4.2	112	Recommendation 13: 'people should understand that CB is communicating an unmet need' That statement is far too strong given the poverty of evidence. Should at least be qualified by 'is often' or 'is generally'	Thank you for this comment. The focus of this guideline is on improving care and the quality of life for people with behaviour which challenges. From this perspective we see 'needs' requirements for personal, psychological and physical care and well-being which can be met by a broad range of formal and informal relationships and related health and social care interventions. Nevertheless, the wording has been revised to add some circumspection ('often indicates an unmet need').

Nottinghamshire Healthcare NHS Trust	3	NICE/Full	1.1.3/6.4.2	112	Recommendation 13: should specify under 'what people should understand', perhaps in individual and environmental factors: 'including the role of histories of abuse and attachment difficulties'	Thank you for your comment, the role of abuse is addressed in recommendation 1.5.8.
Nottinghamshire Healthcare NHS Trust	4	NICE/Full	1.4.3/7.4	148	*(pages 148-9)* *None of the scales reviewed had good psychometric properties: this should be explicitly mentioned in the recommendations NB also 8.2: no evidence regarding assessment methods is available!*	Thank you for your comment, but as described in the introduction to the NICE guideline, where the GDG felt that a recommendation was warranted, weaker recommendations were made using the word 'consider'. It is not usual for NICE recommendations to refer to the evidence base.
Nottinghamshire Healthcare NHS Trust	5	NICE/Full	1.5.2/8.5	163	Recommendation 21: 'all individual and environmental factors that may lead to behaviour that challenges are taken into account' should be changed to all individual and environmental, including historical factors…'	Thank you for your comment, the recommendation has been revised to say 'current and past personal and environmental factors'.
Nottinghamshire Healthcare NHS Trust	6	NICE/Full	1.5.4 /8.5.1	164	Recommendation 23: not clear why the Aberrant Behaviour Checklist is selected as an example here. Caution should be expressed as to its psychometric properties	Thank you raising this issue. As described in the full guideline (8.5.8), although the evidence was poor, the GDG felt that providing examples of commonly used scales was appropriate.
Nottinghamshire Healthcare NHS Trust	7	NICE/Full	1.5.5/8.5.1	164	Recommendation 24: the wording: 'social and interpersonal history, including relationships with family members, carers or staff, including teachers' is very helpful, and could perhaps address my concern expressed in 5 above regarding recommendation 21, and in 3 regarding recommendation 13.	Thank you for your comment.
Nottinghamshire Healthcare NHS Trust	8	NICE/Full	1.5.7/8.5.2	165	Risk assessment section: appears almost content free, merely asserting that risk should be assessed in a number of areas. No link to research evidence and no specific recommendations re what makes risk assessment good quality/effective. Without this, the paragraph has little utility	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
Nottinghamshire Healthcare NHS Trust	9	NICE/Full	1.5.8/8.5.2	166	Recommendation 27: not clear why the Aberrant Behaviour Checklist and the adaptive behaviour checklist are selected as examples to use here. Caution should be expressed as to its psychometric properties	Thank you for your comment. As described in the full guideline (8.5.8), although the evidence was poor, the GDG felt that providing examples of commonly used scales was appropriate. Caution has been denoted by recommending health care professionals 'consider' these assessment tools.

Nottinghamshire Healthcare NHS Trust	10	Full	General	General	Checklists are mentioned as examples to be considered, but will bias selection by repeatedly mentioning specific ones especially the Aberrant Behaviour Checklist. Apart from being frequently used by psychiatrists, there does not appear to be any specific evidence that this one is any better than others.	Thank you, but the GDG reconsidered this, and decided that because they have given two or three examples, so this seems unlikely.
Nottinghamshire Healthcare NHS Trust	11	NICE/Full	1.5.13/8.5.5	169	Recommendation 32: to develop a behaviour support plan, does not appear to be based on any evidence of the effectiveness of such plans. (NB later intervention section reports generally very low quality evidence for the effectiveness of behavioural interventions.) This should be explicitly recognised. Under 'proactive strategies' and 'environmental adaptations', it should include reference to addressing the social environment in order to respond to attachment issues	Thank you, but as described in the full guideline (8.5.8), the GDG based this recommendation on expert opinion and evidence from the experience of care. It is not NICE policy to describe the quality of the evidence in the actual recommendations, rather the recommendation wording reflects the strength of the evidence. Regarding the social environment, the GDG believes this is adequately captured in what is already an extensive recommendation.
Nottinghamshire Healthcare NHS Trust	12	Full	11.3.2	263	Would be worth having research into other interventions, e.g. to address attachment and/or abuse issues, given the limited evidence for 'pure' behavioural interventions. Ditto re 12.3.1	Thank you for your comment, and while the GDG agrees that in many areas there needs to be further research, they focused on those that they thought would have the greatest impact on care.
Nottinghamshire Healthcare NHS Trust	13	NICE	General	General	There should be an explicit statement early on that most of the evidence base is of low quality, so all recommendations are for consideration only, and clinical judgement remains extremely important in driving practice	Thank you for your comment, it is not NICE policy to make such a statement about the evidence in the NICE guideline. The NICE version of the guideline details all the evidence, how it was reviewed and how the GDG formed the recommendations from the evidence base. The strength of the underpinning evidence is also reflected in the working of the recommendations. As with all NICE guidelines, this is not a replacement for clinical judgement, which should be considered with every individual.
Optical Confederation	1	Full	General	General	We recognise these guidelines do not cover the treatment and management of co-existing conditions such as sight loss. However sensory impairment is a recognised part of learning disabilities at all ages and age-related impairments occur earlier in PLD than others and so may not be spotted. The presence of sensory impairment	Thank you for your comments, the specific treatment and management of sight loss is outside our scope, however the guideline does make recommendations about managing physical health problems for people with a learning disability and behaviour that challenges. See revised recommendation numbers 1.1.13, 1.2.1, 1.4.1,

					impacts not only on a individual's behaviour but on their ability to communicate with health professionals to achieve effective assessment and treatment of their condition.	1.5.8 and 1.10.1.
Optical Confederation	2	Full	2.4	24	(2.4d) We would like to highlight the prevalence of visual impairment in people with learning disability. There is a link between the severity of the learning disability and the likelihood of visual impairment. (*Emerson E, Robertson J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011*.) There is under detection of visual impairment in all groups of patients with learning disability. (*Woodhouse J.M, Ryan B, Davies N, McAvinchey A.(2012) A Clear Vision: Eye Care for Children and Young People in Special Schools in Wales*) It is likely that visual impairment is a factor in challenging behaviour and thus it is important to establish not only baseline visual performance in all patients with learning disability but to take into account any changes in vision when assessing the causes of challenging behaviour. (*Pilling, R. (2011). The management of visual problems in adult patients who have learning disabilities. Ophthalmic Services Guidance, The Royal College of Ophthalmologists.*) Self injury affecting eyes can be the cause of, or result of, eye pathology and should trigger referral for visual assessment by an ophthalmologist or optometrist. The CIPOLD report's finding that 50% of those dying prematurely have visual loss should be noted. It should also be noted that the effectiveness of any	Thank you for your comment, the GDG felt that visual impairments are discussed sufficiently in section 2.4 and 2.5.1.

					therapy requiring visual input to aid communication will be adversely affected unless the visual ability of the patient is taken into account when developing the treatment or assessment plan.	
Optical Confederation	3	Full	2.5.1	26	We ask that acquired visual loss is added to the conditions listed on page 26 line 19 eg retinal detachment or cataract	Thank you for your comment. 'Sensory impairments' has been added to section 2.5.1.
Optical Confederation	4	Full	2.5.1	27	Also add the research by Cooper SA, Smiley E, Allan L, Jackson A, Finlayson J, Mantry D, et al. Re the connection between Self-injurious behaviour and visual impairment. (Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour and related factors. Journal of Intellectual Disability Research 2009;53:200-16).	Thank you for your comment, the GDG felt that visual impairments are discussed sufficiently in section 2.4 and 2.5.1.
Optical Confederation	5	Full	2.5.1	28	No mention is made of 'functional vision assessment' or related tools such as the SeeAbility FVA tool.	Thank you for your comment, the GDG felt that visual impairments are discussed sufficiently in section 2.4 and 2.5.1.
Optical Confederation	6	Full	2.6	33	Children and Families Bill is mentioned and where an Education, Health & Care plan for children and young people with LD is formulated, visual assessment should be included.	Thank you for your comment. We agree with your point, but at this point in the text no details of the plan are being given, so it seems inappropriate to single out vision.
Optical Confederation	7	Full	4.5	77	(Page 77-8) There is no mention of investigation of physical or sensory (visual) problems which may lead to challenging behaviour	Thank you for your comment. The need to investigate risk factors for behaviour that challenges, such as visual impairment and physical health problems has been highlighted in recommendation18 (section 7.4, page 148) and evidence for this described in section 7.2.1.10 (pages 133-134).
Optical Confederation	8	NICE/ Full	1.1.5/6. 4.2.1.1	113	Paragraph 6.4 and in particular 6.4.2.1 Team working (page 113) describes professionals who should be part of the assessment team. No mention is made of the eye-care professions; this should be corrected and the LOCSU pathway emphasised as a way of commissioning and delivering these services. The LOCSU Enhanced Service Community Eye Care for Adults & Young People with Learning Disabilities Pathway was launched in 2012 with leading charities, SeeAbility and Mencap. This	Thank you for your comment, the GDG did not consider it necessary to have an eye-care professional as a core member of the team to support a person with a learning disability and behaviour that challenges.

					provides an established pathway to facilitate eye examinations for people with learning disability. This may help prevent some challenging behaviour in the first instance therefore Clinical Commissioning Groups can work with providers in primary care to increase awareness of resources available to this cohort. The need for awareness of and wider use of functional vision assessment tools amongst staff should also be emphasised.	
Optical Confederation	9	NICE/Full	1.4.1/7.4	148	Under recommendation 18, add to the point about visual impairment, the requirement for a visual assessment to be made by an ophthalmologist or optometrist, making clear that the service user does not need to be able to read or speak for this to be effective.	Thank you for your comment. Revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8, 1.8.1, 1.8.2 and 1.9.3 relate to identifying and addressing the physical health needs of people with a learning disability and behaviour that challenges. The GDG believe these recommendations address the issues you have raised, and it would be beyond the scope of the guideline to recommend anything further.
Optical Confederation	10	Full	8.1	150	Paragraph 8.1 outlines the potentially complex causes of BWC and on line 7 physical health is mentioned as one factor to be considered. Line 18 mentions a 'tooth abcess' causing pain as a cause of BWC and lines 25 and 26 professionals included in the assessment team. It would be useful to have acquired visual loss as a cause of BWC mentioned and also for professionals from the eye-care sector, such as optometrists, mentioned in the document.	Thank you for your comment. Visual impairment has been described as a risk factor for challenging behaviour in chapter 7 (pages133-134) and in recommendation 18 (section 7.4, page 148).
Optical Confederation	11	Full	8.2	151	It is likely that sensory deprivation, especially if this is an acquired loss, may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but	Thank you for your comment, whilst we agree this is an important issue, and highlight assessment of visual impairment in revised recommendation number 1.4.1, the level of detail you suggest is outside the scope of this guideline.

					a full eye examination, visual field and results of a functional visual assessment.	
Optical Confederation	12	Full	8.3	152	Assessment of visual performance and sight testing of all patients at risk of developing challenging behaviour and those who have developed challenging behaviour should be considered to ensure sight loss is not a contributory factor in such behaviour and to facilitate the provision of other therapy and assessment in an appropriate fashion.	Thank you for your comments, the specific treatment and management of sight loss is outside our scope, however the guideline does make recommendations about managing physical health problems for people with a learning disability and behaviour that challenges. See revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8 and 1.10.1.
Optical Confederation	13	Full	8.4	159	We would encourage greater training in the importance of sight tests, the ability to carry out functional visual assessment, and recognition of behaviour possibly caused by visual impairment for all health and social care professionals. Such information should also be available for families supporting or caring for people with learning disabilities and challenging behaviour	Thank you for your comments, the specific treatment and management of sight loss is outside our scope, however the guideline does make recommendations about managing physical health problems for people with a learning disability and behaviour that challenges. See revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8 and 1.10.1.
Optical Confederation	14	NICE/Full	1.5.1/8.5	163	This mentions a graduated approach to investigating the factors which are causing BWC. The risk here is that in not considering the urgent conditions such as corneal ulcers, retinal detachment or acute glaucoma (or indeed other acute health conditions) that by the time these conditions are considered the situation will be too far advanced for there to be successful treatment. Paragraphs 21 page 163 and paragraph 24 on page 164 allude to the need to investigate physical or sensory causes but only when further investigations at paragraph 27 page 166 are suggested is full mention of physical health problem mentioned. Only when certain acute problems have been ruled out then this graduated response should be followed.	Thank you for your comment, recommendation 1.5.5 outlines that physical health problems should be considered as part of an initial assessment.
Optical Confederation	15	NICE/Full	1.5.4-5/8.5.2	164	Recommendations 23 and 24: visual assessment, even if a functional one carried out by carer, should occur at the onset of new challenging behaviour rather than waiting to see if controlling strategies	Thank you for this suggestion. The GDG considered this and believe that the recommendations made in the subsection on early identification in the NICE version of the guideline

					work first.	cover the issue you raised.
Optical Confederation	16	NICE/Full	1.5.8/8.5.2	166	• Recommendation 27: visual assessment, even if a functional one carried out by carer, should occur at the onset of new challenging behaviour rather than waiting to see if controlling strategies work first.	Thank you for your comment. Revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8, 1.8.1, 1.8.2 and 1.9.3 relate to identifying and addressing the physical health needs of people with a learning disability and behaviour that challenges. The GDG believe these recommendations address the issues you have raised, and it would be beyond the scope of the guideline to recommend anything further.
Optical Confederation	17	NICE/Full	1.2.1/9.5.2	194	(Pages 194-5) “offer an annual physical health check”: it should be made explicit that this contains a sensory assessment, including visual assessment. Refer to guidance that adults would benefit from 2 yearly optometric assessment, and that the same would apply for adults with learning disability, to specify that assessments can take place even if the service user is unable to read or speak. Refer to LOCSU pathway. For children, refer to National Screening Guidance which recommends visual assessment in school at age 4-5 for all children. Refer to "a clear vision" data, and children in focus project	Thank you for your comment. Insofar as this guideline is concerned with behaviour that challenges in the context of learning disabilities, the recommendation makes reference to ‘any physical health problems’ and a ‘physical health’ review. The GDG would expect that this would cover any visual impairment.
Optical Confederation	18	NICE/Full	1.2.1/9.5.2	195	Para 9.5.2 page 195 recommends the annual health check takes place in whatever the most appropriate setting may be and also in this section mention is made of the importance of the annual health check in raising the proportion of people with LD having regular sight tests. Mention should be made of the availability of domiciliary sight tests as well as the opportunity for commissioning of the LOCSU pathway to support the uptake of sight tests by PwLD.	Thank you for your comment. This level of detail would not be appropriate for a recommendation, however the GDG will draw your comment to the attention of the NICE implementation team
Optical Confederation	19	NICE	1.2	22	We note that sensory impairment is mentioned as a contributory factor for challenging behaviour and would like to highlight the prevalence of visual impairment in people with learning disability. People with learning disability are 10 times more likely to have a visual impairment. (*Emerson E, Robertson*	Thank you for your comment. Insofar as this guideline is concerned with behaviour that challenges in the context of learning disabilities, the recommendation makes reference to ‘any physical health problems’ and a ‘physical health’ review. The GDG would expect that this would cover any visual

					J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011.) It is likely that sensory deprivation especially if this is an acquired loss may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but a full eye examination, visual field and results of a functional visual assessment.	impairment.
Optical Confederation	20	NICE	1.5.5	26	Assessment of visual performance and sight testing of all patients at risk of developing challenging behaviour and those who have developed challenging behaviour should be considered to ensure sight loss is not a contributory factor in such behaviour and to facilitate the provision of other therapy and assessment in an appropriate fashion	Thank you for your comment. Revised recommendation numbers 1.1.12, 1.2.1, 1.4.1, 1.5.8, 1.7.1 and 1.9.3 relate to identifying and addressing the physical health needs of people with a learning disability and behaviour that challenges. The GDG believe these recommendations address the issues you have raised, and it would be beyond the scope of the guideline to recommend anything further.
Optical Confederation	21	NICE	1.5.13	30	It is likely that sensory deprivation especially if this is an acquired loss may add to a defensive response to unusual experiences or abnormal environments, hence testing for sensory impairments should be part of any investigation as to the cause of the challenging behaviour in order to avoid the risk of diagnostic overshadowing. To establish change in visual function it is of course important to establish a baseline visual ability which should be recorded in a patient's notes. This should as far as possible include not only visual acuity, but a full eye examination, visual field and results of a functional visual assessment	Thank you for your comment. The points you have listed are covered in the initial assessment. The purpose of the behaviour support plan is to set out strategies to support the person.

Optical Confederation	22	General	General	General	The Optical Confederation represents the 12,000 optometrists, 6,000 dispensing opticians and 7,000 optical practices in the UK who provide high quality and accessible eye care services to the whole population. The Confederation is a coalition of the five optical representative bodies: the Association of British Dispensing Opticians (ABDO); the Association of Contact Lens Manufacturers (ACLM); the Association of Optometrists (AOP); the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.	Thank you for your comments.
Oxleas NHSFT	1	Full	General	General	Information in many sections is repeated under different heading which makes the document very repetitive.	Thank you for your comment. Without knowing which precise area of the guideline to which you are referring, the GDG would like to point out that with regard to the recommendations, these have been substantively revised to reduce repetition.
Oxleas NHSFT	2	Full	2.6	30	CTLD's often do have expertise in assessment and treatment for challenging behaviour, but in isolation these interventions are often not effective. Often service providers are not 'capable' enough to implement interventions and carers may lack the resources including additional support from social services i.e. respite care.	Thank you for your comment, the GDG agree and feel this section reflects that.
Oxleas NHSFT	3	Full	4.5	78	It is recommended that independent advocacy be offered to family and carers. This is not currently widely available.	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.
Oxleas NHSFT	4	Full	6.4	110	It is not clear who is accountable for setting up care pathways.	Thank you for your comment, the responsibility for setting up pathways is clearly set out in revised recommendation number 1.1.11.
Oxleas NHSFT	5	NICE/ Full	1.1.5/6.4.2.1.1	113	Occupational therapists should be included in list of required professionals.	Thank you for your comment. The recommendation has been revised to be more inclusive.
Oxleas NHSFT	6	NICE/Full	1.1.7/6.4.2.2	114	Use of routine session outcome measures may not be appropriate, indeed change may take place over a longer period of time. Monitoring and evaluating adherence to	Thank you for your comment. The recommendation has been revised to remove the word 'sessional' and to say that routine outcome measures should be used at each contact with the person. The GDG

					interventions in the ways suggested would be costly, and would not always be justified by the seriousness of the behaviours.	felt that this was about good governance and disputes that the costs would not be justified, especially in the wake of Winterbourne View. If done well it will identify and reinforce good practice.
Oxleas NHSFT	7	Full	8.3.1.1.	153	The ABC is listed as a suggested measure for challenging behaviour. This may be a robust tool, however, some of the language is outdated i.e. item 18 'disobedient and difficult to control' seems inappropriate in the assessment of adults.	Thank you for your comment. The GDG acknowledged during several discussions that the language of several tools may be considered out-dated. However, these tools are widely used in both practice and research, so it would be difficult for a guideline to make changes.
Oxleas NHSFT	8	NICE	1.1.7	19	Insufficient information given about 'relevant' materials, What is meant by 'sessional' in relation to use of outcome measures and ways of evaluating adherence to interventions or practitioner competence.	Thank you for your comment. Regarding your point about 'relevant materials', the GDG thinks that you mean 'manuals', and has added a definition to the glossary for clarity. In reference to your second point, the recommendation has been revised to remove the word 'sessional' and to say that routine outcome measures should be used at each contact with the person.
Oxleas NHSFT	9	NICE	1.5.8	27	Consideration should be given to when specialist assessment is required and who should do assessment i.e. for communication assessments specialist speech and language therapist and assessment for co-existing conditions and mental health assessment by psychiatrist specialising in LD.	Thank you for your comment. The GDG reviewed your comment and decided that who conducts these assessments is a matter of local implementation and therefore have not amended the recommendation.
Oxleas NHSFT	10	NICE	1.5.13	30	Proactive strategies should make reference to appropriate communication with the client.	Thank you for your comment. The GDG agrees, and feels this point is adequately covered by the second bullet point of this recommendation.
Oxleas NHSFT	11	NICE	1	8	The 'strength of recommendations' is not clear from the wording in every section of the document. A system or colour coding would make it clearer..	Thank you for your comment. This is standard text explaining the strength of recommendations used in all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Oxleas NHSFT	12	NICE	1	15	Definition of expressive and receptive language does not include use of non-verbal equivalents.	Thank you for your comment. The definitions have been revised to address your concerns.
Oxleas NHSFT	13	NICE	1.1.6	19	Emphasis is put on developing alternative communication strategies, however it is equally important to improve staff communication skills and ability to 'read' client communication and use of	Thank you for your comment. The GDG feels that the point you have raised is covered in this recommendation with reference to training to develop strategies to help the person develop a

					Augmentative and Alternative Communication (AAC).	new skill, including improved communication.
PBS4	1	Full	2	18	The second sentence implies that challenging behaviour is functional for the person and not challenging for them. Many people with challenging behaviour, their behaviour is expressed when they are distressed. The sentence implies that people with challenging behaviour are not challenged by it.	Thank you for your comment, the text has been amended in line with your suggestion.
PBS4	2	Full	2	18	There should be reference here that the same behaviour can serve different functions in different environments. For example a child may lie down on the floor and scream at school to avoid tasks, they may do the same behaviour at home to gain their mothers attention. The same approach would increase the behaviour in one environment and reduce it in another.	Thank you for your comment, the issues you raise would be covered by a functional assessment, as discussed in revised recommendation numbers 1.5.4 and 1.5.8 of the NICE guideline.
PBS4	3	Full	2.1.2	20	Whilst the social model of disability is accepted and welcomed, there could be more focus on the functionality of the behaviour in this section. When a person has a learning disability, or disability in learning, the environment needs to provide the prosthetics to help people learn and develop new skills or make existing skills more functional. For example, if a person uses physical aggression to gain attention it is likely that 1) this is the most convenient behaviour the person has learnt to gain attention in this environment, and 2) the environment is most responsive to this behaviour. In order to support the person to develop alternative behaviours to meet this function both the person needs to be supported to increase/develop alternative behaviours and the environment needs to be responsive to these behaviours. There is concern that this section focusses exclusively on the need to change the environment, with no discussion on how to support people to overcome their disability in learning and develop/increase skills. This approach would be focussed on managing the person instead of supporting the	Thank you for your comment, the points you raise are addressed later on in the introduction.

					development of positive behaviours to improve quality of life.	
PBS4	4	Full	2.5.3	28	Whilst the causative factors for behaviour that challenges may be linked to environmental causes, there are significant problems associated with creating “capable environments”. These environmental antecedent manipulations can be easily misused by staff and carers that lead people to living impoverished lives, or create ideal environments in the person’s home that the person can never leave. For example, if a person becomes aggressive when they see a dog then a capable environment would eliminate exposure to dogs, ensuring the person never leaves the house. It would be more appropriate to develop “enabling environments” that support the person to use their existing skills to be as independent as they can, and promote the gradual learning of new skills for independence to improve quality of life. The quote from Ted Carr in this section quotes him describing “educational and systems change methods”. This section focusses on the systems change with a sole focus on behaviour management rather than the educational needs and how the systems change can promote this.	Thank you for your comment. The GDG agrees that simply changing the environment is not the only approach to managing behaviour that challenges. Any environmental change needs to be considered alongside other approaches and interventions as set out in the behaviour support plan (see recommendation 1.6.1 in the short guideline).
PBS4	5	Full	2.6	29	(Pages 29-30) This section has omitted the contribution of Board Certified Behaviour Analysts and other professionals who have completed a MSc in ABA or above. Positive Behaviour Support is the intervention of choice for people with behaviour that challenges, and it is an application of Applied Behaviour Analysis (see LaVigna & Willis, 2012). Professionals in the UK are commonly not trained in ABA, including psychologists, where professional training has long neglected behavioural approaches with cognitive models taking dominance. There are approximately 130 Board Certified Behaviour	Thank you for your comment, a reference to BCBAs has been added to section 2.6 of the full guideline.

					Analysts in the UK and this number is rapidly growing. There are even more professionals who are registered with a professional body (e.g. NMC, HCPC) who have completed a MSc or above in ABA to have this competence. The BACB code of conduct states that a functional analysis should only be completed by people who are competent to do this. Whilst several NHS trusts have begun appointing Board Certified Behaviour Analysts or equivalent, for many teams there is still a significant skill gap.	
PBS4	6	Full	3.5.1	38	For the search it may have been useful to search the Journal of Applied Behaviour Analysis. This has provided a great deal of research into challenging behaviour since 1968, including many single subject design research articles on the use of behavioural approaches to behaviours that challenge. There is concern that by focussing on the UK context developments in the UK have been made without the competence in Applied Behaviour Analysis (as discussed above in comment 5). The availability of practitioners competent in ABA is much more prevalent in other countries, therefore evidence with a UK context will largely omit this.	Thank you for this suggestion. We did not search specific journals, but note that some of the existing systematic reviews included as evidence did search the journal you mentioned.
PBS4	7	Full	4.2.1	55	(Pages 55-6) There should be acknowledgement here that the majority of people with challenging behaviour may not be able to express their views, and whilst there is some research into institutional and residential settings similar research has not been carried out in supported living settings or family homes and it is not known whether similar restrictive practices or environments are also present. There also appears to be bias that the link between institutional setting and challenging behaviour indicates causality when this may be the initial reason for admission and not a resultative factor.	Thank you for your comment. The GDG acknowledged from the outset that it may be difficult to get representative views from published qualitative research. Thus, the expert advisory group validation was commissioned. However, in light of your comment we have updated section 4.5 to address the generalizability of the evidence.
PBS4	8	Full	4.5	78	The table seems to have omitted the call from	Thank you for your comment. Other chapters of the

					parents to have access to ABA, or PBS underpinned by ABA, from competent practitioners on p76.	guideline review interventions for prevention and reactive strategies, so recommendations for interventions can be found in those chapters.
PBS4	9	Full	6.1.1	94	Line 16 small typo – “my” should be “may”	Thank you for your comment, this has been amended.
PBS4	10	Full	6.1.2	95	The first paragraph may benefit from re-wording. It reads as though people with learning disabilities undergo teaching to reduce behaviour not that the teaching of professionals has been focussed on reductionist approaches. Unless it is referring here to punishment based approaches that are often used by professionals to “learn” not to do a behaviour. Punishment approaches are commonly seen in practice yet are rarely described as punishment due to misunderstandings of the terminology and science.	Thank you for your comment. This has now been amended.
PBS4	11	Full	6.1.2	95	We would like to suggest the authors consider the Enablement Model (Beebee & Abdulla, 2014) as a framework for the training needs of people who support people with learning disabilities. This reflects the Recovery Model and Re-ablement model that have been successfully applied to other fields.	Thank you for your comment. We have reviewed the training evidence and this framework did not emerge from our search.
PBS4	12	Full	6.3.3	110	There is a poor understanding of what Positive Behaviour Support is, with many providers and professionals claiming to use this intervention without fully understanding it or being competent in its delivery. Another challenge to the evidence here is, other than the study claiming the training is Positive Behaviour Support there is limited information to guarantee it is this, and the loose definitions of PBS mean that the quality and integrity of training is hard to judge.	Thank you for your comment. We understand your concern, but we utilised an existing systematic review of Positive Behaviour Support, recognising the problems with this review and downgrading the evidence to poor quality.
PBS4	13	NICE/Full	1.1.3/6.4.2	112	The statement “behaviour that challenges is communicating an unmet need” over-simplifies the functionality of behaviour and disregards that the behaviour is being reinforced. The behaviour is meeting a function, resulting in reinforcement for the person and therefore the behaviour is more	Thank you for this comment. The focus of this guideline is on improving care and the quality of life for people with behaviour which challenges. From this perspective we see ‘needs’ requirements for personal, psychological and physical care and well-being which can be met by a broad range of formal

					likely to happen in the future. Therefore the behaviour is effectively meeting needs, and is reinforcing. Saying that the need is unmet would appear inaccurate.	and informal relationships and related health and social care interventions. Nevertheless, the wording has been revised to add some circumspection ('often indicates an unmet need').
PBS4	14	Full	1.1.6/6.4.2.2	113	As 11, the Enablement Model (Beebee & Abdulla, 2014) may be a model for conceptualising this training.	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.
PBS4	15	Full	7.2.1.1	116	The inclusion of autism and other factors that are causative and internal to the person appears to conflict with earlier statements of challenging behaviour being a challenge to support and not to the person, looking at a social model and not a medical model. The factors described here are internal and not social.	Thank you for your comment. This section was based on the synthesis of 20 studies, and we think it is important to report what was shown to be risk factors and antecedents.
PBS4	16	Full	7.3.1	139	ABA based assessment tools of functioning may be worth considering here, such as ABLLS, VB-MAPP, and Essential for Living. This is in line with the understanding that behaviour is functional. It meets a need for a person which if they had learned other behaviours to achieve, the challenging behaviour would be redundant. These tools map current skill levels and promote structured skill acquisition.	Thank you for your comment. This review question was focused on methods and tools to assess the circumstances, risk factors and antecedents associated with the development of behaviour that challenges (as specified in the review protocol). We included only methods and tools for which there were studies that reported sensitivity, specificity, reliability and validity.
PBS4	17	Full	8.1	150	In the second paragraph the professionals Board Certified Behaviour Analyst and Registered Learning Disability Nurse are missing.	Many thanks for your comment. We have reviewed our recommendations to include a broader range of staff.
PBS4	18	Full	8.2.1.3	157	The tools described in this section do not make up a functional analysis in itself, and the authors of these tools often acknowledge this. For example, the FAST has a clear statement directly on the tool that this tool does not replace a full functional assessment. The BACB code of professional conduct also advises that a functional analysis should only be completed by people who demonstrate they meet the relevant training requirements and competencies to do so. It is a wider issue than identifying which tools to pick up. In comparison, anyone working in a hospital setting	Thank you for your comment. The GDG agree that the assessment is more complicated than using one tool, and for this reason provided the sub-section on functional assessment of behaviour, including several recommendations.

					can pick up a scalpel. This doesn't mean they have the competence to use it.	
PBS4	19	NICE/Full	1.5.1/8.5	163	Typo in first paragraph – error message.	Thank you for your comment, this has been amended.
PBS4	20	NICE/Full	1.5/8.5.2	164	The assessment process should include interviews, reviews of recorded information, and direct observational assessment. The assessment process included currently could lead to assessments relying solely on reported information.	Thank you for your comment, *direct observational assessment* specifically means it's not based solely on reported information.
PBS4	21	NICE/Full	1.5.10/8.5.5	168	It is important a functional assessment and analysis is completed by someone who is competent to do so. We feel this is more important than giving health professionals a list of tools they could go through.	Thank you for your comment. The level of skills and the training needed are set out in the general principles section, particularly in revised recommendation numbers 1.1.4-1.1.8.
PBS4	22	NICE/Full	1.5.13/8.5.5	169	The proactive strategies discussed in the first bullet are reactive. They are aimed at preventing challenging behaviour rather than supporting the person to meet the functionality in a different way. It is acknowledged in the second bullet function is considered, but the section would benefit from re-structuring to accurately reflect "proactive".	Thank you for your comment. The GDG has made some alterations to indicate that the aim of the strategies is to support the person by improving their quality of life.
PBS4	23	NICE/Full	1.5.13/8.5.5	169	The guidance for writing the behaviour support plan appears to be largely taken from one approach. Other approaches may look at this differently. There is a risk the focus is more on the behaviour and risk management than function.	Thank you for your comment. The GDG consisted of multiple experts in this field who brought experience of multiple-models to the table. Much of the terminology in this section is in common use and widely understood, and the GDG feels it is quite clear at the beginning of this recommendation that the focus is on function.
PBS4	24	Full	9.1	172	Using the term "prevention" seems against the grain for Positive Behaviour Support and Health "Promotion" in general where the focus is on what is wanted to be achieved rather than what is to be avoided. We suggest that enablement based approaches that focus on supporting people to increase and develop independence is better terminology.	Thank you for your comment. The term 'prevention' is no longer used in the NICE guideline (this has been changed to 'early intervention'). However, the term is retained in the full guideline, chapter, because of the nature of the reviews.
PBS4	25	NICE/Full	1.4.2/10.3	205	There could be a recommendation here about supporting capable environments to achieve function, as a proactive approach to reducing challenging behaviour.	Thank you for your comment, but this recommendation has been deleted (and nevertheless the review did not identify any evidence about capable environments).

PBS4	26	Full	10.3	205	Is it that Snoozelen rooms were found to be harmful or Sensory Integration Therapy? We are aware of evidence that SIT may be harmful.	Thank you for raising this. As described in 10.3, reporting of harms was limited but in the case of sensory interventions (such as Snoezelen rooms) there was an indication that the provision of such interventions (which have been in widespread use) may not be beneficial and could be harmful to some people.
PBS4	27	NICE/Full	1.4.2/10.3	205	There is a slight dichotomy in recommending removing things from the environment that "trigger" behaviours and then describing impoverished environments as causative.	Thank you for your comment. This recommendation has been deleted.
PBS4	28	Full	11.1	207	The statement that behavioural approaches rejects internal events and thoughts is untrue and a common misconception. CBT may also be better described as a second wave behavioural intervention, with third wave approaches being DBT, ACT etc.	Many thanks for your comment, however the current description adequately describes the key features of various treatment approaches.
PBS4	29	NICE/Full	1.6/11.3.1	261	It may be worth noting that parent training, CBT, and behavioural approaches are all underpinned by the application of ABA.	Thank you for your comment, it is the overall consensus of the GDG that ABA does not underpin parent training or CBT. Different theoretical models, such as social learning theory or cognitive behavioural theory underpin these interventions.
PBS4	30	NICE/Full	1.8/13.3	321	There is a possible argument that using least restrictive approaches could be harmful. Physical interventions may aim to have a punishment (i.e. reductive) effect on challenging behaviour, but from a behavioural sciences perspective if you start small with a punishment people can become habituated to it and it will therefore gradually increase over time. Much like the analogy of how to boil a frog. This is not to condone more restrictive interventions, but it should be acknowledged that starting small with restrictions may lead to habituation and gradual increase if following the laws of behavioural science. This further strengthens the environment for the availability of staff who are competent in behavioural science.	Thank you for your comment. The GDG re-considered this issue and were clear that it would be unethical to not use the least restrictive approach. They made some changes to the section on 'reactive strategies' and believe that following these recommendations will avoid the situation you are describing.
PBS4	31	Full - Apx B	General	15	(Pages 15-22) Have all declarations of interest been made? For	Thank you we have reviewed and revised the DOIs as a result of your comment.

					example some members on the list are known to have interests related to physical intervention packages that have not been declared here.	
Public Health England	1	NICE	General	General	Most of the document is framed in terms of working with people with a learning disability and behaviour that challenges, and their families and carers**.** We think it is important that paid staff are included throughout the guidance.	Thank you for your comment. Paid staff are included in the document - unless otherwise stated the recommendations are directed at all staff involved in the care of people with a learning disability and behaviour that challenges.
Public Health England	2	NICE	General	General	Although physical health problems are identified as a factor that may increase the risk of challenging behaviour, there is only one reference to pain in this guidance (1.8.3). Unmanaged pain will very often be a cause of challenging behaviour and we think the issue of unmanaged pain should be given <u>much</u> more emphasis in this guidance, for example it should be mentioned in section 1.4.1.	Thank you for your comment, in light of yours and others' comments pain management has been added to revised recommendation number 1.2.1.
Public Health England	3	NICE	1.8.5	36	In this section there is a reference to needing to act in accordance with DoLs in relation to restrictive interventions. We think there should be some more explicit information about DoLs in this guidance. For example, it should highlight the need for care homes or hospitals to request a standard authorisation if someone is going to be deprived of their liberty.	Thank you for your comment. There is further information about DOLs and links to the relevant documentation in the section on person-centred care at the start of the guideline.
Public Health England	4	NICE	1.7.3	34	The specialist who is prescribing medication should consider if this constitutes a deprivation of liberty and act in accordance with the DoLs guidance.	Thank you for your comment, the introduction to the guideline outlines the responsibilities all staff have in relation to consent and capacity.
Public Health England	5	NICE	1.7	33	We think this section needs to be clearer about what types of medication it is talking about. Section 1.7.1 seems to be ambiguous about whether medications are for a specific physical health problem, for a mental health problem (so psychotropic of some sort), or for the 'challenging behaviour' itself (i.e. antipsychotics). There should be some recognition that antipsychotics have no specific impact on challenging behaviour – the effect is generally	Thank you for your comment. The section on medication has been revised substantively to address your concerns about the types of medication being referred to. However your point about antipsychotics 'having no specific impact' on behaviour that challenges was not shared by the GDG following their review of the evidence and their expert opinion. With regard to your point about polypharmacy, the GDG felt very strongly that this should be avoided in people with a learning disability and has made very clear recommendations about this. The need for review

					sedative. There is a need for clearer guidelines about polypharmacy, particularly in relation to existing long-term medications that people may have been prescribed (e.g. medication for epilepsy). There should be medication reviews, before people are prescribed new medication, with the relevant specialist(s) (e.g. neurologist when considering epilepsy; other physical health specialists depending on the physical health condition). It should not only be psychiatry included.	for all staff involved in the care of the person with a learning disability has also been expressly stated.
Public Health England	6	NICE	1.1.1	17	There is a reference here to providing easy read information about available interventions and services. It is important that people are also given appropriate support to understand the easy read information.	Thank you for your comment. The GDG agrees that it is important that the person is given support, and expects that this would be part of any good-quality care.
Public Health England	7	NICE	1.7.2	33	In 1.7.2 it says “When prescribing medication for behaviour that challenges, take into account side effects and develop a care plan that includes a rationale for medication, explained to family members and carers” We think that there should also be an attempt to explain this to the person with learning disabilities who is being prescribed the medication.	Thank you for your comment. The point you have raised has now been included in the recommendation.
Public Health England	8	NICE	2.2	37	Many families talk about ‘challenging behaviours’ rising in the teenage years, which can lock people into catastrophic trajectories for the rest of their lives. We would like to see a research recommendation around understanding these issues much more and working on ways to help young people through it.	Thank you for your comment, we agree that a better understanding of the nature and development of behaviour that challenges in adolescents would be helpful and may be a worthy focus for further research. However the GDG did not identify this as a prioritised area for further research.
Public Health England	9	NICE	2.1	37	(Sections 2.1-2 pages 37-9) The research recommendations seem to assume that early intervention and applied behavioural analysis/positive behaviour support are synonymous. There are other models of early intervention that might be relevant.	Thank you for this comment. There is some evidence to support the use of skills teaching (which is not synonymous with applied behavioural analysis) and environmental adaptation but this evidence is limited and this was the reason for the development of this research recommendation. In the absence of any specific examples in your comment it is difficult to make any further response.

Public Health England	10	NICE	2.3	39	(Sections 2.3-4 pages 39-40) The research recommendations seem to assume that 'not living with your family' equals 'residential care'. There are alternatives such as supported living, tenancy options and shared lives which could presumably work just as well if not better. We would prefer to see a much less restrictive term used instead of 'residential care', for example, individualised support in the community.	Thank you for this comment, the terminology has been changed to 'care settings'.
Queen's University Belfast	1	Full	General	General	There are still some misrepresentations of ABA as 'an intervention' rather than the application of the science of behaviour analysis that underpins more or less all evidence based interventions (see National Autism Centre, 2009). It would be important to correct this.	Thank you for your comment, reference has now been made to the 'science and practice of ABA' in the introduction, however it is the overall consensus of the GDG that ABA does not underpin all evidence based interventions. Different theoretical models, such as social learning theory or cognitive behavioural theory underpin the interventions recommended in this guideline.
Queen's University Belfast	2	Full	3.4	36	There are quasi-experimental single subject research designs with high internal and external validity that would also weld studies with robust results. These studies should be used in systematic reviews in conjunction with RCT, pre-post and interrupted time-series designs.	Thank you for this suggestion. However, there are difficulties searching for single subject and small n research, therefore we had to rely on existing systematic reviews, which were used where available.
Queen's University Belfast	3	Full	3.5.3	40	Specific single subject research design address irreversibility in a satisfactory manner (e.g., multiple baseline across participants research design).	Thank you, we have revised this section to clarify this.
Queen's University Belfast	4	Full	4.5	77	Given the amount of evidence and families' views on PBS or ABA, I would expect to see an explicit recommendation for the availability of PBS/ABA and staff/family training. Psychosocial or psychological interventions, as it stands now, is a very generic term that leaves space for non-evidence based interventions.	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the

						guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Queen's University Belfast	5	NICE/ Full	1.1.5/6.4.2.1.1	113	Competent staff should include certified behaviour analysts (i.e., Board Certified Behavior Analysts), since the aims mentioned here (e.g., understand nature of behaviour, conduct specialist assessments including functional assessments, develop new skills, etc.) are the core areas of expertise of these professionals, while the professionals mentioned might not have received any training at all in these areas.	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has now included them in revised recommendation number 1.1.5.
Queen's University Belfast	6	NICE/Full	1.4.1/7.4	148	In the environmental factors, the lack of well trained staff that can trigger or reinforce challenging behaviours or cannot identify the needs communicated through a challenging behaviour (i.e., cannot identify function) should be added as a determinant factor.	Thank you for your comment, a bullet point that captures your suggestion has been added.
Queen's University Belfast	7	Full	8.5.2	164	The use of "a scale (such as the Functional Analysis Screening Tool)" is recommended "to understand its function." However, descriptive and especially indirect methods (i.e., questionnaires) used for the identification of behaviour function have shown to have significantly lower reliability than experimental methods (i.e., functional analyses). BCBAs are the staff trained to conduct experimental functional analyses safely and explicit recommendations for the use of this method should be included. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3546636/pdf/i1998-1929-5-1-54.pdf	Thank you for your comment. The GDG agree that the assessment is more complicated than using one tool, and for this reason provided the sub-section on functional assessment of behaviour, including several recommendations. However, NICE recommendations do not routinely specify who should conduct the assessment.
Queen's University Belfast	8	Full	11.3.2	263	Expression "applied behavioural analysis interventions" should be substituted by "interventions based on the science of Applied Behaviour Analysis" or "Applied Behaviour Analysis (ABA)-based interventions".	Thank you for your comment, we have updated the guideline to read: 'Are interventions based on the science and practice of Applied Behaviour Analysis…'
Queen's University Belfast	9	NICE/Full	1.7.1/12.3	312	"…psychosocial, psychological or other interventions" should explicitly state ABA-based interventions.	Thank you for your comment, it is the overall consensus of the GDG that ABA does not underpin these interventions. In fact, social learning theory

						underpins the evidence for a number of the interventions reviewed, such as Triple P.
Real Life Options	1	NICE	6	General	We feel that the overall approach of the guidance is very person centred, are supportive of this and pleased to see that this emphasis is articulated strongly from the start.	Thank you for your comments.
Real Life Options	2	NICE	11	General	RLO is pleased to see that family members are drawn into the process to develop consistency of approach	Thank you for your comments.
Real Life Options	3	NICE	General	General	We are pleased to see the emphasis on communication and receptive communication	Thank you for your comments.
Real Life Options	4	NICE	11	General	We feel that the guidance is strong on the need for assessment to be based on understanding the person behind the behaviour, and for seeking early identification.	Thank you for your comments.
Real Life Options	5	NICE	General	General	We are enthusiastic about the guidance and therefore hope that there will be some attention given to a version that is accessible and usable for staff	Thank you for your comment, the guideline will be translated into an online pathway for staff to easily access the recommendations.
Real Life Options	6	NICE	General	General	We feel the approach taken to medication is to be commended. Our experience is that some people may have been on the same medication for many years and welcome the setting of goals to reduce, review and stop.	Thank you for your comments.
Real Life Options	7	NICE	1.8	35	The Section, Reactive Strategies, is particularly strong and we support the approach taken in identifying risks that are associated with interventions.	Thank you for your comment.
Real Life Options	8	NICE	2.3	39	RLO strongly supports the proposal for a programme of research in order to provide an evidence base for reducing out-of-area-placements.	Thank you for this comment.
Real Life Options	9	NICE	2.3	40	We do not understand why there should be a register of people who 'need' an out- of- area placement. Our view is that it may be there should be a register of people who need specific types of care (such as people who need a secure environment) but we cannot think of many situations where someone would require an out of area placement per se.	Thank you for this comment we have removed this from the recommendation.

Real Life Options	10	NICE	2.4	40	We are less convinced by the programme of research that is outlined here. There have been numerous programmes and projects that look at this area. We feel it would be more cost effective and beneficial if a process of secondary research is adopted here.	Thank you for this suggestion but this recommendation arose in part because we were unable to find any significant research base on which to develop appropriate recommendations.
Rotherham Doncaster & South Humber NHSFT	1	NICE	General	General	The document captures a lot of information but has the opportunity to be much more refined, focussed and less repetitive. There are also large sections in which the tone of the language is too casual, conversational and anecdotal in nature. The preventative work as outlined by Prof Mansell is to ensure we are getting it right in the first place with inclusive and accessible health & social support https://www.kent.ac.uk/tizard/research/research_projects/dh2007mansellreport.pdf . The pathway needs to be able to articulate that working positively with challenging behaviour means preventing it from escalating and becoming ingrained at an early point in the person's life. Services need to respond across tiers of care that function to support: • Prevention • Early detection • Long term community support • Intensive community support • Crisis response & management The challenge is to develop an integrated and holistic pathway. This is best done by putting everything into LaVingna's multi-element model (it provides a framework on which to capture PBS in its widest and most comprehensive form + all the info in this guidance). http://www.academia.edu/7770815/The_efficacy_of_positive_behavioural_support_with_the_most_challenging_behaviour_The_evidence_and_its_implications • Ecological support • Focussed support	Thank you for your comment. Reference to the Mansell report and the La Vigna multi-element model have now been included in the Introduction to the full guideline. Unfortunately there is no evidence of a sufficient quality to make recommendations about the La Vigna multi-element model.

					• Positive Programming • Risk management The final guidance needs to ensure capable and ethical practice (6C's culture ethos, valuing people/person centred care + restriction reduction) run strongly throughout all aspects of the pathway. We have a strong evidence base from Winterbourne, Mid Staffs and Mind's Mental health in Crisis that when the ethos and culture is not positive and proactive the care provision becomes unethical & dangerous. This could be made clearer in the general principles of care section. Ultimately there needs to be a focus on person centred holistic outcomes that recognise social inclusion, the maintenance of recovery and QoL as key indicators of success.	
Rotherham Doncaster & South Humber NHSFT	2	NICE	0	3	(Introduction) Paragraph 3 – should it be 5-17% in line with Intellect Disabil Res. 2007 Aug;51(Pt 8):625-36. Challenging behaviours: prevalence and topographies. Lowe K[1], Allen D, Jones E, Brophy S, Moore K, James W.	Thank you for your helpful suggestion, this has been amended.
Rotherham Doncaster & South Humber NHSFT	3	NICE	0	4	(Safeguarding children) Typo – unnecessary bracket at the end of the second bullet point.	Thank you for your comment, this has been amended.
Rotherham Doncaster & South Humber NHSFT	4	NICE	0	4	(Safeguarding children) Whilst there is no NICE guidance on safeguarding adults as yet – it would be good to highlight the need to do this at this point in the document.	Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.
Rotherham Doncaster & South Humber NHSFT	5	NICE	1.5.7	12	(Risk assessment) Suicidal ideation and intent should be risk assessed, as should physical health, mental health & substance misuse.	Thank you for your comment. Suicidal ideation has been added to the recommendation. Physical and mental health (including substance misuse) would have been assessed already as part of the assessment of behaviour that challenges, so these are not repeated here.
Rotherham Doncaster & South Humber NHSFT	6	NICE	1.5.8	13	(Risk assessment) Last bullet point – why are we recommending psychiatric tools that have outdated titles that some	Thank you for raising this, the GDG agree, but this issue needs to be taken up by the clinical and research community, as the GDG should base its

					people find offensive?	decisions on the evidence, not the name of the tool.
Rotherham Doncaster & South Humber NHSFT	7	NICE	1.1.1	17	(Working with families and carers) “in an appropriate language” is too vague. Should we be saying that we produce information in people’s first language if they are not proficient English speakers?	Thank you for your comment. ‘Appropriate language’ refers to language that is suitable for the person’s cognitive ability and developmental level. This has been clarified in the recommendation.
Rotherham Doncaster & South Humber NHSFT	8	NICE	1.1.7	19	Can we include the Behaviour Problems Inventory as a measurement tool - http://www.bps.org.uk/networks-and-communities/member-networks/dcp-faculty-learning-disabilities/behavior-problems-invento	Thank you, yes this was included in the review (see section 8.3 of the full guideline).
Rotherham Doncaster & South Humber NHSFT	9	NICE	1.1.8	20	Quality of life needs to be in there as an outcome. https://www.bps.org.uk/system/files/user-files/Faculty%20for%20Learning%20Disabilities%20CPD%20event/paper_validating_a_new_patient_reported_outcome_measure_for_adults_with_intellectual_disabilities_the_mini_mans-ld.pdf	Thank you for your comment, the GDG agree that quality of life is of great importance and this has been added to recommendation 1.1.2, and is also included as an outcome in revised recommendation number 1.5.10.
Rotherham Doncaster & South Humber NHSFT	10	NICE	1.7	33	Should we be linking to the NICE guidelines for antipsychotics and medication management, monitoring and good practice here?	Thank you for your comment. The GDG has added links to the NICE guidelines on psychosis and schizophrenia for further advice on use of antipsychotics including monitoring.
Rotherham Doncaster & South Humber NHSFT	11	NICE	1.7	33	http://www.ncbi.nlm.nih.gov/pubmed/15611982 Is there scope/evidence to refer to naltrexone as a medication to be used where self injury is assessed as being to stimulate endogenous opiates?	Thank you for this comment, but the evidence for naltrexone was reviewed in Section 12.2.1.19 of the full guideline, and the GDG do not believe it supports the use you have suggested.
Rotherham Doncaster & South Humber NHSFT	12	NICE	1.8.2	35	Where available refer to LPA advice or advance directives stipulating personal preferences in relation to restrictive practice.	Thank you for your comment. All staff should be knowledgeable about LPAs and advance directives – it is not specific to this population. Please see the *Service User Experience in Mental Health* for further guidance on this topic.
Rotherham Doncaster & South Humber NHSFT	13	NICE	2.3	39	Isn’t this question out-dated? It is obvious that people would benefit from care close the their family, friends and advocates – see patient experience NICE? Why are we posing a question that has already been answered and in area that goes against national policy to support?	Thank you for this comment, it was the consensus of the GDG that whatever might be intended by national policy, significant out of area placements continue to be made and therefore there was a need for a research recommendation in this area.
Rotherham Doncaster & South Humber NHSFT	14	Full	1.1.3	14	Line 35 and 45 use the numerical number “4” where it should be written in letter form “four”.	Thank you for your comment, it is NCCMH house style to use numerals.

Rotherham Doncaster & South Humber NHSFT	15	Full	1.2.3	16	Line 19: Whilst I understand the national remit for which this work is commissioned (England & Wales), the principles of good practice are wide ranging and the opportunity to share good practice, work outside silos, reduce duplication & support one vision promoting good practice UK wide could be an opportunity lost.	Thank you for your comment, as you state NICE guidelines are only commissioned in England and Wales.
Rotherham Doncaster & South Humber NHSFT	16	Full	2.1.1.	19	Line 18 should be changed to: People with a learning disability may have varying degrees of impairment and ….	Thank you for your comment, this has been amended.
Rotherham Doncaster & South Humber NHSFT	17	Full	2.1.1	19	Line 33: Should be Autistic Spectrum Disorder rather than Asperger syndrome as this is being phased out as a term and tends to be associated with higher levels of functioning (except in the case of Gilbert's Aspergers).	Thank you for your comment, this has been amended.
Rotherham Doncaster & South Humber NHSFT	18	Full	2.1.2	20	(Page 13-14) Lines 13-6: This reads as being quite anecdotal and lacking rigour and conciseness. I would recommend some bullet points and some references.	Thank you for your comment, the GDG believe this chapter has been sufficiently referenced.
Rotherham Doncaster & South Humber NHSFT	19	Full	2.2	21	This section needs to start with an overview of what we know and the range of prevalence taken from studies. Do this first and then state some of the methodological challenges.	Thank you for your comment, however the GDG felt it important to present the methodological challenges first to provide some context for the prevalence range.
Rotherham Doncaster & South Humber NHSFT	20	Full	2.5.1	25	Line 36: Reads too casually - the behaviour in some sense 'sat inside' ….. How about the behaviour was a consequence of a physical condition (e.g., a neurodevelopmental disorder, genetic phenotype or a neurological disorder).	Thank you for your comment, the text has been amended.
Rotherham Doncaster & South Humber NHSFT	21	Full	2.5.2	27	Line 17: Reads too casually - Psychosocial causes have probably been investigated more frequently than any other …. Have they or haven't they? This is a NICE review of evidence!	Thank you for your comment, this section has been revised.
Rotherham Doncaster & South Humber NHSFT	22	Full	2.5.2	28	Line 26: Arson is a crime and it is labelled as such by the police and courts. Is there a danger we are expanding challenging behaviour of include all forms of problematic behaviour including forensic/offending behaviours for which there is a different evidence of base of assessments and treatments.	Thank you for your comment. Fire-setting fits the definition of challenging behaviour, as does sexual offending and aggressive assaults. It is widely accepted that some behaviour that challenges falls within the purview of the Criminal Justice System, and excluding people who happen to have been dealt with by the CJS would be inequitable.

Royal College of General Practitioners	1	Full	General	General	I welcome this draft guideline. While it has many valuable recommendations it has considerable deficiencies and lacks conviction that it will produce any real change for people with behaviors that challenge them and their families. There needs to be a summary of the recommendations specific for each group as the document is too long and difficult to access. The recommendations from Winterbourne - a time for change - A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014 include: https://www.acevo.org.uk/sites/default/files/STRICTLY%20EMBARGOED%200001%2026%20Nov%20-%20Winterbourne%20View%20Time%20for%20Change.pdf To urgently close inappropriate in-patient care institutions; · A Charter of Rights for people with learning disabilities and/or autism and their families; · To give people with learning disabilities and their families a 'right to challenge' decisions and the right to request a personal budget; · A requirement for local decision-makers to follow a mandatory framework that sets out who is responsible, for which services and how they will be held to account, including improved data collection and publication; · Improved training and education for NHS, local government and provider staff; · To start a social investment fund to build capacity in community-based services, to enable them to provide alternative support and empowering people with learning	Thank you for this comment. A summary of the recommendations is provided in the NICE guideline and in an associated pathway that NICE will develop to accompany the guideline. A number of the issues you refer to are dealt with in the guideline (e.g multi-disciplinary assessment), others may be addressed by the forthcoming NICE guidance on service models and others, such as the structure and role of CCGs, are outside the scope of the guideline.

					disabilities by giving them the rights they deserve in determining their care. The clinical guidelines do not specifically address this. Currently there is • Lack of timely access to assessment (recommendation 4.5 page 77 lacks any time target) • No co-ordination between education psychologists and community paediatrics • No long-term planning by Clinical Commissioning Groups for local provision of care • Lack of multi-disciplinary assessment of behaviour and behaviour support plan • Information provided by family carer about the person's needs are not utilised • Staff training issues regarding understanding challenging behaviour, positive behaviour support and communication • Reasonable adjustments to service provision not made • Staff not matched to the person's interests • Lack of consistent staffing • Family carer dissatisfied with service • The individual excluded putting him at risk of out of area placements • Negative impact on the wellbeing of the family • Lack of knowledge of the Mental Capacity Act and adult safeguarding in primary care and community staff Primary care needs: · a variety of timely support including a single point of access rather than having to deal with agencies which have exclusion criteria.	

					· Training and guidance how to investigate to distinguish a physical cause of behaviours that challenge including point of care test for C Reactive protein · Training and guidance about minimum restraint and sedation to perform physical examinations · Toolkits to help assess triggers such http://www.twca.org.uk/documents/Generic%20Documents/Dementia/Understanding%20and%20improving%20the%20care%20of%20a%20person%20with%20challenging%20behaviour%20V4%2018%2008%2010.pdf	
Royal College of General Practitioners	2	General	General	General	The guidance does not include any recognition of the work of intensive interaction, particularly Phoebe Caldwell.	Thank you for raising this, but we found no evidence on the use of intensive interaction that met eligibility criteria that was specific to behaviour that challenges in people with learning disabilities.
Royal College of General Practitioners	3	General	General	General	The guidance does not mention the real risks of disability hate crime particularly in independent non NHS units as evidenced by Eric Emerson https://www.improvinghealthandlives.org.uk/projects/ipbch	Thank you for your comment, we agree this is an important issue, however it is outside the scope of the guideline.
Royal College of General Practitioners	4	General	General	68	(Line 95) Respite is difficult to obtain and is clearly effective (page 69 line 35). Where are the recommendations about this?	Thank you for your comment. Following a number of similar comments, the GDG has made a recommendation about offering advice on accessing short breaks and other respite support.
Royal College of General Practitioners	5	General	General	91	(Line 27) Most carers' assessments are ineffective and really don't address their substantial needs particularly financial ones	Thank you for your comment. It is hoped that this guideline, along with others will improve the quality of care for carers by raising awareness of their needs.
Royal College of General Practitioners	6	General	General	163	(Line 20) There is an error message	Thank you, this has been amended.
Royal College of General Practitioners	7	General	General	192	Annual Health checks Primary care health checks for people with learning disabilities were associated with increases in health related activities, identification of important co-	Thank you for providing this reference. As described in the review protocol (section 9.4 of the full guideline), the review was restricted to RCTs and systematic reviews. Therefore, this study did

					morbidities and referrals to secondary care. Assessment of an incentivized scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study, Marta Buszewicz, Catherine Welch, Laura Horsfall, Irwin Nazareth, David Osborn, Angela Hassiotis, Gyles Glover , Umesh Chauhan , Matthew Hoghton, Sally-Ann Cooper, Gwen Moulster, Rosalyn Hithersay, Rachael Hunter, Pauline Heslop, Ken Courtenay, André Strydom in The Lancet Psychiatry, 1, 7, 522 – 530.	not meet inclusion criteria.
Royal College of Nursing	1	NICE	0	3	A definition of challenging behaviour should be given at the start of the report.	Thank you for your comment. A definition of behaviour that challenges is provided in the second paragraph of the introduction to the NICE guideline.
Royal College of Nursing	2	NICE	0	6	(Pages 6-7) Transition from children to adult services is an important time for young people and their families. Although this is taken into consideration in the report, our research, feedback from service-users and their families have found that they feel that more support should be put in place to ease this transition. Child and adult services need to communicate more effectively with each other, service-users and their families. Therefore, we feel a more holistic person-centred approach is needed. One that allows service-users and their families to make clear informed decisions about their future care and treatment.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Royal College of Nursing	3	NICE	1.1.2	10	It is important that a person-centred approach should be used when developing an intervention. However, in addition there is a need for more consideration for individual needs and preferences to enable service-users and families make informed decisions about their care and treatment. An individual difference along with background information needs to be taken into consideration when developing an intervention. There is a need to be wary of a ‘one size fits all approach’. Individual	Thank you for your comment. The GDG feels that the guideline has highlighted the importance of person-centred care, notably in revised recommendation numbers 1.1.1, 1.1.9 and 1.5.5, and in 1.1.2 by emphasising that the focus of support and interventions should not be changing the person but improving their care. The GDG has added to this that it is also important to increase the person’s skills.

					needs need to be at the forefront.	
Royal College of Nursing	4	NICE	1.4.1	12	In addition to personal and environmental risks, other factors that can influence the challenging behaviour a person may present in their interaction with services; staff working with people with learning disabilities should have enough background information on each person so as to be able to recognise any early warning signs or triggers that could increase the risk of them displaying challenging behaviour. Background data should be collected for all service–users at point of entry and all staff working closely with them should be briefed.	Thank you for making this suggestion. The GDG reviewed both the recommendation and the evidence, and decided that some changes should be made, in particular with regard to the environment.
Royal College of Nursing	5	NICE	1.1.12	21	To ensure effective communication regarding the functioning of care pathways, it is crucial that primary and secondary care professionals, managers and commissioners all work together.	Thank you for your comment, the GDG agree this is crucial.
Royal College of Nursing	6	NICE	1.7.3	34	Antipsychotic medication should only be considered if all other interventions are inadequate. Medication should be reviewed regularly for effectiveness and side effects. The service user and family members' preferences should be taken into consideration before prescribing any medication unless in an emergency situation.	Thank you for your comment. The section on medication has been revised substantively and restructured to emphasise the important points you have raised. Moreover, further detail has been added to this section about monitoring side effects.
Royal College of Nursing	7	NICE	2.1	38	Local and accessible residential placements have been proved to be beneficial. High proportions of people with learning disabilities have been placed in residential facilities/supported living schemes as a result of challenging behaviour. However, early intervention to promote positive behaviour change may lead to less people having to be placed in residential facilities as a result of challenging behaviour. Positive behaviour support that aims to reduce behaviour that challenges and increases quality of life through teaching new skills needs to be highlighted and made a priority. Early intervention with children at risk of developing behaviour that challenges is very beneficial and offers an opportunity to significantly enhance their	Thank you for the comment and its endorsement of our research recommendation.

					life and that of their family members or carers. There is a need for early interventions to be developed and their feasibility and cost-effectiveness along with the benefits for young people with learning disabilities and their families/carers taken into account and further assessed.	
Royal College of Paediatrics and Child Health	1	Full	General	General	We feel that it is very difficult to do a whole lifetime approach in one document, but parent training should figure largely for the under 5/6 year olds. The document appears bias is towards older people with leaning difficulties.	Thank you for your comment, we have revised the document to make it clear that the recommendations apply to children, young people and adults unless otherwise specified.
Royal College of Paediatrics and Child Health	2	NICE	1.1.5	General	What does specialist mean in this context? It could be interpreted as one service for the nation whereas all localities should have someone who understands how to deal with challenging behaviour in LD with a network in every region of more highly specialised support, e.g. if there is autism.	Thank you for your comment. The GDG feels it is clear that in this context specialist means people with the additional skills, knowledge and expertise required to support other professionals and staff in conducting assessment and providing interventions. Specialist skills and knowledge would be over and above what staff and professionals providing routine care would be expected to possess.
Royal College of Paediatrics and Child Health	3	Full	General	General	We feel that there is insufficient emphasis on communication difficulties and expression of mood/feelings as functions of challenging behaviour.	Thank you for your comment. The GDG felt that the issue of communication was addressed sufficiently in revised recommendation numbers 1.1.3, 1.4.1, 1.5.5, 1.5.8, 1.6.1, 1.7.2 and 1.7.4. Difficulties with communication have also been added to revised recommendation numbers 1.1.2 and 1.8.7.
Royal College of Paediatrics and Child Health	4	NICE	1.2.1	General	(Physical exam) This is a good section.	Thank you for your comments.
Royal College of Paediatrics and Child Health	5	NICE	1.4	General	(Early identification) What about a database of all children under 5 (to be kept by health/social care) with challenging behaviour so that early intervention can be assessed and follow up/outcome assessed as an audit of the success of a service?	Thank you for your comment, such a recommendation is outside the scope of the guideline. However, it may be of value to support implementation of the guideline, and we will draw it to the attention of the NICE implementation team.
Royal College of Paediatrics and Child Health	6	Full	General	General	Thinking about the outcome standards that will follow from this guideline, we cannot see many recs that are suitable and measurable. Physical exam is one, so is knowing how many	Thank you for this comment. We agree developing quality standards for this guideline will be challenging. We will forward your comment to the NICE group responsible for Quality Standards.

					people including children have aggressive challenging behaviour and LD in a locality whose behaviour improves; a specialist service that can deliver home and school based interventions is another. Could some thought be given to the quality standards?	
Royal College of Paediatrics and Child Health	7	NICE	General	General	There is a much higher incidence in children in care (looked after Children) of not only autism spectrum disorder but also behaviour and learning disability due to genetic background. It is essential there is a clear recognition in guidance for this group as they frequently move addresses and there are more disadvantaged due to poor transition and are already coming from neglect/safeguarding background more than 62%.Reference :**Statutory Guidance on Promoting the Health and Wellbeing of Looked After Children 2009**	Thank you for your comment, the GDG agree this is an important issue which is addressed in revised recommendation number 1.1.9 where transitions are discussed.
Royal College of Paediatrics and Child Health	8	NICE	1.10	General	(Sleep) It is essential that it is recognised that evidence to support use of melatonin for sleep difficulties is weak due to the availability of high quality studies .Clear guidance on tranquilisers when to be used as a reaction would be helpful as very often CAMHS colleagues may not be available and the decision has to be taken in respite care at antisocial hours by Paediatrician .Reference:G.Giaroli et al. To sleep or not to sleep :a systematic review of the literature of Pharmacological treatments of insomnia in Children and adolescents with Attention – deficit/hyperactivity disorder. Journal of children and adolescent Psychopharmacology .Volume 23,number 10;640-647.2013	Thank you for your comment. Please see Section 12.3 of the full guideline for information about the quality of evidence. The GDG reviewed the use of medication and the recommendations made reflect what they consider to be suitable given the evidence. Please see section 1.11 (NICE guideline).
Royal College of Paediatrics and Child Health	9	NICE	1.7	General	(Medication for aggressive behaviour or behaviour that challenges) There should be guidance on communication and support for Paediatricians and use of medication with a pathway development again with CAMHS for children as very often the waiting list for CAMHS is	Thank you for your comment. The GDG have avoided explicitly stating who should prescribe medication as this is a matter for implementation depending on local resources and appropriately trained staff.

					long and there is a need to act in timely way to minimise the risk to others and improve outcome	
Royal College of Paediatrics and Child Health	10	NICE	0	3	(Introduction, page 3 line 4) In full version (Page 18 line 41) stated dyslexia is specific learning disability ?should be difficulty to avoid confusion. full version does recognise Education using learning Difficulty	Thank you for your comment, this has been amended for clarity.
Royal College of Paediatrics and Child Health	11	NICE	0	1	(Introduction, page 1 second paragraph line 4) Serve the purpose – should be clearer as use to communicate/sensory seeking /avoidance/escape from sensory stimuli etc..	Thank you for your comment, this has been amended for clarity.
Royal College of Paediatrics and Child Health	12	NICE	0	1	(Introduction, page 1 paragraph 4) It would be useful to have some definition for grading behaviour that challenges e.g. severity, frequency, intensity to assess although there will be subjectivity but it would be baseline for management and monitoring .	Thank you for your comment, the assessment section of this guideline (section 1.5) has a clear emphasis on measurement at baseline and monitoring – this would include an assessment of the severity of the behaviour that challenges.
Royal College of Paediatrics and Child Health	13	NICE	0	6	(Person Centered care, page 6 paragraph 2 line 9) It is essential when dealing with children with learning disability that different methods of communication are used and decision are made in the best interest of child .Based on Frasers Competence (modified version of Gillick`s competence)they cannot refuse consent to treatment if they mental age (not chronological age) is below 16	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback. Also, revised recommendation number 1.1.2 does highlight the need for any information to be given in a format that is appropriate and useful for the person with a learning disability and challenging behaviour.
Royal College of Paediatrics and Child Health	14	NICE	0	10	(Key priorities for implementation) It is repetition of full version section 1 would be useful to summarise key priorities in the NICE version and have full recommendation in section 1 in full version	Thank you for your comment, but all NICE guidelines list the key priorities at the start of the guidance followed by the recommendations in full.
Royal College of Paediatrics and Child Health	15	NICE	1.1.6	19	(staff training and supervision) Second line would be useful to have link for proactive strategies just as we have for reactive strategies	Thank you for your comment, but the GDG did not consider that this was necessary, because the definition of proactive strategies is clear from the context and content of the recommendations.
Royal College of Paediatrics and Child Health	16	NICE	1.1.7	19	(Section :staff training and supervision) Clarity on competency of staff would be useful and which member of staff. What guidelines /legislations etc.	Thank you for your comment, but this is a matter for local services to determine.

Royal College of Paediatrics and Child Health	17	NICE	1.2.1	22	(Physical health care) Health check should be needs based and clarity on who does it for children under 18? Allied Health profession? GP. Some clarity on what should be checked would be useful	Thank you for your comment, this recommendation has been amended to specify that a GP should conduct the annual health check. This recommendation also applies to children and young people.
Royal College of Paediatrics and Child Health	18	NICE	1.6.7	32	(Interventions for behaviour that challenges) Does this imply that skilled staff who manages behaviour that challenges should be directing all sensory profile assessments to occupational therapists ever increasing national waiting list and delay intervention even more when we already know behaviour gets worse is early intervention not made. reference www.challengingbehaviour.org.uk	Thank you for your comment. Occupational therapists are part of the specialist service (set out in revised recommendation number 1.1.5), and therefore may be involved in the assessment (see revised section number 1.5), but so might other specialist staff.
Royal College of Paediatrics and Child Health	19	NICE	General	General	Recommends different assessments but would be useful to have a link to a standard format that can be readily accessed via hyperlink e.g. 1.Adoptive behaviour scale 2.Aberrant behaviour check list 3.functional analysis screening tool 4.life expenses checklist 5.Qulaity of life questionnaires 6.Maturation assessment scale 7.Strengths and difficulties questionnaire	Thank you for your comment. The relevant resources and references for these tools will be available from NICE Implementation.
Royal College of Paediatrics and Child Health	20	NICE	2	38	(Research recommendations And 1.7 – pages 38 and 45) Support this [Suggest putting the comment about evidence of 'Considerable overuse of medication..' more prominently in the main document as well in 1.7 ? ie caution and expertise required re medication, part of a response]	Thank you for this comment. We have revised the recommendation on the use of medication in light of your and other comments
Royal College of Paediatrics and Child Health	21	NICE	General	37	(Summary, research recs, pages 37 and 45) Support this	Thank you for your comment
Royal College of Paediatrics and Child Health	22	NICE	1.9	36	(Sections 1.9, 1.6.5 and 1.5.5, pages 36 and 32) Co existing health problems and side effects of medication : are common causes or contributors to challenging behaviours particularly in the elderly and in children . Is this stated clearly	Thank you for your comment. The GDG feels that it has covered coexisting mental and physical health problems, and side effects of medication, sufficiently. As well as in section 1.10, the guideline covers coexisting conditions in revised

					Therefore thorough assessment for and exclusion of or specific treatment for new problems or review of existing medication for side effects or value or dose etc are essential routinely if behaviours are challenging and though mentioned [as in 1.5.5] the value of these seems poorly communicated or emhasised. These comments apply throughout the document eg in 1.6.5 Ie Make sure mental health and Social care teams think to exclude medical issues and so have access to good medical assessment and advice; ie a dr or nurse who knows what they are looking for as medical problems can be harder to identify in this group and be presenting as behavioural primarily!	recommendation number 1.2.1, section 1.5 on assessment, and section 1.8 on medication. Section 1.8 has been substantively revised to make it clear that any mental or physical health problem that has been identified as a factor in the development of behaviour that challenges should be treated before considering medication to manage behaviour that challenges.
Royal College of Paediatrics and Child Health	23	NICE	1.9.1	General	With ref to the comments above : IF there are NICE G s for a condition? Suggest prompts about common conditions, though appreciate the dilemmas of lists..egs chronic constipation/ dental pain/ helicobacter/ epilepsy in children ; UTI / medication SEs as have been mentioned plus esp in elderly	Thank you for your comment. The GDG considers that the wording is clear as it stands. As you point out, it would be very difficult to provide a complete list of common conditions, NICE's guideline programme is fairly comprehensive and covers most of the major disorders.
Royal College of Paediatrics and Child Health	24	NICE	1.10.2	Gener al	Melatonin ....and why this. I.e. maybe '...because of its side effect profile compared with alternatives .'?..and be aware of limited efficacy(and evidence) for melatonin outside some conditions (eg ASD/ Visual impairment)	Thank you for raising this issue. The limited evidence is reflected in the wording of the guideline recommendations, as described in the introduction.
Royal College of Paediatrics and Child Health	25	NICE	1.7.3	General	At end : and communicate clearly to all professionally involved and to carers	Thank you for your comment. The point you have raised about communication with carers is covered by revised recommendation number 1.8.5; the GDG has added to this that 'everyone involved' in the person's care should also be informed about the rationale for medication.
Royal College of Paediatrics and Child Health	26	NICE	1.7	General	See above re overuse and cautions about medication. Plus : Not clear if this section is all about psycho active medication or any medication? Confusing statement here '... if they have a co	Thank you for your comment. The GDG has redrafted the section on medication and separated recommendations for coexisting mental and physical health problems from antipsychotic medication for behaviour that challenges.

					existing physical health problem..' and then details about anti psychotics, suggesting these are particularly relevant for physical health problems ..?? ...rather than separating out co- existing physical health and its management incl use of medication	
Royal College of Paediatrics and Child Health	27	NICE	1.6.5	General	As in 1.5.5 Place emphasis on the importance of assessing and addressing the person's communication abitities and alternative systems especially applicable in children with LDs . Lots of practical experience of challenging behaviours reflecting difficulties with communjcation under pinning challenging behaviours . Must be as good evidence as for other recommendations!	Thank you for your comment. The recommendation to which you refer is specifically about interventions based on behavioural principles, and the points you have raised about communication are more general and sufficiently covered elsewhere in the guideline.
Royal College of Paediatrics and Child Health	28	NICE	1.2	General	Drs / nurses may need to go to the patient to do these checks as patients may not manage the Drs/ns ' settings	Thank you for your comment, revised recommendation number 1.1.2 states that healthcare professionals should: *aim to provide support and interventions in the person's home, or as close to their home as possible, in the least restrictive setting*
Royal College of Paediatrics and Child Health	29	NICE	1.5.8	General	Assess for and exclude any physical health problems such as ....as above	Thank you for your comment. Physical health would have been assessed already as part of the assessment of behaviour that challenges, so is not repeated here.
Royal College of Paediatrics and Child Health	30	NICE	General	General	(NICE summary) Dividing it up as it does means each section should be complete and not miss aspects eg outcome of assessment and communication abilities, systems and needs in 1.6.5 for interventions 1.6 is prevention then incomplete on Intervention 1.6.5 Ie Review and edit from a user's perspective?	Thank you for your comment. The guideline has been revised to include further links between sections, without repeating recommendations. Communication needs have been highlighted throughout the document. Please note that the section on prevention has been renamed as 'early intervention'.
Royal College of Paediatrics and Child Health	31	NICE	1.1.2	17	This guideline aims to support for managing behaviour difficulties in patients with learning disabilities which means that patient should already have a diagnosis of learning disability. Diagnosis of learning disability in mild and moderated learning disabilities is not easy and can be delayed due to	Thank you for this comment. Unfortunately the diagnosis of learning disability per se is outside of the scope of the guideline but the recommendations in the guideline do take into account the severity of the learning disability

					local service provision and referral bouncing between CAMHS LD team and community paediatrics. Introduction on page 3 mentions that this guideline will be applicable for patients with IQ<70 which includes mild and moderate cases as well. In general principles of care there is clear suggestion about taking severity of learning problem and developmental age in context. To make this guidance as a tool to improve quality guidance can emphasize to assess for learning disabilities in behaviour context if diagnosis of learning disability is not already made.	
Royal College of Paediatrics and Child Health	32	NICE	1	15	Age categories used in guidance groups children under 12 years together. I would like to suggest that < 5years to be considered as a separate category for all the reasons guidance explains in section 2.1, page 37. Service delivery for patients with learning disabilities is different for <5years. Under 5s are managed by community paediatrics in most places in the UK. Adding under 5s as separate group will prompt quality improvement specifically in community paediatrics.	Thank you for your comment. It was not possible to introduce a separate category for the under 5s as you suggest because there was not enough evidence for this age group, other than for preschool classroom-based interventions (recommendation 1.7.3). However we would draw your attention to the NICE guideline of service models for people with a learning disability and behaviour that challenges that is currently in development.
Royal College of Psychiatrists	1	NICE	General	General	The guideline appears to assume there will be a swift psychological response to behaviour that challenges and may allow an assumption that rapid tranquilisation will apply to those in community settings.	Thank you for this comment but we can reassure you that this is not the view of the GDG. The recommendations in the guideline indicate careful and considered assessment of the structured and closely monitored individualised interventions be they psychological or pharmacological. The recommendations also may it very clear that the use of drugs is not a first line choice except where it is not possible to first try a range of other interventions (see revised recommendation number 1.8.1, 1.8.2). This clearly applies in community settings.
Royal College of Psychiatrists	2	NICE	General	General	There is no mention of the graded medication approach as featured in the University of Birmingham guidelines; these NICE guidelines assume that only antipsychotics are useful in the	Thank you for raising this, but as described in detail in Chapter 12, the GDG examined a relatively wide range of pharmacological interventions, and the rationale for the recommendations is given in

					management of challenging behaviour, despite the weak evidence base for this assumption.	section 12.3, which we believe does address your concern.
Royal College of Psychiatrists	3	NICE	General	General	Overall the Faculty of the Psychiatry of Intellectual Disability of the Royal College of Psychiatrists welcomes the NICE Guidelines on Challenging Behaviours and looks forward to the consultation on the NICE Guidelines on Mental Health Problems in People with Learning Disabilities	Thank you for your comments.
Royal College of Psychiatrists	4	NICE	1.7.1	34	ABC and ABS measure behaviour so it is difficult to accurately document the impact in function. Perhaps it would be better to consider using Clinical Global Impression instead.	Thank you for your comment. The GDG have revised the examples they give, but it should be noted that these are just examples. Health care professionals should decide on the measure to use.
Royal College of Psychiatrists	5	NICE	1.7.1	34	How realistic is a single anti-psychotic drug? Perhaps it would be better to consider formulations or local clinical practice use (PRN not necessarily the same antipsychotic).	Thank you for your comment. The GDG felt strongly that drugs should only be prescribed one at a time because of the lack of evidence for combination drug treatment, and that each drug should be properly evaluated before considering prescribing a second either as an alternative, or in the case of a partial response, in addition.
Royal Mencap Society	1	Full	General	General	The inclusion of the consultation with people with learning disabilities is really good to see. However the format and lack of accessible documentation that goes with this guide means that the actual recommendations are very hard to navigate and to share with people. The release of this consultation would be well supported by an accessible guide to how this was done, what were the things that were not agreed on as useful, and the recommendations that are useful to people with learning disabilities, their families, carers and paid staff.	Thank you for your comment, an easy read guide to the consultation process was available, please see: http://www.nice.org.uk/guidance/gid-cgwave0654/documents/challenging-behaviour-and-learning-disabilities-easy-read-information-about-nice2 Unfortunately it was not possible to develop an easy read version of the guideline for consultation, however there will be one when the guideline is published.
Royal Mencap Society	2	Full	2.1.2	20	While the description of challenging behaviour as being a challenge to others is good, there is a risk that the sentence that talks about it being functional to the person may lead it to appear that it is not also a challenge to them. There is a risk that the way that this is arranged could lead to people interpreting the focus of this document as being managing the person (and any	Thank you for your comment, the beginning of the introduction has been amended to take account of your suggestion, and your earlier comment.

					behaviours that challenge) and not the development of positive behaviours/skills to improve quality of life.	
Royal Mencap Society	3	Full	2.1.2	20	The definition doesn't help account for people who have good and bad days. It doesn't allow the behaviour to be difficult at a point in time but for there not to be a therapeutic need. The Emerson Definition does clarify that it is of such *Intensity, frequency and duration…* and helps to clarify that a bad day does not lead to a person having behaviours that challenge, but although the example of sleep highlights what the challenge is well, there is no comparative example that highlights what may be the result of a bad day and should not be thought of as being a behaviour that challenges It does imply that some people have a poor Quality of life and the behaviour is a product of this, but as the focus is still on solving the behaviour there is a risk that it means people will forget that simple improvements in peoples lives may be sufficient to remove this issue.	Thank you for your comment. The possible causes for behaviour that challenges are discussed in detail through the introduction – no one should be considered to have severe behaviour that challenges if assessed and it only occurs occasionally. There is a considerable amount of discussion on improving quality of life under 'capable environments' later on.
Royal Mencap Society	4	Full	2.5.2	27	While the description of challenging behaviour as being functional for the person is good, there is a risk that this may lead it to appear that it is not also a challenge to them to have to use behaviours that challenge as a way of obtaining their needs.	Thank you for your comment. The GDG agrees that whatever the underlying function of behaviour that challenges, the performance of that behaviour may be disadvantageous to the individual and therefore modification can be advantageous for them. This is a central theme that runs throughout the guideline.
Royal Mencap Society	5	Full	2.6	30	"may refer", this identifies that there is no consistency in the reasons why people are referred, and across the country the ability to access support from specialist services is varied. The experience of families in trying to navigate this is included but it may be helpful to highlight that for staff supporting people at times of crisis this inability to pinpoint exactly who will provide support is also difficult.	Thank you for your comment, this has been amended.
Royal Mencap Society	6	Full	3.6	45	The health economics models focus on the interventions that would be most beneficial to families and young people. This is good, but there	As stated in Section 3.6, "economic modelling was undertaken in areas with likely major resource implications, where the current extent of uncertainty

					is not model considering the health economics of adults with learning disabilities.	over cost effectiveness was significant and economic analysis was expected to reduce this uncertainty". Economic modelling of interventions for children was considered a higher priority than adults, because there was very limited existing economic evidence on children (exclusively on EIBI, with all studies being non-UK), and the available clinical data on children were suitable to inform an economic model and thus reduce the uncertainty over cost effectiveness. In contrast, there was adequate existing economic evidence on adults, all UK-based, which has been presented in the guideline (Romeo et al on health awareness, Hassiotis et al. and Felce et al. on psychosocial interventions, Romeo et al. on pharmacological interventions). Therefore, economic modelling of interventions for adults was considered a lower priority.
Royal Mencap Society	7	Full	4.1	52	The introduction to this section rightly talks about the difficulties that families and carers have but although in the earlier section staff are identified as a separate entity there is no recognition here of the difficulties that they may face. The first inclusion of staff in this section is on Pg 53 and is in relation to staff and services overlooking examples of abuse. This would benefit from some balance adding	Thank you for your comment. This chapter is specifically about the experience of care of service users and their family carers, therefore the GDG believe the introduction is suitable.
Royal Mencap Society	8	Full	4.2.1.3.2	59	The statement about whether this is about a lack of understanding be people with learning disabilities about the sanctions that are available does not sit well below the examples, all of which appear to be describing abusive practices	Thank you for your comment. These statements have been extracted from the Griffith 2013a review upon which this section is based. It was supposed to provide examples that were indicative of unethical and abusive practice, but we feel important to make it clear that in other instances the distinction between abuse and restrictive practices may be difficult for some people with LD.
Royal Mencap Society	9	Full	4.2.1.4	60	The statements used in other sections about the experience of care and support are really helpful, is there any additional statements that could be added here that bring to life the positives	Thank you for your comment. We appreciate what you have mentioned, however the statements used in this section have been extracted from an existing review (Griffith 2013a), and there are no additional

						statements which can be added.
Royal Mencap Society	10	Full	4.2.1.2	56	Up until this section people have been described as People with learning disabilities or people once in this section the language reverts to that of service user, could this remain as people with learning disabilities or people as in other parts of the document	Thank you for this suggestion, but 'service user' is a standard term used in NICE guidelines. We have reviewed how the term is used, but do not propose changing every use of 'service user'.
Royal Mencap Society	11	Full	2.5.2	27	While the description of challenging behaviour as being functional for the person is good, there is a risk that this may lead it to appear that it is not also a challenge to them to have to use behaviours that challenge as a way of obtaining their needs.	Thank you for your comment. Thank you for your comment. The GDG agrees that whatever the underlying function of behaviour that challenges, the performance of that behaviour may be disadvantageous to the individual and therefore modification can be advantageous for them. This is a central theme that runs throughout the guideline.
Royal Mencap Society	12	NICE/ Full	1.1.2/4.5	78	Point 2 refers to the need to focus on improving the support not just the focus on changing the person, It would be helpful to include a statement about what the support leads to (an improved Quality of life)	Thank you for your comment. The GDG agrees that quality of life is fundamental, and has added 'improve quality of life' to this recommendation.
Royal Mencap Society	13	Full	6.2	95	Reference to the individual support setting is useful, it may be useful to make explicit the funding arrangements for the provision of the service, as the following paragraph implies that the service provider has a choice about the training they can provide, and doe not offer any context about where the funding of this may come from	Thank you for your comment, this level of detail about funding is outside the scope of the guideline and a matter for local implementation.
Royal Mencap Society	14	Full	6.4.1	110	This section included a part on training of staff and the need for people to be well trained, however although there is reference to PBS and ABA in other parts of the document and a reference to training in the operation of the care pathway there is no reference about what the training offered to people providing support (Families, carers and staff) would be and how to access/fund this	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges. Funding decisions are a matter for local implementation.
Royal Mencap Society	15	NICE/Full	1.1.4/6.4.2.1	113	Reference to the need to have teams with appropriate skills but no reference to what these skills are (PBS/ABA) or where the funding for these skills will come from	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning

						disability and behaviour that challenges.
Royal Mencap Society	16	Full	1.1.6/6.4.2.2	114	With the inclusion of PBS in many recent documents is this not an opportunity to specify this in the training of staff as a recommendation. Is there a need to make explicit the need to only train staff in reactive ways of working that have been BILD accredited. Reference to Aberrant behaviour checklist and periodic service review may need some reference to how commissioners describe requirements of services and provide the funding for these ways of working	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.
Royal Mencap Society	17	Full	7.1	115	The reference is for families and carers, and there is some reference to services, it does not make clear whether these are support services, or provider services delivering care. There is no reference to staff in provider services and the offer of support to them	Thank you for your comment. The matter raised is outside the scope of the guideline and a matter for local implementation.
Royal Mencap Society	18	Full	7.2	115	The risk factors that are highlighted reflect things that make the likelihood of people using behaviours that challenge higher, there is a possibility that the description included leads to the assumption these are causative and this contradicts previous descriptions that refer to the 'external/environmental' causes of behaviours	Thank you for raising this issue. The GDG believe that this problem is mitigated by the recommendations. In particular, in the NICE version of the guideline, see revised recommendation numbers 1.1.6 and 1.4.1.
Royal Mencap Society	19	Full	7.3.2.5	144	Is there a place for a reference to the DISDAT tool for pain assessment as this is a tool that is commonly used across a wide range of services	Thank you for your comment. As reported in Appendix L, the DisDAT was excluded on the basis that it is an assessment of mental health needs, and not used to assess the circumstances, risk factors and antecedents associated with the development of behaviour that challenges (as specified in the review protocol).
Royal Mencap Society	20	NICE/Full	1.4.3/7.4	148	*Consider using the Aberrant behaviour checklist or formal ratings scale implies that this is optional however in the recommendation for 6.4.2.2 this is something that providers are expected to do as part of a good service provision, this seems contradictory*	Thank you for your comment. The recommendations have been revised so that they are consistent – both now say 'consider using…'
Royal Mencap	21	Full	8.1	150	Reference to the adverse impact on those in caring	Many thanks for your comment, this has been

Society					roles, does not include staff	amended. Please see revised recommendation number 1.1.7 in the NICE guideline.
Royal Mencap Society	22	Full	8.3.1.1	153	References and details about the checklists does not consistently clarify if there is any training required to use these tools	Thank you for your comment. Information about training requirements is generally provided by the publisher or the instrument or available by searching online. The exact training requirements would depend on the experience of the person completing the checklist, and would be difficult to cover in a guideline however revised recommendation number 1.1.10 outlines the responsibilities of the designated leadership team for providing training and support on care pathway operation.
Royal Mencap Society	23	NICE/Full	1.5.1/8.5	163	ERROR reference statement There is no reference to paid carers (staff) being involved in the assessment Although the previous section has highlighted a tool that looks at staff burnout, there is no reference to staff in the resilience section. Throughout this section It does not make clear who is responsible for completing this assessment. Is this the support services, or where people are supported by providers is this the provider organisation	Thank you for your comment. Paid carers are defined as 'staff' (please see the 'Terms used in this guideline'), therefore would be involved in assessment. The guideline addresses all staff involved in the care of a person with learning disability and behaviour that challenges, and therefore does not usually specify individual roles unless it is clearer to do so. Regarding your point about staff burnout, a recommendation has been added to the guideline about staff support (revised recommendation number 1.1.7).
Royal Mencap Society	24	NICE/Full	1.5.10/8.5.5	168	Who is responsible for completing a functional assessment and what are the skills that they must have. It is not clear whether this can be done by people who have not been trained, and the possible harm that this may lead to.	Thank you for your comment. The level of skills and the training needed are set out in the general principles section, particularly in revised recommendation numbers 1.1.4-1.1.8.
Royal Mencap Society	25	NICE/Full	1.5.13/8.5.5	169	The description of the Proactive strategies at the start are ones that would more often be thought of as preventative, the term proactive is more often used to describe the things that will support people by developing new skills Does it need to make explicit that any interventions that involve restraint/restriction need to be developed in line with guidance produced by BILD and any training that it used must be BILD accredited	Thank you for your comment. The GDG did look at the evidence for training and found no evidence to support one type of training package over another and therefore was unable to refer to any training specifically. A BILD professional was a member of the GDG and played an important role in the development of these recommendations along with other members of the GDG.

Royal Mencap Society	26	NICE/Full	1.2.1/9.5.2	194	Not all GPs offer this service. Clarity about The offer of an annual health check needs to be in places where GPs have developed the skills to offer this service. Where GPs are not trained to offer this there needs to be an incentive or imperative to make sure that they will be providing this	Thank you for your comment, this recommendation has been amended to specify that a GP should conduct the annual health check.
Royal Mencap Society	27	Full	10.1	197	The focus on delivering high quality care and support is good, but there is still a focus on how the environment meets a persons needs, this would benefit from some commentary that highlights that this includes the things that people want to do, the outcomes that are important to them and the things that they want to achieve.	Thank you for your comment. This is an important point however it is outside the scope this guideline as there is a limit to what we can cover. This guideline is specifically on challenging behaviour, whereas this point would be better captured in a general guideline about learning disabilities.
Royal Mencap Society	28	NICE/Full	1.4.2/10.3	205	As this area is about environmental changes it would be helpful to include a reference to Capable environments here.	Thank you for your comment, but this recommendation has been deleted (and nevertheless the review did not identify any evidence about capable environments).
Royal Mencap Society	29	NICE/Full	1.7.2/12.3	312	Need to explain the use of medication to the person wherever possible, and also paid carers	Thank you, the recommendation has been revised to address your comment.
Royal Mencap Society	30	Full	13.1	317	Is there a need to refer to BILD guidelines on accredited training for use of restrictive practices, and the new Guidance Positive and Safe	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges. NICE guidelines do not reference policy documents in the recommendations as these often become outdated before the guideline is updated.
Royal Mencap Society	31	NICE/Full	1.8/13.3	322	Is there a need to refer to BILD guidelines on accredited training for use of restrictive practices, and the new Guidance Positive and Safe	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges. It is not NICE practice to include reference to policy documents in an evidence based clinical guideline recommendations as these often change and would quickly become obsolete.
Royal Mencap Society	32	Full	General	General	Some further general points: In the introduction it would be useful to make	Thank you for your comment. The GDG feel the policy background, including the Transforming Care

					reference to the wealth of policy and guidance that exists and which underpins the Government's Transforming Care agenda – which says that most people with a learning disability and behaviour that challenges should be able to get the support they need in their local communities and should not need to go into inpatient settings e.g. Mansell. Later on in the guidance there is a focus on identifying whether physical health needs are causing the behaviour. It would be useful to mention this in the Causes section at the beginning e.g. that behaviour that challenges can be someone expressing they are in pain, for example due to unmet physical health needs. In the 'Current care in the UK' section it refers Winterbourne View and the Transforming Care however it doesn't clearly explain that this is about culture change. It has been acknowledged by the Government that there is currently an over-reliance on inpatient care for this group of people. The Transforming Care agenda is about ensuring people with a learning disability and behaviour that challenges can get the right support and services in their local communities and ensuring that people inappropriately placed in inpatient units are moved back to their local communities. The Government's report said it expects to see a dramatic reduction in the use of inpatient beds. The Current Care in the UK section says the Joint Improvement Programme has produced a draft 'Core Principles Commissioning Tool' to help commissioners – however, the recent NHS plan (Transforming Care – next steps) have said they are going to produce a new model of care/ spec/ standards as commissioners are still not clear what the model of care is. So it will be important to link to	agenda, is sufficiently covered in the introductions to the chapters and in the 'Current care in the UK' section in chapter 2. NICE guidelines focus on the evidence for interventions and therefore whilst acknowledging the policy frameworks in place, make limited reference to them as they often become outdated before the guideline is updated. Regarding your points about expression of pain due to an unmet physical health need, the GDG considers that this is sufficiently covered in section 2.5.1 (biological causes) of the full guideline. They have also added pain to the recommendation about the annual physical health check (1.2.1 in the short guideline) In response to your point about culture change following the Transforming Care agenda, the GDG feels that it has sufficiently acknowledged throughout the guideline that there is a need to provide support and interventions 'in the least restrictive setting, such as the person's home or as close to their home as possible' (recommendation 1.1.2 in the short guideline). Regarding your point about out of area placements, the placements that are being referred to in the 'Current care in the UK' section are not solely hospital based, but might include residential schools and other residential care. Following your comment about reference to the 2013 census, the GDG has updated the start of chapter 4 (experience of care) to refer to the 2014 census, including use of medication. Regarding your point about including context in the recommendations, it is not NICE practice to do this, although the GDG feels that most of the

					this new model/standards. The Current Care in the UK section refers to people ending up in 'out of area' placements. It might be helpful to explain these are often hospitals and people are often sectioned under the Mental Health Act – which is why it can be such a fight for families to get their loved ones out. Since the development of the guideline started there have been programmes of work and learning that could useful inform the guideline. For example the NHS England Improving Lives team has done in depth reviews of individuals in inpatient units and there have been many Care and Treatment reviews. It is important this learning is used – e.g. evidence that people who have been subject to highly restrictive practices in inpatient units (seclusion, high medication, high levels of restraint) can be supported and are flourishing when receiving bespoke packages of care in their local community. It is important professionals are given the opportunity to share these 'case reviews' – so it is not just families highlighting individual stories which can all too often be dismissed. In the Experience of care for service users, families and carers section. It may be worth highlighting that many families report not being involved in decision-making despite legal rights that exist e.g. under the MCA. Findings from the Census 2013 are referred to – these could be updated with findings from the recently published Census 2014. Many people will not read all the context in the guidelines and will just read the recommendations. It is important the recommendations themselves include some context e.g. that it is recognised there	recommendations are applicable to all people with a learning disability and behaviour that challenges, regardless of the care setting. The GDG agrees that families and carers will often have important information about the person's needs, which is why the recommendations emphasise and encourage active involvement of family members and carers. Regarding your points about the assessment process, the GDG has simplified this section and also strengthened the need for training and support (see recommendations 1.1.4 and 1.1.5 in the short guideline). In response to your point about the MCA, recommendation 1.9.5 in the short guideline refers to the MCA and MHA code of practice, and has added a cross-reference to the updated violence and aggression guideline in recommendation 1.9.6, which has further detail on the safe use of restrictive interventions.

					is too much reliance on inpatient care. In the section on recommendations re: Involving families and carers – include recognising that they will often have important information about the person's needs (i.e. not just tokenistic involvement but recognising the expertise that they will often have about the individual). In the recommendations about assessment – recognise the importance of involving people with up to date knowledge and expertise e.g. people working in line with the principles of positive behaviour support. Professionals often don't know what they don't know. It has been recognised that culture change around supporting people with a learning disability and behaviour that challenges is needed. It is important that 'experts' involved are genuine experts who understand current best practice. It is recognised that an initial assessment should take into account any physical or mental health problems. It is important that there is constant question of 'might the person have an underlying unmet health need that is not known about'. In the Pharmacological interventions section (12) it says that 'local audits and small observational studies suggest that between 21 and 29% may be prescribed antipsychotics in the absence of a mental disorder. It would be good to reference the recently published national Learning Disability Census 2014 that found 29% of people in inpatient units didn't have a psychotic disorder however 73% were being prescribed antipsychotic medication. It would be welcome to have more of an emphasis in the guideline on the least restrictive principle in	

					the MCA, and also underpinning the MHA Code of Practice.	
Sirona Care &Health CIC	1	NICE	0	3	(Introduction, pages 3-4) Helpful to have such a broad definition with emphasis on function and quality of life.	Thank you for your comment.
Sirona Care &Health CIC	2	NICE	0	8	(Introduction) Helpful to emphasise importance of involving clients in planning intervention- this is routine practice with other difficulties.	Thank you for your comment. This is also highlighted in revised recommendation number 1.1.1.
Sirona Care &Health CIC	3	NICE	1.1.6	19	I would suggest that staff also need to be able to provide general emotional support.	Thank you for your comment. The GDG feels that is implicit throughout the guideline and does not need specifying in this recommendation, which is about training in strategies to reduce the risk of behaviour that challenges.
Sirona Care &Health CIC	4	NICE	1.4.1	23	Personal factors should include general emotional issues; environmental could emphasise that restrictive environments lead to clients feeling they have no control.	Thank you for your comment. The review of personal risk factors did not identify general emotional issues and therefore the GDG is unable to include it in the recommendation. Regarding restrictive environments, the GDG did not think that lack of control was necessarily a risk factor.
Sirona Care &Health CIC	5	NICE	1.5.2	24	I would suggest that bullet point 4 about person being at centre should be first on the list.	Thank you for your comment. The bullet point has been moved as you have suggested.
Sirona Care &Health CIC	6	NICE	1.6.5	32	I would suggest that emotional literacy & broader emotional issues should be addressed, not just anger management.	Thank you for your comment, however no evidence was found for emotional literacy and broader emotional issues, only for anger.
Sirona Care &Health CIC	7	NICE	General	General	Although the initial definition of challenging behaviour suggests the scope of the guidance is wide-ranging, the actual recommendations seem to be more relevant to quite specific types of challenging behaviour.	Thank you for your comment, the GDG believe the guideline has a wide application. It is difficult to be more detailed in our response as you have not highlighted what you feel is missing.
South Staffordshire and Shropshire Healthcare NHSFT	1	NICE	General	General	Overly long and repetitive – many sections seem to be repeated identically twice.	Thank you for your comment. Some recommendations are repeated by necessity. Those recommendations that are 'key priorities for implementation' appear both at the start of the guideline and in the main body of the guideline.
South Staffordshire and Shropshire Healthcare NHSFT	2	NICE	1	15	Expressive communication – this may necessarily purely verbal communication as the current definition here implies – expressive communication can be via signing, use of talking mats or	Thank you for your comment. The definition has been revised to address your concerns.

					gesture/use of objects of reference too.	
South Staffordshire and Shropshire Healthcare NHSFT	3	NICE		16	Stereotypy is sometimes indicative of underlying chronic health issues e.g. chest banging and severe rocking can be indicative of un treated reflux.	Thank you for your comment. The definition for stereotypy has been revised, taking into account your comments.
South Staffordshire and Shropshire Healthcare NHSFT	4	NICE	1.2.1	22	Please insert additional point to clarify that although an annual health check is essential component of good quality care, it is not necessary or sufficient to rule out acute physical factors being related to an increase or exacerbation of behaviour that challenges. As such, a physical health check/review,should always form part of the assessment process (Section number 1.5). Explicit mention of the importance of physical health checks in the assessment section would also be helpful.	Thank you for your comment, the consideration of physical health needs is recommended in the assessment section in revised recommendation number 1.4.1 and 1.5.8.
South Staffordshire and Shropshire Healthcare NHSFT	5	NICE	1.5.2	24	Please insert explicit reference to the importance of assessing cultural factors in this section as per the guidance in Birmingham University's "*Learning Disabilities and BME Communities: Principles for Best Practice*" Tonkiss and Staite (2012). Indeed, in the NICE guidance, I don't think there is a single explicit mention of cultural factors, and while assessing/considering the role of these may be implied, a specific mention would be helpful.	Thank you for your comment. The University of Birmingham guidance which you cite does not explicitly discuss behaviour that challenges in the context of a learning disability. However, the GDG agrees that assessment of cultural factors in so far as they pertain to behaviour that challenges is important, and has been included in the assessment section.
South Staffordshire and Shropshire Healthcare NHSFT	6	NICE	1.5.5	26	Make explicit reference to OT led sensory assessment in this section.	Thank you for your comment, amendments have been made to expand this recommendation, however as this guideline will be delivered by a multidisciplinary team the GDG did not feel it appropriate to make specific reference to OTs.
South Staffordshire and Shropshire Healthcare NHSFT	7	NICE	1.5.7	26	(Pages 26-7) Suggest addition of risk of choking and risk of offending to the list of factors to consider in the risk assessment.	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
South Staffordshire and Shropshire Healthcare NHSFT	8	NICE	1.7.3	34	The draft guidance recommends stopping medication if no response is noted after 6 weeks post initiation of the medication. Because the medications started are often started at very low doses, it can sometimes take more than 6 weeks to get the client up to a therapeutic dose, hence the reality is a client may be on medication	Thank you for your comment. Regarding indication of response, the GDG would expect to see some response begin to emerge by 6 weeks, although they accept that a full response to medication may take longer than 6 weeks.

					for longer than the 6 weeks recommended if titration of the dose is still taking place. The rest of the recommendations are in keeping with Prof Deb et al's Best Practice Guidelines for the effective use of antipsychotic medication in the management of behaviour problems (2007) which most doctors adhere to. Perhaps additional clarification could help reduce any potential confusion re this issue here.	
Southern Health NHSFT	1	NICE	0	3	Paragraph 2: should state that challenging behaviour "serves a purpose for the person with a learning disability" rather than "may serve a purpose for the person with a learning disability". This will make clear that behaviour is always functional.	Thank you for your comment, however it was the consensus of the GDG that behaviour is not always functional, for example some syndromes such as Prader-Willi may lead to behaviour that challenges.
Southern Health NHSFT	2	NICE	0	3	Definition of challenging behaviour should also include disengagement / withdrawal	Thank you for your comment, this has been amended.
Southern Health NHSFT	3	NICE	0	4	In this section it begins to state that "It may be used by the person for reasons such as creating sensory stimulation." This is the only potential reason given. This would be better framed by stating that the behaviour has a function e.g. sensory, avoid, gain, communication.	Thank you for your comment, this has been amended.
Southern Health NHSFT	4	NICE	0	4	There is a section on Safeguarding Children but not on Safeguarding Adults. A section on safeguarding adults should be added. Abuse of adults in care should specifically referred to, including as in restrictive or abusive / institutional practice.	**Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.**
Southern Health NHSFT	5	NICE	0	5	There is a very brief comment on medication which lacks detail and seems out of place in the introduction.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Southern Health NHSFT	6	NICE	0	8	(Strength of recommendations) Paragraph 2 should be qualified with a statement about capacity/best interests decision making as it is not always possible to discuss interventions with clients who show behaviour that challenges.	Thank you for your comment. This is standard text common to all NICE guidelines, so the Guideline Development Group is unable to change it. NICE will, however, consider the feedback.
Southern Health	7	NICE	1.1.2	10	(Pages 10 and 17)	Thank you for your comment. Please see the

NHSFT					Need to ensure the principles of consent to sharing information are followed, in line with the MCA	'Person centred care' section of the guideline with links to the relevant documentation on consent and mental capacity.
Southern Health NHSFT	8	NICE	1.1.2	10	(Pages 10 and 17) Point under bullet point 1 stating "aim to provide support and interventions in the person's home, or as close to their home as possible" would be clearer if it read "aim to provide support and interventions in relevant settings, as close to their home/family as possible" as some support and interventions will occur in other settings.	Comment 427: Thank you. In light of your comments, and the comments of other stakeholders, the recommendation has been revised to include other settings in which the person regularly spends time.
Southern Health NHSFT	9	NICE	1.1.2	10	(Pages 10 and 17) Should add "take into account secondary disabilities and communication problems" to list under bullet point 1.	Thank you for your comment. The recommendation has been revised to include communication difficulties and physical and mental health problems.
Southern Health NHSFT	10	NICE	1.1.2	10	Under bullet point 1, should add a point emphasising/explicitly stating that improving quality of life is a key outcome.	Thank you for your comment, quality of life has been added to this recommendation.
Southern Health NHSFT	11	NICE	1.1.5	10	(Pages 10-1) Page 10, Bullet point 2: Needs to make clearer that multi-disciplinary team working is essential in effectively supporting people who challenge.	Thank you for your comment, but the GDG was of the opinion that the team working with a person with a learning disability and behaviour that challenges would not necessarily be multidisciplinary – it would depend on the individual and what factors were involved in the development of behaviour that challenges.
Southern Health NHSFT	12	NICE	1.1.5	10	(Pages 10 and 18) "Specialist assessment" and "specialist support" is vague and not defined.	Thank you for your comment. The components of specialist support and intervention services are set out in the final paragraph of the recommendation.
Southern Health NHSFT	13	NICE	1.1.10	20	The use of the terms primary and secondary to refer to professional support is not well defined or understood	Thank you for your comment. In light of your comments, and comments from other stakeholders, the terminology has been revised.
Southern Health NHSFT	14	NICE	1.1.5	11	This section states that "Specialist support and intervention services should include nurses, psychologists, psychiatrists, social workers, and speech and language therapists. Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved." Given the strong focus on environment / meaningful	Thank you for your comment. The recommendation has been revised to be more inclusive.

					occupation and sensory need I think it should be Mandatory that Occupational Therapist are included in the required professionals not the “May be Involved” We are confused about why some professionals have been stated as being included in teams or not, when it talks of need for multidisciplinary assessment. We think that this could say “This could include some or all of…..” Other professions that are useful and may be involved, include Art Therapists, Behaviour Specialists/Behaviour Support Workers.	
Southern Health NHSFT	15	NICE	1.3.3	11	Should specify/give examples of “disability-specific support groups”	Thank you for your comment, it is not possible to give such examples as these may differ across the country or be outdated very quickly.
Southern Health NHSFT	16	NICE	1.4.1	11	Awareness of risk should make reference to the high probability of presence of vulnerable “others” who are at greater risk.	Thank you for making this suggestion. The GDG reviewed both the recommendation and the evidence, and decided that some changes should be made, in particular with regard to the environment.
Southern Health NHSFT	17	NICE	1.4.1	11	Where says “expressive or receptive” it should “expressive and receptive”	Thank you for your comment, this change has been made.
Southern Health NHSFT	18	NICE	1.4.1	11	Change “Physical health problems” to “unmet physical health needs” or “issues” but take the negative connotation of “problems” out.	Thank you for your comment, but the preferred term in this guideline, and other mental health and behavioural guidelines, is ‘physical health problem’.
Southern Health NHSFT	19	NICE	1.4.1	11	Should add gender, organic factors (e.g. Prader Willi, Cornelia de Lange etc), mental health problems to list of personal factors as all associated with increased risk of challenging behaviour.	Thank you for your comment. The review of personal risk factors did not identify syndromes conditions and behavioural phenotypes, life changes, emotional aspects and therefore the GDG is unable to include these in the recommendation.
Southern Health NHSFT	20	NICE	1.4.1	11	(Pages 11-2) Environmental factors: Need to include where the person has changed/moved environment. Also to include where the environment has changed e.g. staffing Should add “uncomfortable levels of stimulation” and “poor service organisation” to list of environmental risk factors	Thank you for your comment. The recommendation has been revised to include some of your suggestions regarding moving and changing environments as examples.
Southern Health	21	NICE	1.5.2	12	“Environments where….poor communication is	Thank you for your comment.

NHSFT					typical" We think this is very important and well said.	
Southern Health NHSFT	22	NICE	1.5.2	12	No mention of joint working/assessment in the assessment process.	Thank you for your comment. Joint working is covered in revised recommendation numbers 1.1.4 and 1.1.5.
Southern Health NHSFT	23	NICE	1.5.2	12	States "everyone involved in delivering an assessment understands the criteria for moving to more complex and intensive assessment" We are not clear that the guidelines give any recommendation of what this criteria is.	Thank you for your comment. The section on assessment has been redrafted to improve clarity and changes also made to 1.5.1 to makes it clear when further assessment, which will be more complex and intensive, will be required.
Southern Health NHSFT	24	NICE	1.5.2	12	"Assessment is flexible…" This sentence is vague and ill defined.	Thank you for your comment. The GDG felt that it was clear from the context what this meant, but has nevertheless made some minor revisions.
Southern Health NHSFT	25	NICE	1.5.2	12	"Assessments are repeated after any changes in behaviour". This is very vague and unworkable. All assessments? Any change? Alternatively write something like "Ongoing assessment to reflect and monitor changes in behaviour"	Thank you for your comment. The recommendation has been revised to say that assessment should be a continuing process.
Southern Health NHSFT	26	NICE	1.5.2	12	States "assessment is outcome focused" Maybe more specific to state "focused on dual outcome of reduction in behaviour and increase in QOL"	Thank you, this has been amended in light of your and others' comments.
Southern Health NHSFT	27	NICE	1.5.2	12	Should change the last point/statement from "assessed" to "considered" as may not always be possible to formally assess (e.g. when working with families who have concerns about being blamed).	Thank you for your comment. The bullet point has been revised to say that resilience, resources and skills of family members and carers should be 'taken into account'.
Southern Health NHSFT	28	NICE	1.5.7	13	Risk assessment should include physical health	Thank you for your comment. Physical health would have been assessed already as part of the assessment of behaviour that challenges, so is not repeated here.
Southern Health NHSFT	29	NICE	1.5.7	13	"….Or level of risk" Unclear. Take out? The other things stated are what determines the level of risk.	Thank you for your comment. 'Level of risk' has been deleted.
Southern Health NHSFT	30	NICE	1.5.7	13	Risk assessment should be ongoing/reviewed	Thank you for your comment, the recommendation has been revised to say risk should be regularly reviewed.
Southern Health NHSFT	31	NICE	1.5.7	13	Add "and crisis plan" to statement "ensure that the behaviour support plan includes risk management"	Thank you for your comment, the GDG felt that risk management was sufficient to cover the point you raised.
Southern Health	32	NICE	1.5.12	13	"Carry out pre-assessment data gathering to help	Thank you for your comment, this has been

NHSFT					shape the focus and level of the assessment" should be 1st point in list	amended.
Southern Health NHSFT	33	NICE	1.5.12	14	"If the behaviour poses a risk to the person or others carry out a risk assessment" Doesn't make sense - you have already completed a risk assessment. Should always risk assess.	Thank you for your comment, the GDG agrees and has revised this recommendation accordingly.
Southern Health NHSFT	34	NICE	1.6.5	14	"Clearly defined intervention " should be clarified and ensure includes both Proactive and Reactive.	Thank you for your comment. The text to which you refer has been removed from the recommendation.
Southern Health NHSFT	35	NICE	1.6.5	14	"A clear schedule of reinforcement…" may be appropriate but included under "clearly defined intervention". Not a section in itself	Thank you for your comment. The bullet point 'clearly defined intervention' has been removed from the recommendation.
Southern Health NHSFT	36	NICE	1.6.5	14	Interventions – this does not include reference to skills teaching, although other modes of PBS planning are included but just worded differently. Section should emphasise interventions that enhance/improve quality of life (including general skills development) and communication (e.g. PECS, Object of Reference work).	Thank you for your comment. The recommendation explicitly states that the intervention should be based on behavioural principles, which the GDG considers is sufficient.
Southern Health NHSFT	37	NICE	1.7.1	14	Add "unless risk very serious" to statement "Only offer medication in combination with psychosocial, psychological or other interventions".	Thank you for your comment. The GDG felt that antipsychotic medication should always be offered in combination with psychosocial, psychological or other interventions regardless of the level of risk.
Southern Health NHSFT	38	NICE	1	15	"Expressive communication" – poorly defined. Not encompassing alternative and augmentative communication. Inappropriate emphasis on grammar.	Thank you for your comment. The definitions have been revised to address your concerns.
Southern Health NHSFT	39	NICE	1	15	"Receptive language" – only refers to spoken or written but does not include visual modality and other communication modes e.g. signing and objects of reference.	Thank you for your comment. The definition has been revised to address your concerns.
Southern Health NHSFT	40	NICE	1	15	Need to also define primary prevention, secondary prevention.	Thank you for your comment. The title 'primary and secondary prevention' has been changed to 'early intervention'.
Southern Health NHSFT	41	NICE		16	Definition of reinforcer: replace the word "reward" with "anything" and then say that synonyms for reinforce are "reward" and "incentive".	Thank you for your comment. The definition has been revised to say 'Any event or situation that follows a behaviour and increases the likelihood of that behaviour happening again.'
Southern Health NHSFT	42	NICE		16	Need to expand definition of self-injury to include something about sensory stimulation and pain.	Thank you for your comment. Pain has been added to the definition, but sensory stimulation has been

						omitted because it is one of a number of different factors.
Southern Health NHSFT	43	NICE		16	Need to expand definition of “restrictive interventions” to include something about people having limited access to things (e.g. food, drink etc)	Thank you for your comment, but restricting access to food and drink would be seen as unethical and was not part of the GDG’s definition of restrictive interventions.
Southern Health NHSFT	44	NICE	1.1.1	17	We liked the reference to easy-read information.	Thank you for your comments.
Southern Health NHSFT	45	NICE	1.1.1	17	The range of interventions should include “physical”	Thank you for your comment. The list of interventions provides examples, not a complete list; this has now been made clear in the recommendation.
Southern Health NHSFT	46	NICE	1.1.2	17	Point under bullet point 2 stating “aim to provide support and interventions in the person’s home, or as close to their home as possible” would be clearer if it read “aim to provide support and interventions in relevant settings, as close to their home/family as possible” as some support and interventions will occur in other settings.	Thank you. In light of your comments, and the comments of other stakeholders, the recommendation has been revised to include other settings in which the person regularly spends time.
Southern Health NHSFT	47	NICE	1.1.3	18	“course of learning disabilties” – what does that mean?	Thank you for your comment; the recommendation has been revised and ‘course of’ has been removed.
Southern Health NHSFT	48	NICE	1.1.3	18	Unclear who this applies to and how they should gain this knowledge. Should this refer to paid carers? Or training needs? Or included in 1.1.6.	Thank you for your comment. The recommendation specifies that this is for ‘everyone involved in delivering support and interventions for people with a learning disability and behaviour that challenges’, which would include paid carers. Commissioners have been specified to ensure that they can provide the right training, as set out in revised recommendation number 1.1.6.
Southern Health NHSFT	49	NICE	1.1.3	18	Bullet point 4: Implication is that everyone should have “awareness level training”. Make this explicit?	Thank you for your comment, but this recommendation is about everyone involved in delivering support and interventions having a basic understanding of both learning disabilities and what can lead to behaviour that challenges. Training is covered in other recommendations (for example, revised recommendation number 1.1.6).
Southern Health NHSFT	50	NICE	1.1.4	18	Need to be clearer about exactly what type(s) of team you are referring to (LDTs, ISTs, support	Thank you for your comment, but the guideline sets out clear principles for all teams involved in the care

					providers etc).	of a person with a learning disability and behaviour that challenges. The GDG felt that it would to be appropriate to specify individual teams because the behaviour that challenges needs to be seen in a wider context, which involve more than one team.
Southern Health NHSFT	51	NICE	1.1.4	18	Need to stipulate the skills in challenging behaviour.	Thank you for your comment. The recommendation has been revised to say that skills and competencies need to be in assessment and intervention methods relevant to deliver the interventions recommended in this guideline
Southern Health NHSFT	52	NICE	1.1.5	18	“Specialist assessment” and ”specialist support” is vague and not defined.	Thank you for your comment. The components of specialist support and intervention services are set out in the recommendation
Southern Health NHSFT	53	NICE	1.1.5	19	This section states that “Specialist support and intervention services should include nurses, psychologists, psychiatrists, social workers, and speech and language therapists. Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved.” Given the strong focus on environment / meaningful occupation and sensory need I think it should be Mandatory that Occupational Therapist are included in the required professionals not the “May be Involved” We are confused about why some professionals have been stated as being included in teams or not, when it talks of need for multidisciplinary assessment. We think that this could say “This could include some or all of…..” Other professions that are useful and may be involved, include Art Therapists, Behaviour Specialists/Behaviour Support workers.	Thank you for your comment. The recommendation has been revised to be more inclusive.
Southern Health NHSFT	54	NICE	1.1.6	19	What would you suggest the training looks like – the quality of training. We are concerned that ‘all staff should be trained’ could lead to a too varied level of attainment and evidence competency. Staff who work with the individual on a <u>regular</u> basis should be trained (i.e. not everyone e.g. dentist).	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.

Southern Health NHSFT	55	NICE	1.1.6	19	Add “and participation records” to “developing personalised daily activities” Add something about general skills development Add something about opportunity planning ? terminology of “manage behaviour that is not preventable” – instead, say “manage behaviour that has not been prevented” Add something about helping network better understand the person’s communication.	Thank you for your comment. The GDG feels that many of your points are implicit throughout the guideline and do not need specifying in this recommendation, which is about training in strategies to reduce the risk of behaviour that challenges. Regarding your penultimate point about ‘manage behaviour that is not preventable’, the GDG agrees and has reworded this sentence.
Southern Health NHSFT	56	NICE	1.1.7	19	It is unclear whether this section is about clinical work or supervision.	Thank you for your comment. It is about both, which the GDG thinks is clear.
Southern Health NHSFT	57	NICE	1.1.7	19	Change ‘based on the relevant manuals’ to ‘evidence-based interventions’? Within the context of LD it is unusual to talk of “manuals”. What does this mean?	Thank you for your comment. A definition of treatment manuals has been added to the glossary.
Southern Health NHSFT	58	NICE	1.1.7	19	‘Use routine sessional outcome measures’ – sessional is inappropriate in this context. Maybe use “regular”?	Thank you for your comment. The recommendation has been revised to remove the word ‘sessional’ and to say that routine outcome measures should be used at each contact with the person.
Southern Health NHSFT	59	NICE	1.1.7	19	“use routine sessional outcome measures (for example, the Adaptive Behaviour Scale and the Aberrant Behaviour Checklist)” These measures are well directed to the absence of target behaviour but also sessional outcomes should seek to measure QOL or occupational performance e.g generic GAS monitoring or more session specific OT MOHOST measures the quality of the session opposed to (or in conjunction with absence of behaviour)	Thank you for your comment. The outcome measures that have been recommended are selected on the best available evidence. The use of measures looking at quality of life are recommended in the assessment section, see revised recommendation number 1.5.8.
Southern Health NHSFT	60	NICE	1.1.7	20	Add something about Positive Monitoring as well as PSR + make clear that people need to provide capacity for recording	Thank you for your comment. The GDG feels that principles of positive monitoring and PSR are captured in the recommendations as they stand. Capacity is covered in the ‘Person centred care’ section of the guideline with links to the relevant documentation provided.
Southern Health NHSFT	61	NICE	1.1.8	20	Unclear what is meant by ‘integrated’, and who with.	Thank you for your comment, but the GDG feels that the meaning is clear from the context.
Southern Health	62	NICE	1.1.8	20	We find this section ill-defined and confusing.	Thank you for your comment, this section has been

NHSFT						redrafted in light of your comments and comments from other stakeholders, for example, to make it clear who is responsible for developing care pathways.
Southern Health NHSFT	63	NICE	1.1.8	20	No need to state that these are adapted from the common mental health disorders.	Thank you for your comment, but it is NICE practice to highlight recommendations that have been adapted from another guideline in this way.
Southern Health NHSFT	64	NICE	1.1.8	20	We do not like the reference to primary and secondary care professionals – it is ill-defined.	Thank you for your comment. In light of your comments, and comments from other stakeholders, the terminology has been revised.
Southern Health NHSFT	65	NICE	1.2.1	22	Stipulate who will offer the annual physical health check, in a suitable environment by an appropriate professional. Include issue of consent by the individual. Need to add something about ongoing health assessment and reviewing physical healthcare assessment at challenging behaviour assessment.	Thank you for your comment, this recommendation has been amended to specify that a GP should conduct the annual health check.
Southern Health NHSFT	66	NICE	1.2.1	22	Refer to Mental Capacity Act	Thank you for your comment. There is a section on use of the Mental Capacity Act in the section on 'Person centred care', which applies to all recommendations and, in the view of the GDG, does not need to be specified here.
Southern Health NHSFT	67	NICE	1.2.1	22	Need reference to Health Action Plans / Hospital Passports	Thank you for your comment, however the GDG could find no evidence to support the use of health action plans/hospital passports, and in their experience they are not widely used.
Southern Health NHSFT	68	NICE	1.3.2	22	Specify that it is unpaid carers who have a right to a formal carer's assessment.	Thank you for your comment. In this guideline, and throughout NICE guidance, carers are defined as unpaid, therefore the GDG does not feel that this needs re-stating. (Please see the 'Term used in this guideline' section.)
Southern Health NHSFT	69	NICE	1.3.3	22	Change to 'access advocacy services' – we did not know what family advocacy services were. Need to apply to adult services as well as children.	Thank you for your comment but in the context of this recommendation the GDG means family advocacy.
Southern Health NHSFT	70	NICE	1.3.4	23	Change wording to 'signpost as appropriate'. We would not make the actual referral. This is not appropriately worded for the context and role of adult learning disability care.	Thank you for your comment, it is for services to determine if they will implement the referral of families and carers to the relevant services, however the GDG would very much hope that they would follow this principle to promote good care for

						people with a learning disability and behaviour that challenges and their families.
Southern Health NHSFT	71	NICE	1.4.1	23	Specify something about typical age of onset. + in environmental factors section, specify quality of engagement + too much sensory stimulation as well as too little sensory stimulation	Thank you for your comment. Age of onset is referenced in the Introduction to the NICE guideline. Regarding your second point, the recommendation has been revised to include environments with too much stimulation.
Southern Health NHSFT	72	NICE	1.5.1	24	Need to say something about looking at quality, and implementation, of person-centred planning and assessing quality of life	Thank you for your comment, the GDG agree that quality of life is of great importance and this has been added to revised recommendation number 1.1.2, and is also included as an outcome in revised recommendation number 1.5.11.
Southern Health NHSFT	73	NICE	1.5.2	24	"Everyone involved in delivering an assessment understands the criteria for moving to a more complex and intensive assessment." We are not clear that the guidelines give any recommendation of what this criteria is.	Thank you for your comment. Although these criteria will be different for different people, the GDG has revised the section on assessment to make it clearer in broad terms when further assessment might be required – see revised recommendation numbers 1.5.1 and 1.5.8.
Southern Health NHSFT	74	NICE	1.5.2	25	"Assessments are repeated after any changes in behaviour". This is very vague and unworkable. All assessments? Any change? Alternatively write something like "Ongoing assessment to reflect and monitor changes in behaviour"	Thank you for your comment. The recommendation has been revised to say that assessment should be a continuing process.
Southern Health NHSFT	75	NICE	1.5.4	25	Define who should carry out the initial assessment or state 'by the appropriate professional'.	Thank you for your comment, but the recommendations in the section on assessment apply to all staff involved in the care of a person with a learning disability.
Southern Health NHSFT	76	NICE	1.5.4	25	Quality of Life measures?	Thank you for your comment. Quality of life measures are included in revised recommendation number 1.5.10.
Southern Health NHSFT	77	NICE	1.5.4	26	Perhaps the section on initial assessment gathering could be related to bringing it all together into a recognised Clinical Formulation	Thank you for your comment, however the GDG felt it more appropriate to use plain English to explain the principles of formulation.
Southern Health NHSFT	78	NICE	1.5.5	26	Take into account: add person's wishes	Thank you for your comment. The initial assessment covers personal preferences.
Southern Health NHSFT	79	NICE	1.5.7	26	Should the assessment of risk include risk of exposure to restrictive practice ? perhaps the harm to and from others may be useful to state physical and psychological risk.	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.

Southern Health NHSFT	80	NICE	1.5.7	27	Include physical health	Thank you for your comment. Physical health would have been assessed already as part of the assessment of behaviour that challenges, so is not repeated here.
Southern Health NHSFT	81	NICE	1.5.8	27	Remove 'integrated with an assessment of need' – what is the definition and what does it add?	Thank you for your comment, this has been removed.
Southern Health NHSFT	82	NICE	1.5.8	27	We are unclear about the distinction between initial assessment and further assessment – it appears that we have already considered these items.	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
Southern Health NHSFT	83	NICE	1.5.8	27	As it moves into asking for a Functional Assessment it asks to " "Consider including the following in the further assessment: " I think this should be a mandatory prequel to any behavioural assessment.	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
Southern Health NHSFT	84	NICE	1.5.8	27	Add into further assessment section: Communication environment Quantity and quality of social interaction Engagement/occupation	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
Southern Health NHSFT	85	NICE	1.5.8	27	Receptive and expressive skills rather than problems	Thank you for your comment. This recommendation has been redrafted following consultation, and all areas of assessment are now listed in revised recommendation number 1.5.5. In 1.5.5, the first bullet point refers to 'receptive and expressive communication' and omits with the word 'problems'.
Southern Health NHSFT	86	NICE	1.5.8	28	Sensory abnormalities or sensitivities should be reworded.	Thank you for your comment. This recommendation has been redrafted following consultation, and all areas of assessment are now listed in revised recommendation number 1.5.5. The term 'sensory abnormalities or sensitivities' has been changed to 'sensory profile'.
Southern Health NHSFT	87	NICE	1.5.9	28	Functional assessment should inform formulation and be part of it, rather than be something separate	Thank you for your comment. This recommendation has been moved to the end of the section and revised. It should now be clearer that functional

						assessment informs the written statement (formulation).
Southern Health NHSFT	88	NICE	1.5.9	28	Formulation should inform the behaviour support plan.	Thank you for your comment. This recommendation has been moved to the end of the section and revised. It should now be clearer that the written statement (formulation) derived from assessment informs the behaviour support plan.
Southern Health NHSFT	89	NICE	1.5.9	28	This does not appear to differ from 1.5.6 – should there be a difference between these?	Thank you for your comment. This recommendation has been moved to follow functional assessment, and has been revised to make it clear that the initial formulation needs to be revised following further assessment.
Southern Health NHSFT	90	NICE	1.5.11	29	QOL measures need greater emphasis earlier in document	Thank you for your comment, the GDG agree that quality of life is of great importance and this has been added to recommendation 1.1.2.
Southern Health NHSFT	91	NICE	1.5.13	30	Delete initial paragraph as it is unclear and already previously discussed. It is sufficient to say 'A behaviour support plan should identify x,y, z. '	Thank you for your comment, the recommendation has been revised as you have suggested.
Southern Health NHSFT	92	NICE	1.5.13	30	Add skills teaching (specific and general) to proactive strategies section + possibility of other (psychodynamic, systemic therapy) psychological interventions (if functional analysis/formulation indicates it) to proactive strategies section Last bullet point: Add in using positive monitoring + line management/supervision arrangements for addressing practice issues	Thank you for your comment, but the evidence for the interventions you have suggested was not available. Regarding your final point, supervision is covered in other recommendations (see section 1.1).
Southern Health NHSFT	93	NICE	1.5.13	31	Include bullet point 'Ensure behaviour support plan is consistently delivered across all environments'	Thank you for your comment. An additional bullet point has been inserted to address your point.
Southern Health NHSFT	94	NICE	1.5.13	31	It should also state that your behaviour support plan should be clear about who is responsible for implementation.	Thank you for your comment. An additional bullet point has been inserted to address your point.
Southern Health NHSFT	95	NICE	1.6.5	32	4th bullet point (clearly defined intervention strategies) is a superfluous extra bullet point. This section is describing intervention strategies.	Thank you for your comment. The bullet point has been deleted.
Southern Health NHSFT	96	NICE	1.6.5	32	? including psychodynamic psychotherapy (Nigel Beail's research) ? naming specific behavioural interventions, e.g. DRO, non-contingent reinforcement etc	Thank you for your comment. The GDG reconsidered this recommendation and have made some changes for clarity. However, the important issue is that health care professionals should consider using personalised psychosocial

						interventions based on behavioural principles and functional assessment of behaviour. The GDG felt that naming interventions was not appropriate. This gives some flexibility while remaining evidence based.
Southern Health NHSFT	97	NICE	1.6.6	32	Some concern about having this as a stand alone point – anger management should only be offered if (a) functional assessment indicates anger is a significant trigger for the challenging behaviour, (b) the anger is inappropriate, and (c) person is able to engage with CBT…	Thank you for your comment. The points you have raised would have been part of the assessment process (see revised section number 1.5) and the behaviour support plan (see revised recommendation number 1.6.1).
Southern Health NHSFT	98	NICE	1.6.7	32	States :"Do not offer sensory interventions (for example, Snoezelen rooms) before carrying out a functional assessment to establish the person's sensory profile. Bear in mind that the sensory profile may change. " The functional assessment does not define the persons sensory profile, this needs to read "sensory assessment". Research on the impact of Snoezelen is scarce and I really think this should not be referred to.	Thank you for offering this suggestion. The GDG reconsidered this issue, but felt given the recommendations on functional assessment there was no justification to not use the term sensory profile.
Southern Health NHSFT	99	NICE	1.7.3	33	The guidance on who should be prescribing is a little confusing as it doesn't mention "Psychiatrist with expertise in Learning Disability".	Thank you for your comment. The recommendation has been clarified by removing 'with expertise in learning disabilities' after neurodevelopmental paediatrician.
Southern Health NHSFT	100	NICE	1.7.3	34	"Only prescribe a single drug" - It's unclear if this is only during initial treatment or a guideline to be observed throughout the client's management. NICE Experience is that many clients may respond well to a combination of meds (e.g. SSRI and antipsychotic). Suggest changing to: "provide minimum number of drugs possible, ideally 1".	Thank you for your comment. There is no evidence base for the medications being added in combinations. The GDG felt strongly that drugs should only be prescribed one at a time and each drug properly evaluated before considering prescribing a second either as an alternative, or in the case of a partial response, in addition.
Southern Health NHSFT	101	NICE	1.7.3	34	"Stop the medication if there is no indication of a response after 6 weeks". With an initial low dose and subsequent slow titration (usually a small increase every 2 weeks or so) 6 weeks can be too short a time period to find an optimum or even effective dose.	Thank you for your comment. Regarding indication of response, the GDG would expect to see some response begin to emerge by 6 weeks, although they accept that a full response to medication may take longer than 6 weeks
Southern Health	102	NICE	1.7.3	34	-"do not prescribe prn for more than 4 weeks". It is	Thank you for your comment. The GDG has revised

NHSFT					unclear if this means the client should not be having regular prn for more than 4 weeks or that the client should not be written up for prn for more than 4 weeks. If the latter I would suggest that many clients have intermittent “breakthrough” episodes of CB that respond well to infrequent use of prn as a long term management option. Removing this option would increase the risk such clients pose to themselves or others during such an episode. This should be written up as part of an agreed reactive management plan.	the recommendation to say that p.r.n.medication should be used for as short a time as possible.
Southern Health NHSFT	103	NICE	1.8.1	35	We are concerned that ‘or breakdown in the persons living arrangements’ is not an appropriate reason to use a reactive strategy as an initial intervention.	Thank you for your comment. The GDG appreciate your concerns and agree that if a reactive strategy becomes the default strategy it would lead to negative outcomes. However, the GDG were also concerned that behaviour that challenges can lead to displacement from services which can also have very negative outcomes for the individual.
Southern Health NHSFT	104	NICE	1.8.1	35	A reactive strategy should never be the initial strategy, rather that you have considered all the pro-active strategies have not worked or are not feasible to implement at that point in time.	Thank you for your comment, the GDG strongly agree with your point, as recommended in revised recommendation number 1.9.2.
Southern Health NHSFT	105	NICE	1.8.3	35	Not sure if cardiovascular is a type of biomechanical risk –is it not a physical risk?	Thank you for your comment, cardiovascular has been removed as an example of a biomechanical risk.
Southern Health NHSFT	106	NICE	2.2	38	Is there really no evidence for ABA interventions with this client group? Rest of guidelines suggest otherwise…	Thank you for your comment. The purpose of the recommendation is to provide better evidence on the relative efficacy of both behavioural and pharmacological interventions, direct comparison of the two or use in combination is very limited.
Southern Health NHSFT	107	NICE	General	General	- Quite a lot of repetition in the document - Document doesn’t feel very readable at present as sections on children dotted in quite randomly. Might work better if had a general section on cb, a section on (specific assessment and interventions for) cb in children, and a section on (specific	Thank you for your comment. Some recommendations are repeated by necessity. Those recommendations that are ‘key priorities for implementation’ appear both at the start of the guideline and in the main body of the guideline. We have revised the recommendations to make it

					assessment and interventions for) cb in adults… Why is PBS not explicitly mentioned in the main body of the text? Guidelines are clearly based on PBS approach…	clear that unless specified otherwise they apply to children, young people and adults We acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Southern Health NHSFT	108	NICE	General	General	We are unclear about the roles and responsibilities of families, carers, professionals throughout the guidelines.	Thank you for this comment. A number of recommendations set out the roles of families (and any support needed) and professionals. See for example revised recommendation numbers 1.1.6, 1.1.8-1.1.14 and section 1.3 of the NICE guideline.
Southern Health NHSFT	109	Full	General	General	(Line 19) The environment is not just the physical space that a person occupies, but also the people, 19 culture, social factors and opportunities that surround and influence the person – PBS would indicate that this should also include staff approach as an ecological factor.	Thank you for your comment, unfortunately it was not possible to understand which section your comment related to.
Southern Health NHSFT	110	Full	General	General	(Line 26-35) There is a mass of factors that could be subdivided down into established environment al design e.g. ROBUSTNESS – Support TOOLS – TRIGGERS – GROWTH	Thank you for your comment, unfortunately it was not possible to understand which section your comment related to.
Southern Health NHSFT	111	Full	General	General	Environment this is focused on the provision of sensory interventions – in some cases this may be changing the environment but in sensory integration it is changing the persons response to sensory information (e.g. it is a biological intervention not an environmental one) It appears that the study listed	Thank you for these comments. Both issues you mention are important and the GDG have made some amendments to the recommendations on interventions to take account of the impact of the environment and the sensory sensitivity of individuals. Regarding your second point we have

					indicates an integration approach without distinguishing environmental adaptation. The section that looks at motivating operators and focuses on "effectiveness of reinforcement or punishment" it makes no reference to removal of trigger, or the provision of environment to meet function, which is a primary function of a PBS plan, rather than operant effectiveness of reinforcement or punishment	explicitly dealt with these issue in revised recommendation numbers 1.1.3 and 1.4.1.
Southern Health NHSFT	112	Full	General	184	(Line 9-11) Document states that more needs to be done to encourage carers to identify early signs and offer practical help – but recommendations for adults appear to focus only on annual health checks.	Thank you for your comment. There are recommendations that address your concern. In the NICE guideline, these can be found in revised recommendation numbers 1.3 and 1.5.
Southern Health NHSFT	113	NICE/Full	1.6.4/35	194	Communication skills training needs to be included for parents as well as children. No reference to Identifying underlying pain/health related issues with children/young people.	Thank you for your suggestions. Revised recommendation number 1.7.2 includes developing communication skills in parents. Regarding underlying pain/health related issues – the recommendation is about the intervention, not reasons for behaviour, therefore not appropriate here.
Southern Health NHSFT	114	NICE/Full	1.2.1/9.5.2	195	The agreed and shared care plan for managing health problems needs to be an ongoing document rather than something that is reviewed at annual health checks.	Thank you for your comment, the GDG assumes that this document will be ongoing.
Southern Health NHSFT	115	Full	General	General	Seems to be limited involvement of Occupational Therapy in the guideline development, which does not reflect the broad role that OTs take in challenging behaviour work locally.	Thank you for your comment, although there was an occupational therapist on the guideline development group this was not properly described in the full guideline, which has now been amended to reflect this.
Southern Health NHSFT	116	Full	4.1	52	Unclear if reference Aman et al. 1986 relates to Winterbourne View…??	Thank you for comment. The reference was incorrect and has now been amended.
Southern Health NHSFT	117	Full	4.1	53	Unclear if reference Linaker 1991 relates to LD census 2013…??	Thank you for comment. The reference was incorrect and has now been amended.
Southern Health NHSFT	118	Full	11.2.2.1	225-6	The cost information is drawn from three services offering PBS, but these services all only offer support to children and young people. It would be good to include a service that provides support to adults with LD as well as a comparison.	Thank you. The service in Halton offers support to both children and adults, as reported in the guideline. This cost information was made available to us by researchers working in this field. We have not identified any further cost information on

						services providing support to adults, and therefore we could not include such information in the full guideline.
Southern Health NHSFT	119	Full	11.2.3.5	257	The evidence considered appears to relate only to CBT for anger. Why does the guidance not also include evidence for CBT for anxiety of depression with people with LD, or other form of psychological intervention such as brief mindfulness training (Singh et al.)?	Thank you for raising this issue. The guideline is only about behaviour that challenges. There is another guideline about mental health problems in people with learning disabilities that is currently being developed: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0684
St. Oswald's Hospice	1	Full	7.3	139	*(Pages 139-40)* This section covers a number of assessment tools, but makes no mention of distress tools or the fact that the pain tools mentioned have not been tested against non-pain distress. Pain tools have a high false positive rate for non-pain distress (see Jordan et al). DisDAT (Disability Distress Assessment Tool) was first piloted in 2003, formally evaluated in 2007 and is used in many learning disability services in the UK. The full tool is available on www.disdat.co.uk Refs: Regnard C, Mathews M, Gibson L, Clarke C. Difficulties in identifying distress and its causes in people with severe communication problems *International Journal of Palliative Nursing,* 2003, **9**(3): 173-6. Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disability Res*. 2007; **51(4)**: 277-292. Jordan A, Regnard C, O'Brien JT, Hughes JC. Pain and distress in advanced dementia: Choosing the right tools for the job. *Palliative Medicine* **26**(7): 873–878, 2011	Thank you for your comment. As reported in Appendix L, the DisDAT was excluded on the basis that it is an assessment of mental health needs, and not used to assess the circumstances, risk factors and antecedents associated with the development of behaviour that challenges (as specified in the review protocol).

					van der Steen JT, Regnard C, Volicer L, Van Den Noortgate NJA, Sampson EL. Systematic observation of signs of un-wellbeing in people with dementia to detect pain or distress due to other causes: a critical appraisal of two strategies. *Eur J Pall Care* 2015. *In press*	
Surrey and Borders Partnership NHSFT	1	General	General	General	We welcome this guidance to assist in promoting positive approaches to the support of people who engage in behaviours that challenge.	Thank you for your comments.
Surrey and Borders Partnership NHSFT	2	General	General	General	We are pleased to see the inclusion of a psychological approach to both assessment and intervention. However, there needs to be a greater use of the term 'formulation' to link assessment with interventions. We also would like an emphasis on professionals working together to produce a single shared formulation	Thank you for these comments. The GDG did consider using the term formulation but decided not to do so as they felt it was possible, and potentially clearer to a wider readership, to explain what is covered by the term in simpler, more direct language. We have revised the recommendations (see revised numbers 1.1.9 -1.1.14) on joint working in light of your and a number of other comments to clarify team membership and competences.
Surrey and Borders Partnership NHSFT	3	NICE	General	General	We would like to see links made to the DH Positive and Safe agenda which promotes the reduction in restrictive practices and using a PBS approach to proactive care. It is important that readers of the NICE guidance understand the link between all the different work being promulgated in this area.	Thank you for your comment. It is not NICE practice to include reference to documents in guideline recommendations as these often change and would quickly become obsolete.
Surrey and Borders Partnership NHSFT	4	NICE	General	General	We are concerned that the overall guidance reads as only being about people with severe learning disabilities. We work with people with mild learning disabilities who also display behaviours that challenge, and the guidance needs to be more inclusive.	Thank you for your comment. The guideline covers mild, moderate, severe and profound learning disabilities, and the recommendations apply to all severities, unless stated otherwise.
Surrey and Borders Partnership NHSFT	5	NICE	General	General	There is no mention of behaviour specialists if they do not hold a professional qualification	Thank you for your comment, in light of yours and others' comments revised recommendation number 1.1.5 has been amended to more fully characterise the range of professions and their competencies to effectively support people with a learning disability and behaviour that challenges.
Surrey and Borders	6	NICE	0	3	(Introduction)	Thank you for your comment. The definition of

Partnership NHSFT					We think that the definition of challenging behaviour in the Challenging Behaviour – a unified approach should be used in the document. *"Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion"* (Challenging behaviour – a unified approach; RCPsych, BPS, RCSLT, 2007)	behaviour that challenges from the Royal College of Psychiatrists has been quoted in the introduction to the full guideline. The NICE guideline introduction is intended as a brief overview only.
Surrey and Borders Partnership NHSFT	7	NICE	0	3	(Introduction) We would like people who have a diagnosis of dementia should be included in the list of people for whom behaviour that challenges might be more likely (outlined at the end of the third paragraph).	Thank you for your comment, this has now been included.
Surrey and Borders Partnership NHSFT	8	NICE	0	4	(Introduction) We would like the importance of physical health support in care environments emphasised here, as this can have a key role in behaviours that challenge. E.g. • " ….those that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse *and those that do not pay attention to physical health needs and pain recognition and management"*	Thank you for your comment, this has been amended.
Surrey and Borders Partnership NHSFT	9	NICE	0	4	(Safeguarding children) We are concerned that there is a Section on Safeguarding Children, but no section on Safeguarding adults.	Thank you for your helpful suggestion, a section has been added about the safeguarding of vulnerable adults.
Surrey and Borders Partnership NHSFT	10	NICE	0	15	(Terms used in this guideline) We think it is very helpful that the definition of 'Functional assessment' differentiates between assessment of the function of the behaviour and functional analysis. It would, however, be helpful to also include a definition of the latter term.	Thank you for your comment. Functional assessment is the preferred term in the guideline and the GDG thinks it is clear from the context what functional analysis means.
Surrey and Borders Partnership NHSFT	11	NICE	1.1	16	We think that this section should include reference to paid staff and advocates	Thank you for your comment. Paid care staff are addressed by the recommendation, which applies

						to all professionals and staff working with a person with a learning disability and behaviour that challenges. The role of advocates is covered in other recommendations, for example revised recommendation number 1.5.4.
Surrey and Borders Partnership NHSFT	12	NICE	1.1.2	17	We believe that this needs to take into account not just the severity of the disability but also other systemic issues/ psychological issues etc. We are concerned that this seems to put everything down to the disability.	Thank you for your comment. The recommendation has been revised to say “take into account the severity of the person’s learning disability, their developmental stage, and any communication difficulties or physical or mental health problems”, which the GDG feels covers the points that you and other stakeholders have raised, while keeping the recommendation as succinct as possible.
Surrey and Borders Partnership NHSFT	13	NICE	1.1.3	18	We think this should include: the nature of LD and other co-morbid conditions e.g. autism, PD, dementia	Thank you for your comment, this recommendation is about the overall understanding of learning disabilities and behaviour that challenges. Recommendations are made regarding the treatment of coexisting conditions but it would not be practical to ask staff to have an understanding of any possible condition relevant to an individual.
Surrey and Borders Partnership NHSFT	14	NICE	1.1.6	19	We ask that this can include ‘understanding of physical health issues including pain recognition and management’	Thank you for your comment, pain management has been added to revised recommendation number 1.2.1.
Surrey and Borders Partnership NHSFT	15	NICE	1.1.6	19	(1.1.6-7) We would like to include: support to help staff and carers recognise and manage better their own stress responses to the impact that client's behaviour has on them.	Thank you for your comment, the GDG agreed that it is important to include support for staff and have added a recommendation to reflect your suggestion, see new recommendation 1.1.7.
Surrey and Borders Partnership NHSFT	16	NICE	1.1.9	20	We think that Social Services should be part of the designated leadership team.	Thank you for your comment. Social care has been added to the designated leadership team.
Surrey and Borders Partnership NHSFT	17	NICE	1.2.1	22	We ask that pain management is included here.	Thank you for your comment, the recommendation has been revised to include a reference to pain.
Surrey and Borders Partnership NHSFT	18	NICE	1.4.1	23	We ask that dementia should be included here	Thank you for your comment; dementia has been added to the list.
Surrey and Borders Partnership NHSFT	19	NICE	1.4.1	24	We are concerned about congregant environments which the person hasn’t chosen where other people’s behaviour or interactions cause the person problems e.g. other people’s noise	Thank you for your comment. The recommendation has been revised to include reference to environments where staff do not have the capacity or resources to respond to people’s needs, which the GDG feels captures your point, and points

						raised by other stakeholders.
Surrey and Borders Partnership NHSFT	20	NICE	1.5.2	24	We think staff and advocates should be included in the first bullet point.	Thank you for your comment. The GDG would expect staff to be fully involved in the assessment process as a matter of course. Advocates would have a particular role to play, that would require a different level of involvement than families and carers.
Surrey and Borders Partnership NHSFT	21	NICE	1.5.2	25	We would like included in the second last bullet reference to the resilience of staff and other people with LD they may be living with	Thank you for your comment, revised recommendation number 1.5.5 has been amended to include your suggestion.
Surrey and Borders Partnership NHSFT	22	NICE	1.5.5	26	We would included a reference to assessment of the relationships with other people that the person with a learning disability might live with in the third bullet point	Thank you for your comment. Relationships with other people that the person might live with has been added to the recommendation.
Surrey and Borders Partnership NHSFT	24	NICE	1.5.8	27	We would like to see some comment about how teams should approach this work – that it should be multidisciplinary and include concurrent assessments whenever possible, rather than sequential assessments from different professional groups. The focus should be on the developing a shared formulation of the person and their behaviour.	Thank you for your comment, the recommendation has been revised to state that further assessment should be multidisciplinary, and revised recommendation number 1.5.2 makes it clear that the assessment process should be flexible and continuing.
Surrey and Borders Partnership NHSFT	25	NICE	1.5.10	28	We think that re Functional Analysis that this should go beyond the ABC linear model described to include how the client's behaviour impacts on staff / carers / families and then how their reaction impacts on the client and how this sets up a fixed and stuck interactional pattern.	Thank you for your comment, but the impact of behaviour that challenges has been covered in the recommendations on initial assessment.
Surrey and Borders Partnership NHSFT	26	NICE	1.5.12	29	We think there should always be a risk assessment.	Thank you for your comment, the GDG agrees and has revised this recommendation accordingly.
Surrey and Borders Partnership NHSFT	27	NICE	1.5.13	29	With reference to the Behaviour Support Plan we think that as well as identifying strategies that stop conditions that promote challenging behaviour, a first step is to identify constructive opportunities that the client finds positive which includes relational opportunities i.e., an awareness and description of the patterns of interaction between the client and those people who get on best / worst with them.	Thank you for your comment, the suggestions you make would be covered by the first two bullet points that recommend identifying and adapting the environment of the individual.

Surrey and Borders Partnership NHSFT	28	NICE	1.5.13	30	We think this should include better management of physical health issues and pain	Thank you for your comment. Physical health is covered in revised recommendation number 1.2.1.
Surrey and Borders Partnership NHSFT	29	NICE	1.6.6	32	We think this should not just state anger management – but could include modified CBT for other psychological problems. Should also include social and relational factors.	Thank you for your comment, however no evidence was found for social and emotional factors, only cognitive and behavioural, and only for anger management
Surrey and Borders Partnership NHSFT	30	NICE	1.8.2	35	We recommend that the Department of Health's 'Positive and Proactive Care' (2014) guidance is referenced here	Thank you for your comment, NICE guidelines do not reference policy documents in the recommendations as these often become outdated before the guideline is updated.
Surrey and Borders Partnership NHSFT	31	NICE	1.8.5	36	We recommend that the Department of Health's 'Positive and Proactive Care' (2014) guidance is referenced here	Thank you for your comment, NICE guidelines do not reference policy documents in the recommendations as these often become outdated before the guideline is updated.
Surrey and Borders Partnership NHSFT	32	NICE	2	37	We have other suggestions for future research: • Comparing outcomes in residential care vs supported living for people with behaviour that challenges. • Comparison of the outcome and cost of placements made by LD specialist vs generic care managers for people who engage in behaviours that challenge.	Thank you for this comment. The GDG considered that your suggestions may well be dealt with by the programme of work set out in research recommendation 2.4
Surrey and Borders Partnership NHSFT	33	NICE	3.2	41	We think the NICE guidance on dementia should be added to the list of related NICE guidance.	Thank you for your comment, this guideline has been added.
Surrey and Borders Partnership NHSFT	34	NICE/Full	1.5.4/8.5.2	164	We think it would be helpful if it gave some indication about the number of hours they would expect to complete an initial assessment.	Thank you for your comment, but this is a matter for clinical judgement.
Surrey and Borders Partnership NHSFT	35	NICE/Full	1.5.8/8.5.2	166	We would like further detail of what other assessment could be undertaken	Thank you for your comment, the section on assessment has been redrafted and the difference between initial and further assessment clarified to indicate that all elements of initial assessment would need to be explored in greater depth at further assessment.
Surrey and Borders Partnership NHSFT	36	NICE/Full	1.5.11/8.5.5	167	We think it would be helpful if the terminology was consistent ie primary prevention as well as secondary rather than proactive secondary reactive	Thank you for your comment. Changes have been made to the terminology for consistency.

Surrey and Borders Partnership NHSFT	37	NICE/Full	1.2.1/9.5.2	195	We think that Health Action Plan should be included	Thank you for your comment, however the GDG could find no evidence to support the use of health action plans, and in their experience they are not widely used.
Sutton Council	1	NICE	1.5.7	27	When assessing risk there should be some evaluation of the impact of existing behaviour management strategies (i.e. physical, medical environmental restrictions in place), as these are often an important contributing factor to the current problems and direct impact on the quality of life of the client (i.e. impact on Autonomy, Choice and Control).	Thank you for your comment, but what you have suggested here is not a risk but part of the assessment of the intervention, which the guideline covers elsewhere (see revised recommendation number 1.7.1, for example).
Sutton Council	2	NICE	1.5.2	25	The advice does not seem clear on what would constitute a change in behaviour a change in which dimension of behaviour for example locus, frequency, intensity and duration. Would it be more useful to suggest that assessments should be repeated after interventions have been implemented or looking at alternative outcome measures or changes in the level of risk, rather than just repeating the initial assessment.	Thank you for your comment, this has been amended in line with yours and others' comments to include 'significant change'.
Sutton Council	3	NICE	1.5.2	General	The advice is not clear on what constitutes a complex and intensive assessment and what would constitute a less intensive or complex assessment.	Thank you for your comment. The section on assessment has been redrafted to improve clarity and reduce repetition. Further cross-references have been added.
Sutton Council	4	NICE	1.5.10	28	(Pages 28-9) How does the advice around recording information dovetail or relate to the existing statutory recording requirements in place for residential services or school settings.	Thank you for your comment. This recommendation sets out advice for health and social care staff on the contents and components of an assessment. Procedures and protocols for recording of this information will be determined by agreed national and local guidance. The GDG see nothing in this recommendation that would present any difficulties relating to existing statutory requirements.
Sutton Council	5	NICE		16	Why has the profession of Board Certified Behaviour Analysts been excluded from the list of staff who would provide support to this client group especially as the best practice examples of a PBS service referenced the Halton service which is staffed primarily by this profession.	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has added them to the definition of 'staff' and has included them in revised recommendation1.1.5, which defines the specialist support and intervention service.

Sutton Council	6	NICE	1.1.6	19	Would suggest changing the word 'calm' which has subjective value judgements about the client to prevent the possibility of further escalation. This places the onus on those supporting the person to change the way in which they are responding the behaviour rather than the onus on the client to "calm".	Thank you for your comment, but the GDG felt that the word 'calm' would be readily understood in this context as an important component of the strategies used when a person with a learning disability begins to show signs of distress.
Sutton Council	7	NICE	1.5.5	26	This section should include an understanding of the adaptive and functional skills of the client as the lack of a effective skills repertoire is often the primary reason why the person will engage in behaviour that challenges to meet unmet need.	Thank you for your comment, the recommendation has been amended to take account of yours and others' comments.
Sutton Council	8	NICE	1.5.11	29	Unsure the only way of measuring quality of life would be through structured measures and finding out general information around the person's daily living and adaptive skills. The person's ability and opportunity to express choice and the types of activities that person enjoys or takes part in, which generally feels a lot more person centred in approach. Often normalised structured assessments on their own are unable to capture the complexity of human life and represent the period of time in which they were created rather than the activities which people may participate in today.	Thank you for your comment, the GDG agree that quality of life is of great importance and this has been added to revised recommendation number 1.1.2. We would also expect that the needs of a person, broader than just their behaviour that challenges, is captured in the assessment and behaviour support plan, see revised recommendation numbers 1.5.1, 1.5.2 and 1.6.1
Sutton Council	9	NICE	1.5.13	30	The behaviour support plan should also include a number of other approaches and this does not seem a comprehensive list of potential useful strategies, much of which has been discussed widely in the behavioural literature including; increasing client autonomy and control, ensuring and developing choice making, looking to interrupt earlier in sequences of behaviour to remove stimulus which leads to behaviour that challenges and ensuring that the persons environment contains enough objects or activities that they find interesting or important throughout their day (Non Contingent Reinforcement) not dependent on their behaviour.	Thank you for your comment, the GDG consensus was that there are sufficient examples of strategies and therefore no change was made to the recommendation.
Sutton Council	10	NICE	General	General	Does not make enough reference to the need for highly trained professional leads in specialist	Thank you for your comment, revised recommendation numbers 1.1.6-1.1.8 all refer to

					services. People should be trained to at least a Masters level, and their training should include significant content in behaviour analytic approaches. I would expect NICE to be much more prescriptive about the expertise needed for professionals or at least suggest this as a desirable outcome.	the need for staff to be appropriately trained and competent to work with people with a learning disability and behaviour that challenges.
Tees Esk & Wear Valleys NHSFT	1	NICE	1.5.13	30	The opening paragraph infers that a functional assessment will resolve behavioural challenges and that a behaviour support plan is only required if it doesn't. Functional assessment and formulation lead to the development of evidence based behaviour support plans. We feel this point needs refining to reflect this.	Thank you for your comment, the recommendation has been revised to address your concerns.
Tees Esk & Wear Valleys NHSFT	2	NICE	General	General	We would have expected greater emphasis on the adoption of Positive Behaviour Support and in particular the crucial role proactive interventions play in bringing about behaviour change.	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended.
Tees Esk & Wear Valleys NHSFT	3	NICE		16	Description of term Reinforcer. We feel that the word reward is a very value laden term and too easily misunderstood. For example If a staff team are advised that their response to someone's behavioural challenge for attention is the reinforcer/reward maintaining the behaviour and this is subsequently interpreted by them as **rewarding** "bad behaviour" they may withdraw attention to avoid giving a reward rather than seeking alternative ways to help the person get their need for attention met.	Thank you for your comment. The change you have suggested has been made.

					We suggest the following description **Reinforcer –** Any event or situation that follows a behaviour and increases the likelihood of that behaviour happening again.	
Tees Esk & Wear Valleys NHSFT	4	NICE	1.5.11	29	We feel the quality of life measures suggested are simply not suitable or fit for purpose on many occasions (The Life Experiences Checklist and the Quality of Life Questionnaire). There is definitely a need for a Quality of Life measure to be used but those yet available are not wholly suitable and we suggest this should be acknowledged.	Thank you for your comment, we agree that some measures may not be wholly suitable but it is outside the remit of NICE guidance to change this.
Tees Esk & Wear Valleys NHSFT	5	NICE	1.1.5	10	We welcome the Key Priority on Team Working and in particular the need for organisations providing routine assessment and interventions to have access to: specialist assessment; specialist support and intervention services and advice, supervision and training to support the implementation of any care or intervention"	Thank you for your comment.
Tees Esk & Wear Valleys NHSFT	6	NICE	1.1.2	10	We fully support the recommendation to "ensure that the focus is on improving the person's support rather than changing the person" This is especially important for some hospital services where there can be at times a strong emphasis upon changing the person (e.g. their taking responsibility for their actions) rather than placing at least as much emphasis upon the person's support needs (as opposed to their need for supervision).	Thank you for comments.
Tees Esk & Wear Valleys NHSFT	7	NICE	1.5.2	25	We feel it could be equally useful to recognise that the recommendation "all individual and environmental factors that may lead to behaviour that challenges are taken into account" may prove particularly important/challenging for some hospital units, as it requires them to acknowledge the role their physical & social environment plus the style of support/interaction provided on the unit, may have in provoking behaviours that challenge.	Thank you for your comment. The guideline applies to all settings in which a person with a learning disability might develop behaviour that challenges, and the GDG agrees that it is important that all staff reflect on their practices.
The Disabilities Trust	1	General	General	General	The Disabilities Trust is pleased to respond to this consultation through our autism and learning	Thank you for your comments.

					disability division, Autism Spectrum Partners. The Trust offers a range of individually tailored support services, for people with complex needs aimed at helping people achieve their personal potential and to empower them to live their lives as independently as possible. We provide services for individuals who are autistic and/or who have a learning disability. Learning Disability can be a complex set of impairments and no two people have the same needs. Our detailed assessment procedure, is carried out in advance of admission to our services and regularly afterwards. It is designed by experts to determine the level of support needed by each individual. We are committed to finding new ways of understanding the views of those who have communication difficulties and tailor our communication methods to best meet the needs of that person. This concurs with research that says those with poorer communication have higher rates of behaviour that challenges.	
The Disabilities Trust	2	NICE	1.1	General	General principles We agree with the General Principles set out in 1.1.3, however we recommend that this includes understanding the “sensory environment,” as well as the effect of the social and physical environment on learning disabilities and behaviour that challenges. Our own experience suggests that sensory impairments such as visual and hearing impairments also contribute to challenging behaviour. If the ‘sensory environment’ is included here we believe it could contribute to assisting in decreasing challenging behaviours in relation to sensory issues.	Thank you for your comment. The GDG has made revisions throughout the document to ensure that assessment, and if necessary, adjustment, of the environment includes any sensory needs (see, for example, revised recommendation number 1.7.5).
The Disabilities Trust	3	NICE	1.2	General	1.2 Physical Healthcare The need for annual health check - There should be a mention of where the health checks should or can	Thank you for your comment, this recommendation has been amended to specify that a GP should conduct the annual health check. The location has

					take place and who has the main responsibility to ensure they are completed, for example a lead practitioner. We feel strongly that at the heart of all health action planning should be the individual's preferred or available method of communication. This would support all the disciplines and health care professionals who are accessing the health care action plan.	not been specified as this health check could take place in a variety of settings (GP surgery, home, residential unit, secure unit etc.), depending on the individual circumstances.
The Disabilities Trust	4	NICE	1.3	General	1.3 - Support and interventions for family members or carers The Trust welcomes this guideline is specifically aimed at the sometimes difficult and all-consuming roles family members and carers play in providing care and support for these individuals. In offering advice and support as well as access to 'support groups' NICE should consider highlighting that some families or carers might benefit from advice, support and training in using techniques and interventions to de-escalate situations where the individual may be reacting negatively towards the families, carers or environment.	Thank you for your suggestion, the GDG agree that support and training for families is important and have amended recommendation number 1.3.3 to ensure families are provided education about skills and emotional support to enable them to participate in interventions for the person with a learning disability and behaviour that challenges.
The Disabilities Trust	5	NICE	1.4	General	Early Identification of the emergence of initial behaviour that challenges The Trust is keen that it is not just visual impairment that is highlighted as a potential trigger towards behaviour that challenges in an individual with a learning disability. We are clear that other sensory losses should be taken into account as they commonly contribute towards challenging behaviours. Therefore, we would suggest that visual impairment is changed to sensory impairment, for example visual or hearing impairment.	Thank you for your comment, but the review of personal risk factors found evidence for visual impairment only, not sensory impairment more generally. The evidence for hearing impairment was not of sufficient quality to allow the GDG to specify it as a risk factor.
The Disabilities Trust	6	NICE	1.5	General	1.5.7 Risk Assessment We would ask that 'harm or aggression directed towards the environment' is added into this list.	Thank you for your comment, however this recommendation sets out areas of risk rather than what precipitates risk, which the recommendation now makes clear.
The Disabilities	7	NICE	1.6	General	1.6.1 Psychosocial psychological and	Thank you for your comment. Are you referring to

Trust					environmental interventions We would ask that 'parent-training' programmes are extended to parents and/or carers who have responsibility for individuals of any change who are at risk of, or who have developed a behaviour that challenges.	people of 'any age'? The evidence reviewed was for children under 12 only.
The Disabilities Trust	8	NICE	1.6	General	1.6.5 We would recommend that the guidance avoids the use of the word 'escape' it suggests the individual is trying to run away and has connotations of security and secure environments.	Thank you for your comment, the term 'escape-motivated' has been changed to 'avoidant'.
The Disabilities Trust	9	NICE	1.6	General	1.6.7 Whilst we agree that no interventions should be offered without assessment, the guideline is quite negative in the way it is phrased. We would perhaps suggest 'sensory interventions should be offered only after a sensory assessment has been completed.	Thank you for your comment. The GDG debated the wording of the recommendation at some length and decided based on the quality of the evidence and the possibility of harm to make a 'strong' recommendation in this area.
The Disabilities Trust	10	NICE	1.8	General	Reactive Strategies The Trust fully supports the emphasis on reactive interventions being the last resort for people with a learning disability and behaviour that challenges. The Trust would like to see some guidance for family members and those that act as carers on reactive strategies are included within the final guidelines. This should include 'reactive break away' techniques to assure the safety of the carer/family member. We recognise this goes beyond what the GDG advise in the main document but feel that this should be reconsidered. There is little emphasis on the emergence of learnt behaviours –for example behaviours that have been developed by the service user to achieve an outcome to need which have failed to be communicated more appropriately. Overall the Trust believes that the guidelines have covered this area well but it should emphasise that the assessment should be inclusive and detailed with both proactive management linked to reactive management, thus assuring that all elements are met, with clear guidance and emphasis on the	Thank you for your comment. The GDG has made some additions to revised section number 1.3 on support and interventions for carers about skills training to help family members and carer to take part in the support interventions for the person with a learning disability and behaviour that challenges, which would include the techniques you mention. The issue of learnt behaviour is discussed in the full guideline. The GDG feels that the assessment is sufficiently inclusive and detailed, and the recommendation on the behaviour support plan sets out how proactive and reactive strategies are linked.

					reactive elements being last resort as stated in the document. The approval should focus on regular review and updating of support plans which should be linked with current data recordings in relation to the individual concerned. (see research point for information on our OBS-LADASC)	
The Disabilities Trust	11	NICE	1.9	General	1.9 Co-existing health issues This point focuses only on known co-existing health issues. We feel this should be broadened to include emerging and temporary conditions as well. Whilst the guideline highlights 'physical and/or mental conditions,' there needs to be a flexibility in recognising that even temporary ailments such as the common cold, toothache or skin irritation through hypersensitivity may lead to further interventions than normal in a person with a learning disability with behaviour that challenges. We have experience of challenging behaviour being utilised by the individuals as the only communication method available to signal for more help or support. Therefore it is essential that all these possibilities are taken into account throughout regular updates and assessments of the individual.	Thank you for your comment. The guideline has been revised to highlight issues such as pain in the recognition, assessment and management of behaviour that challenges in people with a learning disability. In this recommendation the GDG has made it clear that suspected mental or physical health problems should also be addressed.
The Disabilities Trust	12	NICE	2.2	General	(Research Recommendations) Research Overall the Trust welcomes that the Guideline Development Group's has made recommendations for research. Part of research recommendation 2.2 asks if 'applied behavioural analysis interventions,' are effective in reducing the frequency and severity of behaviour that challenges in adults with a learning disability. The Trust has developed a tool to help understand why a service user is displaying challenging behaviour by monitoring their behaviour and analysing what is happening to develop appropriate support for individual service users. The 'Overt Behaviour Scale – Learning Disabilities	Thank you for your endorsement of the recommendation and the offer of your scale which is not yet published. Unfortunately the timescale for the development of the guideline prevents us for reviewing evidence which has not been or cannot be submitted. Your suggestion of research into the role of sensory needs on behaviour and quality of life is an interesting one but as it is not directly concerned with intervention efficacy is outside the scope of our possible recommendations.

					and Autism Spectrum Conditions (OBS-LDASC) is a person-centred tool which can be individualised to the behaviours of each service user. Measure of severity, frequency and duration of behaviour are included in the OBS-LDASC as well as information about the antecedents (what happened before) and consequences (what happened after the behaviour). The information gathered is collected, analysed and then shared by the clinical team with staff at multi-disciplinary meetings. The data is also used to inform behaviour support plans and risk assessments. The Tool will shortly undergo the process for peer review. If NICE feel this tool could inform their research recommendation we are happy to keep the GDG abreast of developments. Erin.rodgers@thedtgroup.org The Trust would recommend that further research into the link between sensory needs and the impact on behaviour and quality of life is carried out. It would be helpful for the professional workforce to evidence what experience already tells us but to also enhance understanding for families and carers so they receive better insight into this common co-existing health condition.	
UK Society for Behaviour Analysis	1	Full	2.5.2	27	(Pages 27-8) Psychosocial causes: this section is very well written, recognising 1) the learned (i.e. conditioned) nature of challenging behaviour and 2) the functional nature of challenging behaviour. It also recognises that parents and other carers may inadvertently reinforce (maintain) challenging behaviour by their responses to it. The importance of functional analysis is acknowledged in this section with substantial reference to behaviour-analytic literature.	Thank you for your comment.
UK Society for Behaviour Analysis	2	Full	2.5.3	28	(Pages 28-9) Environmental causes: another clear narrative on the learned nature of challenging behaviour and the	Thank you for your comment.

					need to intervene in environments and social systems. The section acknowledges the important part Positive Behaviour Support (PBS) can play in moving from “challenging” to “capable” environments. The definition given by one of the founding figures of PBS, Ted Carr, is reproduced: (PBS is) “an applied science that uses educational and systems change methods to enhance quality of life and minimise problem behaviour”. Reference to PBS and applied science is appropriate to the field(s) of LD/ASD/challenging behaviour (as in so many other areas of life) and a very welcome inclusion in these guidelines.	
UK Society for Behaviour Analysis	3	Full	6.1.2	95	Text in the first paragraph contradicts text on psychosocial causes on page 28. The relevant contradictory text is: “Herein lies a problem, in that many approaches to behaviour that challenges to date have relied on what can be called ‘reductionist’ behavioural techniques, involving the teaching of specific methods designed to decrease the unwanted behaviours rather than their purpose. Fidelity is usually weak and the approach ineffective because it ignores critical information about the person or their circumstances” (p.95, first paragraph, no citations provided). In contrast (and in contradiction) pages 27-28 on psychosocial causes present a clear narrative on the development of functional behaviour analysis procedures, the importance of identifying function, and the importance of matching interventions to functions – i.e. matching treatments to causes.	Thank you for your comment. We have removed this paragraph from the chapter.
UK Society for Behaviour Analysis	4	Full	6.1.2	95	Given the emphasis on the importance of PBS, applied science, functional analysis, matching intervention strategies to function, (pages 27-29), there are no guidelines in this section on training. To be consistent with its own position, the GDG should recommend training in PBS, Applied	Thank you for your comment. We have reviewed the training evidence and did not feel able to make these recommendations.

					Behaviour Analysis, Experimental Functional Analysis in these guidelines.	
UK Society for Behaviour Analysis	5	NICE/Full	1.1.5/6.4.2.1	113	The text recommends that specialist support and intervention services should include: followed by a list of professionals. Conspicuous by its absence here, and particularly in light of points 1-4 made in this stakeholder response, is any mention of professionals trained and competent in procedures referred to by Carr and quoted in these guidelines as “applied science”. That is, there is no mention of the importance of including professionals trained in Behaviour Analysis (preferably whose training has been certified). In our experience, the professionals alluded to in this section are not trained in the foundational principles and procedures of functional analysis and are thus as likely to inappropriately reinforce and maintain challenging behaviours as is any other kind of carer or professional. We suggest Behaviour Analysts are included in the list of specialist support and intervention services. To not do so would be to cancel-out the recognition of its importance clearly stated in other parts of the guidelines.	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has now included them in revised recommendation number 1.1.5.
UK Society for Behaviour Analysis	6	Full	3.5.3	40	The following statement (lines 28, 29) is incomplete: “Experimental designs typically follow an ABA withdrawal format whilst quasi-experimental designs follow an AB format”. The text has omitted other experimental designs used to assess several dimensions of behaviour-environment relations: ABA, ABAB, Multiple Baseline across participants, across settings, across behaviours (with individuals or groups), Alternating Treatments (also referred to as Multi-Element), Multiple Probe and Changing Criterion. While there are also variations of these designs, the text must at the very least accurately acknowledge these known and widely practiced ways in which	Thank you, we have revised this section to clarify this.

					scientific procedures are brought to bear in attempts to quantify behaviour and its relations to other events.	
UK Society for Behaviour Analysis	7	Full	11.3.2	263	There is surely ample evidence/literature available to answer this question in relation to the impact of Applied Behaviour Analysis. We refer you again to pages 27-29 of the guidelines. It's not at all clear to us why this question – the part relating to Behaviour Analysis – should be raised. There is a very substantial literature on this topic demonstrating positive outcomes when Behaviour Analysis (possibly named as PBS) is applied.	Thank you for raising this issue. As reported in chapter 11, there is a paucity of evidence that met inclusion criteria, and what evidence there is was rated as low or very low quality. Therefore, the GDG believe they are justified in recommending more research.
UK Society for Behaviour Analysis	8	Full	4.5	78	One of the recommendations in this table is to: "develop a shared understanding about the function of the behaviour and what maintains it". Pages 27 to 29 of the guidelines acknowledge the skills, training and specialist knowledge involved in the process of discovering functions of challenging behaviour. In light of that, the recommendation to "develop a shared understanding" seems inadequate. To be consistent with previous text, the recommendation should specify that professionals with specialist training be consulted – i.e. Behaviour Analysts.	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has included them in revised recommendation number 1.1.5, which defines the specialist support and intervention service.
UK Society for Behaviour Analysis	9	Full	9.2.2	179	(Section 9.2.2 and 9.2.9) Note Motiwala et al., (2006) is a Canadian study. So the sentence should read: "Two studies were conducted in the US (citations), one in Canada (citation) and one in the Netherlands (citation).	Thank you. This has been amended.
UK Society for Behaviour Analysis	10	Full	9.2.2	179	(Pages 179-81) Given costs to the public budget of services for persons with learning disabilities and/or ASD, consideration of economic evidence is appropriate and welcome. The first point to make in relation to the treatment of four cost-benefit analyses conducted in three different countries and an RCT conducted in Australia is that they all come to the same conclusion – i.e. EIBI has the potential for very considerable savings to the public budget.	Judgement of applicability of economic studies is based on the NICE Methodology Checklist for economic evaluations, as stated in section 3.6. The completed checklists for all EIBI studies are included in Appendix R of the full guideline. The applicability checklist considers, among other issues, the similarity of the healthcare system in which the study was conducted to the NHS context. This similarity refers to care pathways and associated resource use, funding of services, staff

					The guidelines give no explanation of findings being “only partially applicable to the UK context” p.179 & 180. The taxpaying public deserve an explanation of how/why substantial savings in other currencies would not translate into savings in pounds sterling were the same procedures to be recommended. Such an explanation should be provided.	involved in the care and associated unit costs. NICE considers all studies conducted outside the UK (and even older UK studies), as 'partly' or ‘no’ similar to the current NHS context, depending on the extent of differences in the healthcare settings. Although Australia. Canada and the Netherlands have a relatively similar publicly funded system to the UK, US has a different healthcare system – so overall, given that none of these studies were conducted in the UK, they have been judged to be partially applicable. Note that the applicability of studies is judged using criteria as well, including the relevance of the populations and interventions, the perspective of the analysis, the discount rate, and issues around estimation of QALYs (see NICE Guidelines manual Appendix G for more details).
UK Society for Behaviour Analysis	11	Full	9.2.2	179	(Pages 179-81) Having considered four respectable cost-benefit analyses of EIBI in comparison to other offerings, the guidelines should either 1) consider cost-benefit analyses of other procedures typically provided to children with ASD/LD such as SALT, OT, SPELL, etc. for comparison or 2) acknowledge that no such cost-benefit analyses exist.	As stated in Section 3.6 of the full guideline, “systematic reviews of economic literature were conducted in all areas covered in the guideline”. In each evidence section, we do state whether we have identified relevant economic evidence for the population and interventions assessed in the section, which is subsequently presented, or whether no such evidence was identified.
UK Society for Behaviour Analysis	12	Full	9.2.2	181	(Section 9.2.2/27) Roberts (2011) a RCT referred to in relation to economic evidence is not made available in the reference list at the end of the document	Thank you. The full reference is included in the reference list: “Roberts J, Williams K, Carter M, Evans D, Parmenter T, Silove N, et al. A randomised controlled trial of two early intervention programs for young children with autism: Centre-based with parent program and home-based. Research in Autism Spectrum Disorders. 2011;5:1553-66” (page 367 of the draft full guideline).
UK Society for Behaviour Analysis	13	Full	9.2.3	181	(Pages 181-2) The general principle of considering possibly preventing the development of challenging behaviours by early intervention is most welcome. Our experience is that early training in social,	Thank you for your comments. In the full guideline, existing systematic reviews are generally only cited if they are used as evidence (or mentioned in the introduction). In this case, the GDG restricted the review to RCTs (the best available evidence to

					communicative, self help and academic skills provides children with LD/ASD with repertoires that assist them in navigating their social and physical world. Like others (including the GDG), we acknowledge difficulties inherent in evaluating data from the many scientific yet inconsistently designed studies demonstrating positive outcomes for children exposed to Behaviour Analysis at an early age (the text refers to this as EIBI). Having said that, we are surprised not to see the four meta-analyses published between 2009 and 2011 which address these difficulties and which conclude, unanimously (rather like the cost-effectiveness studies) that early Behaviour Analytic intervention demonstrates gains above and beyond other procedures or treatment as usual. Eldevik, Hastings, Hughes, Jahr, Eikeseth, Cross (2009), Meta-Analysis of Early Intensive Behavioral Intervention for Children with Autism. *Journal of Clinical Child and Adolescent Psychology*. 38(3), 439-450. Eldevik, Hastings, Hughes, Jahr, Eikeseth, Cross (2010). Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children with Autism. *American Journal of Intellectual and Developmental Disabilities*. 115(5), 381-405. Virues-Ortega (2010). Applied behaviour analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review*. 30, 387-399. Peters-Scheffer, Didden, Korzilius, Sturmey (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention	answer this type of question), whereas the reviews that you mention include non-randomised studies.

					programs for children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*. 5, 60-69. The authors noted above have been through the process of making order out of the somewhat chaotic scientific scene that is early intervention literature. A review/comment on these four meta-analyses seems appropriate.	
UK Society for Behaviour Analysis	14	Full	General	General	The well-informed sections on scientific approaches to analysis and treatment/intervention when behaviour challenges, i.e. the sections on Behaviour Analysis, Functional Analysis, Positive Behaviour Support (PBS) are very welcome. Making funders and service providers aware that systematic procedures are now available that can be brought to bear by appropriately trained and qualified professionals can only 1) improve quality of life for persons with LD/ASD and their immediate carers and 2) reduce the burden of high-cost services so often required when families and service providers feel they can no longer meet the needs of a person whose behaviour challenges. In terms of recommendations for training and the purchase of professional services for dealing with behaviour that challenges, we would urge the GDG to include specific reference to the need for persons trained and certified in Behaviour Analysis to conduct functional analyses and provide guidance on function and on matching interventions.	Thank you for your comment, in light of yours and others' comments revised recommendation number 1.1.5 has been amended to more fully characterise the range of professions and their competencies to effectively support people with a learning disability and behaviour that challenges.
UK Society for Behaviour Analysis	15	Full	General	General	Given the clear emphasis on the importance of well-informed functional analysis and Behaviour Analytic interventions, the guidelines would benefit service users, carers, service providers and funders alike by specifying that expertise (appropriate, preferably certified) in Behaviour Analysis is essential to the amelioration of behaviour that challenges. Although the GDG has not yet commented on the meta-analyses relevant to early Behaviour Analytic	Thank you for this suggestion. NICE guidelines do not routinely specify who should conduct the intervention, but rather specify how and what should be included in the intervention. Therefore, anyone with appropriate training could deliver the recommended intervention.

					intervention (noted above), those meta-analyses indicate that preventing the development of behaviour that challenges is in fact possible when scientific principles are invoked in structured and well-run programmes. The long-term implications in terms of cost-benefit is implicit in the outcomes of the meta analyses.	
Ulster University	1	Full	General	General	Applied Behaviour Analysis is a science but is continually referred to as an “intervention”.	Thank you for your comment, the introduction to the full guideline has been amended to make reference to ‘the science and practice of ABA’.
Ulster University	2	Full	3.5.3	40	Single subject research has developed numerous designs to address issues such as irreversibility and carry-over effects (e.g., multiple baseline designs, changing criterion designs, alternating treatment designs to name a few).	Thank you, we have revised this section to clarify this.
Ulster University	3	NICE/ Full	1.1.5/6.4.2.1.1	113	Board Certified Behaviour Analysts should be included among those professionals named as specialist support staff.	Thank you for your comment. The GDG recognises the importance of behavioural analysts and has now included them in revised recommendation number 1.1.5.
United Response	1	NICE/Full	1.5.5/8.5.2	164	Recommendation 24 gives a list of things to take into account as part of the assessment of behaviour. The final bullet point says “the care environment … and how well organised it is”. We think this would be better as “… how well structured it is.” That’s a subtle but significantly different point: structure is how predictable and understandable the environment is; in order to be that it has to be organised but they’re not equivalent terms: you could have a well organised environment that was not understandable to a particular person.	Thank you for your comment, the recommendation has been changed to say "how well structured it is.”
United Response	2	NICE/Full	1.6.8/10.3	205	Below Recommendation 39 – The penultimate paragraph states that “…they decided to recommend that plans for structured daytime activity should be developed.”. However in the actual recommendations (Recommendation 39 itself) it states “Consider developing a structured plan of day time activity…”). These are 2 different levels of recommendation strength: should, as opposed to could. The guidance is good at	Thank you for your comment. The full guideline has been amended to better reflect the recommendation, which the GDG is unable to make stronger because the evidence in this area is lacking, or specifically name Active Support. However, the recommendation has been revised to say that the structured plan of daytime activity should be maintained.

					explaining the different recommendation strength (eg p.8 in the NICE document) so this is not merely nit picking. We think that the actual recommendation should be stronger (given what you say in your own comments), eg start recommendation 39 by stating: “Develop a structured plan … “ We also think that you should specifically name Active Support (as an established approach that does just that) as an approach to use for this purpose. In terms of interventions, our main concern is that you should be highlighting Active Support more clearly. You do mention it, but only in passing.	
United Response	3	NICE	1.6	31	We are concerned about appearance of the terms “primary and secondary intervention or prevention” in the intervention section. Primary Intervention/Prevention isn’t mentioned in the full version, but is in the shorter section on page 31 in a manner that is not justified or explained by the detail of the full version. Secondary prevention appears in the long document for the first time in the recommendations, again without appropriate justification or explanation. In the short document the heading “primary and secondary prevention” doesn’t seem to relate to what follows in section 1.6. We feel that the appearance of these terms is at least confusing in the context of Positive Behaviour Support as described in the guidance, even more so as the terms are similar to other unrelated entities or approaches, and should just be removed.	Thank you for your comment. The title ‘primary and secondary prevention’ has been changed to ‘early intervention’.
United Response	4	Full	12	264	We approve strongly and wholeheartedly with the section on pharmacological interventions. We hope it doesn’t get watered down in consultation –and feel that the recommendations should reflect this. We strongly support the checks and constraints it puts on the prescription of medication in response	Thank you for your comments.

					to challenging behaviour.	
United Response	5	Full	2.5.2	27	We are concerned that this section does not reflect the subconscious nature of learnt behaviour and could reinforce commonly held misconceptions that the person has control of their behaviour and is displaying behaviour intentionally. While there is some clarification of this on lines 44-47 'Many children, young people and adults who show behaviour that challenges have not speech or very little speech, and it seems that much behaviour that challenges can be seen as functioning like communication for those with very poor language skills, even though they may lack intent' – This should be stated more clearly and strongly in recommendations.	Thank you for your comment, this section has been revised to take account of your suggestion.
United Response	6	Full	4.2	57	Section 4.2 (in particular statements on page 57) could also encourage this misunderstanding of conscious use of behaviour that challenges – we feel these comments need to be balanced with clear information earlier in the report and recommendations drawn from this. Further to this we are concerned that the impact of carers, staffs attitudes and attributions has not been discussed adequately in this document (although it is mentioned on pg 57). Specifically, the way carers and staff respond to behaviour and the information they provide as part of assessments etc. is heavily influenced by their beliefs about the individual and their behaviour. It feels like an important factor that is missing throughout this document.	Thank you for this comment. This section serves as an introduction to the guideline and as such does not for the basis for any recommendation. The recommendations are developed following a review of the evidence in subsequent chapters. The GDG acknowledge that the issues that you raise may impact on care. In terms of the role of carers and staff we have revised some current recommendations and added a new recommendation (see revised recommendation number 1.1.7) to address this issue.

United Response	7	Full	10	197	As regards section 10 generally and throughout, with regard to environmental interventions; it would appear that Peter McGill's 'capable environments' description/paper has superseded other research on the impact/importance of Active Support, Effective Communication and quality of life. We strongly believe that Active Support provides the foundation for good services and positive behaviour support, so the lack of discussion/recommendations on this is disappointing. This section should include additional information on the need for structure and predictability too.	Thank you for raising this issue. The GDG don't agree that McGill's 'capable environments' has superseded other research. Positive behavioural support and active support are included in the introduction, and then the GDG reviewed the evidence for 3 different kinds of environmental interventions; sensory interventions, structured daytime activity and motivating operations. The reviews did not find any evidence on the effectiveness of positive behaviour support. The rationale for the recommendations is described in 10.3.
United Response	8	NICE/Full	1.7.3/12.3	312	Recommendation 48 'Consider antipsychotic medication ……' We think this recommendation should be stronger – and would suggest that it states: 'Only consider antipsychotic medication for behaviour that challenges if psychological or other intervention are insufficient or cannot be delivered alone because of the severity of risk to self or others….	Thank you for your comment. 'Only' has been added to the recommendation as you have suggested.
United Response	9	Full	13	317	Section 13 on Reactive Strategies: This section does not reflect the use of reactive strategies in Positive Behaviour Support which focuses 'returning to calm' as soon as possible – and allows the use of a range of non-punitive approaches, including strategic capitulation. This is disappointing as this facet of Positive Behaviour Support provides realistic and effective alternatives to the use of punishment, restraint and sanctions. We feel this section needs considerable work and to be rewritten to take these alternatives into account.	Thank you for your comment, we acknowledge that PBS is increasingly used as an overarching framework to describe a range of appropriate strategies to support people with a learning disability and behaviour that challenges. The GDG considered the evidence for PBS as an overall framework and were unable to identify any evidence of sufficient quality to support a recommendation for the adoption of PBS. However, a number of helpful elements used with a PBS framework are identified and recommended by the guideline. Given the strength of the evidence the GDG concluded this was as far as PBS could be recommended. The GDG carefully considered the available evidence for reactive strategies and concluded the recommendations best represents a positive

						approach. Revised recommendation number 1.6.1 specifically mentions strategies to calm a person with a learning disability at risk of developing behaviour that challenges.
University of Warwick	1	Full	1.2.2	General	It would be helpful to add explicitly that the guidance will also be of use in education services and settings	Thank you for your comment, whilst the guideline may be referred to in education settings, NICE clinical guidelines are unable to make direct recommendations to those in education and therefore we can not add this to the guideline.
University of Warwick	2	Full	2.5.2	General	In this section it needs to be clear that the behaviour of other people is a causal factor for challenging behaviour. Hastings et al.'s (2013) challenging behaviour model integrates this perspective within a framework including other variables described in the draft guideline. This is important because many interventions in practice focus on changing aspects of staff behaviour or changing variables hypothesised to be associated with staff behaviour. Reference Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., Noone, S. J., & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. International Journal of Positive Behavioural Support, 3 (2), 5-13.	Thank you for your comment, however the GDG feel the point you raised in sufficiently covered in this section.
University of Warwick	3	Full	3.5.3	General	Not all single case experimental designs (SCEDs) include a N of 1, thus there is a need to adjust the first sentence to clarify that N of 1 trials are not synonymous with SCEDs. There are several experimental SCEDs, not just ABA designs. For example, multiple baseline designs include multiple (control) comparisons. ABA designs are also typically referred to as reversal designs. Ethically, ABA designs are not usually suitable in the context of treatment studies for challenging behaviour since the person would be left in baseline conditions. It would be preferable to use the example of at least an ABAB design in	Thank you for your suggestions. We agree that this section could be improved and have amended taking into consideration what you suggested.

					this context. Also, although the term withdrawal design may be used more often in a medical research context, most challenging behaviour treatment studies would unlikely leave people with no treatment at all (implied perhaps by the term "withdrawal"). Please consider replacing withdrawal with "reversal". NB. "Reversal design" is used later in Table 77 so the guideline is currently inconsistent anyway.	
University of Warwick	4	NICE/ Full	1.1.1 /4.5	General	In the recommendations box – suggest re-wording of sentence. Replace: "develop a shared understanding about the function of the behaviour and what maintains it", with "develop a shared understanding about the function of the behaviour (what maintains it)". This edit is suggested because understanding function is understanding what maintains behaviour.	Thank you for your comment. The GDG agrees, and has removed 'and what maintains it'.
University of Warwick	5	Full	5	General	(Chapter 5 general comment) The interventions for carers (family and paid) reviewed in this chapter are not all focused on samples of carers of children or adults with learning disability and whose behaviour challenges. Although reviewing the general evidence for interventions for carers is likely useful, this limitation needs to be clearly acknowledged in drawing recommendations.	Thank you for your comment. The GDG did not feel this was a reason for downgrading the evidence, however did agree that section 5.4.1 should be updated to reflect this.
University of Warwick	6	NICE/Full	1.4.3/7.4	General	*Recommendations – number 19. Given the review in Chapter 8 of tools measuring frequency or severity of challenging behaviour, this recommendation would do better to forward-refer to that chapter rather than name two example measures/tools that have no basis for their selection. We appreciate that that these are listed merely as examples, but a full review is included in the guideline and so it makes sense simply to refer to that for detailed information.*	Thank you for this suggestion, but NICE recommendations do not usually refer to or cross-reference evidence in the full guideline. Doing so would make it very difficult for health and social care professionals to follow NICE recommendations.
University of Warwick	7	Full	8.5.2	General	Examples of tools are mentioned also in this section when it would be better to refer a reader to the full reviews of instruments.	Thank you for your comment. According to NICE methodology, recommendations should be clear, understandable by the intended audience without

						reference to the evidence reviews, and based on the best available evidence. The GDG believe that referring the reader to the full reviews would not meet this requirement or be helpful when health care professionals need clear guidance.
University of Warwick	8	Full	8	General	In the review of assessment methods for challenging behaviour, there is no mention of testing the reliability, validity and other psychometric properties of the experimental functional analysis procedure based on Iwata and colleagues' original 1982 methodology. Such a method might need to be used only in relatively rare circumstances to deliver the recommendations in the guideline on understanding a behaviour's function. However, analogue assessment is likely to be needed on rare occasions. In addition, analogue assessment has normally been the gold standard against which to evaluate other functional assessment tools/methods. So, to have no review and related recommendations on analogue assessment in the guideline is a significant omission.	Thank you for raising this issue. Section 2.5.2 addresses to some extent your comment, and section 8.3.1.3 provides the evidence that was identified in the search.
University of Warwick	9	Full	9	General	It is not clear why early intensive behavioural intervention/Lovaas intervention is included in Chapter 9. The primary outcomes, and purpose, for this intervention approach is to increase cognitive and adaptive behaviour outcomes for children with autism (whether or not they have learning disability). Behaviour problems may be measured in some studies as secondary outcomes. Review question 9.2 clearly states that interventions included should be those aimed at preventing behaviour that challenges. EIBI/Lovaas interventions do not have that aim. This is in contrast to Review Question 9.4 where the focus is addressing variables that may be associated with challenging behaviour. Therefore, interventions are relevant here that do not have the aim of preventing challenging behaviour explicitly.	Thank you for raising these issues. The review protocol set out the ideal research for answering the question. However, given the paucity of data, the GDG accepted that early behavioural interventions may provide useful evidence regarding prevention of behaviour that challenges (so although EIBI/Lovaas interventions are not aimed at preventing behaviour that challenges, the GDG felt they should be reviewed). In addition, the GDG recognised that improvements in adaptive functioning would be important and so accepted studies that only reported this outcome. As specified in the review protocol, RCTs or systematic reviews of RCTs were the preferred study design. The IPD meta-analysis by Eldevik et al. (2010) that you mentioned, included the two RCTs that the guideline included, but all other studies were non-

					There is even a study included in this chapter (Sallows) for which no outcome data on challenging behaviour are reported in the guideline. Adaptive behaviour outcomes are reported. If studies reporting cognitive or adaptive behaviour outcomes were in scope, this chapter does not explain why existing high quality systematic reviews and meta-analyses of EIBI (including a very rare Individual Participant Data Meta-Analysis) were not used to inform the guideline. The main problem is the inconsistency here. EIBI does not aim to reduce/prevent challenging behaviour.	randomised. We do not believe there has been inconsistency in the approach used in this chapter because we set out in the protocol that RCTs would be used where available. In addition, Eldevik et al., noted the limitations due to included non-randomised studies, and stated 'Thus, our results should be viewed as preliminary, and future researchers conducting meta-analyses will need to incorporate research quality selection criteria when the body of randomized studies available for analysis is larger.'
University of Warwick	10	Full	General	General	Positive Behaviour(al) Support [PBS] is used widely in services throughout the UK in health, social care, and education settings already and also widely internationally. Although PBS is mentioned briefly in the guideline document, some explicit statement(s) about PBS really need to be included in a definitive guideline about challenging behaviour. Recommendations in the guideline include reference to the use of behavioural approaches, functional assessment methodologies and the like. PBS does offer a framework that brings these recommended practices together in a coherent way and addresses core values such as stakeholder involvement/participation and the need to improve quality of life. The GDG's recommendations clearly indicate the need to offer a comprehensive and co-ordinated approach to "treatment"/support. Frameworks/approaches that address this aim ought to be dealt with in the guideline. A guideline on challenging behaviour that includes no explicit reference to PBS within its recommendations will cause confusion. We encourage the GDG to address this in an appropriate way within the full guideline's recommendations.	Thank you for your comment, following yours and others' comments more explicit reference to PBS has been added to the introduction to the full guideline.

Registered stakeholders: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0654/documents