National Institute for Health and Care Excellence

Challenging Behaviour in People with Learning Disability
Scope Consultation Table
7 May – 4 June 2013

No	Type	Stakeholder	ON o	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	SH	Challenging Behaviour Foundation	1	1	Change "people" to "children & adults" as "people" is usually used to refer to adults. Change "and challenging behaviour" to "who display challenging behaviour"	Thank you for your comment, the 'long title' for this guideline has been amended to include the term 'behaviour that challenges' and the guideline will use this term. 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. The term 'people' here refers to children, young people and adults.
2	SH	Challenging Behaviour Foundation	3	1	Change "people" to "children & adults"	Thank you for your comment, the term 'people' here refers to children, young people and adults
3	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	4	1	A better title in my view would be: Positive approaches to the prevention and management of challenging behaviour. It places the emphasis on proactive joint ownership of the problem rather than places the problem within the individual.	Thank you for your comment, the guideline will also review other procedures, such as medication and restrictive practices, so we think this would not reflect the broad range of approaches we will be considering.
4	SH	South Essex Partnership NHS Foundation Trust	2	1	"What about saying behaviour that challenges? I think it is about making clear the behaviour is a challenge to services otherwise the person is likely to be viewed as a problem."	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' 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.
5	SH	Challenging Behaviour Foundation	2	1.1	Change "people" to "children & adults"	Thank you for your comment, the term 'people' here refers to children, young people and adults
6	SH	National Development Team for Inclusion	1	1.1	There should be recognition that the term 'challenging behaviour', although originally intended to emphasise the environmental and support issues for an individual, is now sometimes used as a label, and so the term, 'people with behaviour that challenges services' is	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' throughout, as this guideline will address behaviour that also challenges families and carers as well as services.

					often used instead. Failure to recognise this could perpetuate the labelling of disabled people – thus affecting their equality of opportunity.	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.
7	SH	Royal College of Nursing	2	1.1 Short Title	There has been a growing trend in recent years to label people with a learning disability as having challenging behaviour as though this were a fault the person had and that it was a pseudo clinical diagnosis. It is not a diagnosis; the term was coined to mean behaviour that challenged us the carers/supporters. Thus it is suggested that the short title be changed to read *Challenging behaviour AND people with a learning disability* (rather than *IN*) Thus the terminology CB will still emerge from an Internet search but by using the word AND it is less reinforcing of the pseudo diagnosis label.	Thank you for your comment, the guideline title has been amended to reflect your suggestion.
8	SH	Royal College of Psychiatrists	1	1.1	The Royal College now prefers the term Intellectual Disability and not Learning Disability. This may need further discussion.	Thank you for your comment. The term 'learning disabilities' is a term which is well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
9	SH	Royal College of Speech and Language Therapists	1	1.1	We believe that 'Challenging Behaviour (CB) is not 'in' people, and this language is therefore unhelpful. People with learning disability are at risk, however, of having their CB understood as being located in their body, leading to those behaviours being associated with the impairment (e.g. Goodley, 2001). This risks further reifying the social construct 'CB' as an illness or 'health problem' located in a person who requires treatment. We would suggest it is not at all clear CB is indeed an illness or 'health problem'.	Thank you for your comment, the scope has been amended to reflect your suggestion and now uses the term 'behaviour that challenges' 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.
10	SH	Southern Health NHS Foundation Trust	5	1.1	Our comments are as follows… replace 'in' with 'and'. This reflects the longer guideline title. Using 'in' places challenging behaviour within the person. Challenging Behaviour is not a diagnostic term and has no classification criteria. DSM & ICD manuals use the term problem behaviour which is a different term .	Thank you for your comment, the guideline title has been amended to reflect your suggestion.
11	SH	Cumbria Partnership NHS Trust	2	3.1	Our comments are as follows: In view of the increasing shift towards the use of the term 'intellectual disability' (internationally; in research; and also the UK RCP adoption of term 'psychiatrist in intellectual disability') might it be more appropriate to review the use of the term 'learning disabilities' especially in view of its confusion with learning difficulties.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
12	SH	Oxleas NHS Foundation Trust	4	3.1	We feel within the epidemiology section reference should be made to offending behaviour, its prevalence, relationship/distinction with challenging behaviour.	Thank you for your comments, the scope has been amended to reflect this.
13	S	South Essex	3	3.1	"Thank goodness learning difficulties are clearly not the same as	Thank you for your comments, the scope has been

	H	Partnership NHS Foundation Trust			learning disabilities." Communication is of huge importance when discussing behaviours that challenge – does this need more emphasis in in the guideline – what is the person saying?	amended to reflect this.
14	S H	Tees Esk and Wear Valley NHS Foundation Trust	4	3.1	A reference in the epidemiology section encouraging services to focus on the individual needs of people with learning disabilities rather than groupings (mild, moderate etc) would help to avoid often erroneous assumptions being made about individuals. The Trust feel improvement has been made in this subsequent draft.	Thank you for your comments, the scope has been amended to reflect this.
15	S H	Betsi Cadwaladr University Health Board	2	3.1 e	Emotional and behavioural clarity needed, anger is not an observable behaviour as are other behaviours listed	Thank you for your comment, this has been removed.
16	S H	South Essex Partnership NHS Foundation Trust	8	3.1 a	"Definition of learning disability is precise, concise and clear."	Thank you for your comment.
17	S H	Southern Health NHS Foundation Trust	6	3.1 a b	Learning Disability should be more clearly defined e.g. WHO definition. The definition used here does not match BPS definition of Learning Disability which recommends differentiating between 'Significant' and 'Severe'. . 'May only need support in certain areas' needs some clarification. The level of support required will vary depending on a variety of factors, one of which may be IQ.	Thank you for your comments, the scope has been amended to reflect this.
18	S H	British Psychological Society	3	3.1 b	The classification of 'learning disability' is a complex and contentious one. The Society welcomes the attempt to describe the difficulties of accurately assessing people's IQ. We suggest adding a reference to the Society publication *Definitions and Contexts*, British Psychological Society, 2000. In this report, it is recommended "*That, in accordance with the various definitions, classification learning disability should only be made on the basis of assessed impairments of both intellectual and adaptive/social functioning which have been acquired before adulthood."* Accordingly, we suggest an addition to the first sentence: *The degree of learning disability is usually defined by the following IQ scores: mild = 50 – 69, moderate = 35 – 49, and profound = under 20,* ***but this should also include a measure of the person's social or adaptive functioning.*** *A person…..*	Thank you for your comment, the scope has been amended to reflect your suggestions.
19	S H	Nottinghamshire Healthcare NHS Trust	2	3.1 b	Re; degree of ID. These IQ classifications are not identified or named in either the WAIS-IV manual or in the British Psychological Society's advice; and schools for relatively able pupils being termed 'mild and	Thank you for your comments, the scope has been amended to reflect this.

					moderate' has resulted in somewhat different conventions in Education and the NHS. The terms still appear to be potentially useful but need to specify according to which criteria.	
20	SH	Nottinghamshire Healthcare NHS Trust	3	3.1 b	Need to acknowledge the significant vulnerability of people with mild LD and challenging behaviour and links with undiagnosed speech, language and communication needs. If communication difficulties are not diagnosed then they will not be included in interventions for that person. Evidence in the 'grey' literature suggests that children may be misdiagnosed as having a conduct disorder or mental health problem when in fact they have an undiagnosed SLCN: Lanz, R. Speech and language therapy within the Milton Keynes YOT, a four month project. 2009	Thank you for your comments, the scope has been amended to reflect this.
21	SH	Oxleas NHS Foundation Trust	1	3.1 b	Within our psychology service they were concerned that sub-classifications of learning disabilities were being used which cannot be measured accurately- although these are widely used it feels important that are not used within this guidance to direct practice. The classifications used by the BPS are more reliable but would be similarly unhelpful in directing a service response to CB.	Thank you for your comments, the scope has been amended to reflect this.
22	SH	Royal College of Psychiatrists	2	3.1 b	Most children do not have their IQ assessed, they are mostly assessed and their abilities levels described in terms of centiles compared to a typically developing child of the same age. Child with a learning disability usually function below the second centile for overall functioning.	Thank you for your comments, the scope has been amended to reflect this.
23	SH	Royal College of Speech and Language Therapists	3	3.1 b	Regarding degrees of ID: these IQ classifications are not identified or named in either the WAIS-IV manual or in the British Psychological Society's advice; and schools for relatively able pupils being termed 'mild and moderate' has resulted in somewhat different conventions in Education and the NHS. The terms still appear to be potentially useful but it must be clear which criteria is being used.	Thank you for your comments, the scope has been amended to reflect this.
24	SH	Royal College of Speech and Language Therapists	4	3.1 b	We would stress the need to acknowledge the significant vulnerability of people with mild LD and challenging behaviour and the links with undiagnosed speech, language and communication needs. If communication difficulties are not diagnosed then they will not be included in interventions for that person. There is evidence that children may be misdiagnosed as having a conduct disorder or mental health problem when in fact they have an undiagnosed SLCN (Lanz, 2009). Lanz, R. Speech and language therapy within the Milton Keynes YOT, a four month project. 2009	Thank you for your comments, the scope has been amended to reflect this.
25	SH	Surrey County Council Adult Social Care	1	3.1 b	Suggest that the Valuing People definition of Learning disability is more useful than that based on IQ: "A significantly reduced ability to understand new or complex	Thank you for your comment. We considered using this definition but felt it was not specific enough and would result in an over-classification of people as having learning

					information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development."	disabilities.
26	SH	Nottinghamshire Healthcare NHS Trust	1	1.3c Title	We advocate name change from LD to ID. Acknowledge that users and carers have not yet had the reasons for another name change explained and so their initial response is to resist moving to ID, but we do not accept the argument that the is no problem in in retaining accustomed British usage independent of international trends. International terminology is dominant. Confusion is generated by people looking up 'LD' on the internet and finding specific impairments such as dyslexia defined in the context of normal intelligence. Stating that in the UK 'LD' does not mean dyslexia in 1.3.c will not address the confusion experienced by members of the public and students alike: continuing increased use of American English in the UK (most recently 'shows' rather than plays, 'stores' rather than shops etc) is clearly evident.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
27	SH	British Psychological Society	4	3.1c	The Society welcomes the distinction made in the scoping document between learning disabilities and learning difficulties and the intent to emphasise that the scope does not relate to the later. However we suggest that in the guideline the distinction is made even clearer by using the commonly used term "specific learning difficulties" i.e. *Learning disabilities are different from **specific** 'learning difficulties' like dyslexia, which do not affect intellectual disability.*	Thank you for your comment, the scope has been amended to reflect your suggestion.
28	SH	Royal College of Psychiatrists	2	3.1c	Some agencies use the terms Learning Disability and Learning Difficulties interchangeably. We may need to properly define terminology e.g. specific learning difficulties	Thank you for your comment, the scope has been amended to reflect your suggestion.
29	SH	Royal College of Speech and Language Therapists	2	3.1c	We would welcome exploration of the relative usefulness of ID against LD in considering the scope of this consultation. We acknowledge that users and carers have not yet had the reasons for another name change explained and so their initial response is to resist moving to ID, but we are not persuaded by the argument that there is no problem in in retaining accustomed British usage independent of international trends, given the dominance of international terminology in online resources and other sources frequently accessed by users.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
30	SH	Sheffield Clinical Commissioning Group	1	3.1c	Welcome the inclusion of the definition of learning disability as distinct from learning difficulty, as a consistent message	Thank you for your comment.
31	SH	Southern Health NHS Foundation	7	3.1c	There is also a need to separate Learning Disability from Learning Difficulty and Educational definitions more clearly . Diagnosis will an impact on access to services.	Thank you for your comments, the scope has been amended to reflect this.

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32	SH	Hounslow and Richmond Community Healthcare Trust	1	3.1 d	Using the term commonly known as "*Learning Disability*". Intellectual and Developmental Disability / Disorder is becoming more the accepted norm. Surely NICE guidance should lead by example and ensure that the most up to date understanding is described - and therefore use IDD rather than 'settling' for a common term. If this approach was always used, then we would still be using terminology such as 'mental retardation; or worse'. Just because something is commonly used, does not mean that it should not change.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
33	SH	Linkage Community Trust	1	3.1 d	We agree that the terms 'intellectual disability' or 'intellectual development disorders' are more appropriate than 'mental retardation'.	Thank you for your comment. 'Mental retardation' would not be used in any NICE guidelines. This guideline will use the term 'learning disabilities', a term which is well understood by professionals in the UK.. The Scope (section 3.1b) has been amended to better reflect this.
34	SH	Royal College of General Practitioners	1	3.1 d	It is helpful to have background and description of use of term learning disabilities that will be used in guideline	Thank you for your comment.
35	SH	Royal College of Psychiatrists	3	3.1 d	Intellectual Disability is now the more accepted term and has much more specific meaning.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
36	SH	Southern Health NHS Foundation Trust	8	3.1 d	'A significantly reduced ability to learn new skills' does not only apply to Severe / profound learning disability. It would be helpful to make reference to the broad range of terms that are used to refer to Learning Disability, including the term 'Intellectual Disability' to be used in DSMV and DSM11. There was no consensus on whether Intellectual Disability should be used in this document with arguments for (consistency of terminology with diagnostic manuals / international term, clearer distinction with Learning Difficulties) and against (difficulty of Service Users / families / carers adopting another term, more descriptive, appropriate term and is accepted) . What - ever definition is used it needs to be referenced and reason for using chosen definition given. The same definition needs to follow through the whole document.	Thank you for your comment. The term 'learning disabilities' is a term which is also well understood by professionals in the UK, and these are UK guidelines. The Scope (section 3.1b) has been amended to better reflect this.
37	SH	Betsi Cadwaladr University Health Board	3	3.1 e	There are more recent definitions of challenging behaviour such as the definition taken from Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices.*	Thank you for your comment. Whilst we agree that the definition of challenging behaviour given in *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices* is a useful one, the definition given by Emerson and colleagues is broader and more culturally inclusive. The

						scope has, however been amended to include reference to the parts of the U*nified approach* definition that the Emerson definition did not include.
38	SH	British Psychological Society	5	3.1 e	The definition of challenging behaviour used currently in the scope is that of Emerson and colleagues from 1995. This definition was further developed in the 'Challenging Behaviour: A Unified Approach' report (RCPsych, BPS, RCS&LT, 2007) to emphasise the quality of life of the person and physical safety of those around them, as well as incorporating the response around the person. Given the context in which these guidelines have been developed, post Winterbourne View, we recommend that this definition is used instead: ***"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 is likely to lead to responses that are restrictive, aversive or result in exclusion".*** (p.14)	Thank you for your comment. Whilst we agree that the definition of challenging behaviour given in *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices* is a useful one, the definition given by Emerson and colleagues is broader and more culturally inclusive. The Scope has, however been amended to include reference to the parts of the U*nified approach* definition that the Emerson definition did not include.
39	SH	Dimensions	1	3.1 e	Anger shouldn't be listed as a type of challenging behaviour. Anger can manifest itself as challenging behaviour but is not observable in and of itself.	Thank you for your comment, this has been removed.
40	SH	Hounslow and Richmond Community Healthcare Trust	2	3.1 e	*"anger"* - this is not an external behaviour but a descriptor of an internal state; and therefore should not be included in this list. *"aggression"* - this should be more topographically defined, at least as "aggression towards others"	Thank you for your comment, this has been removed.
41	SH	Luton and Dunstable Hospital NHS Trust	1	3.1 e	Challenging behaviour is also a form of communication for anyone (whether or not the person is non-verbal) - we need to be more vigilant as to what the individual is trying to tell us e.g. are they in pain or feeling physically unwell?	Thank you for your comment. We recognise this. Communication is referred to in the scope in sections 3.1 d), k), 3.2 b) and 4.3.1 a) b) and c).
42	SH	Northumberland Tyne and Wear NHS Trust	2	3.1 e	It was suggested that the Emerson definition (1995) has been modified in the 2007 'unified approach' joint document to include '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 of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.' It therefore may be important to emphasise the later part of the revised definition).	Thank you for your comment, whilst we agree that the definition of challenging behaviour given in *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices* is a useful one, the definition given by Emerson and colleagues is broader and more culturally inclusive. The Scope has, however been amended to refer to the later part of the U*nified approach* definition, as you suggest.

43	SH	Oxleas NHS Foundation Trust	2	3.1 e j	A general concern that priority might be given to internal factors in the guidance. All relevant research and theoretical models emphasise the importance of environmental factors in challenging behaviour. It would be our view that this guidance in particular should be highlighting the weakness of the medical and psychiatric model at understanding and treating challenging behaviour.	Thank you for your comment. This guideline will address environmental factors, as outlined in sections 4.3.1 a), b) and c).
44	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	5	3.1 e	It is important to note that not all challenging behaviours are overtly action based. Some “silent” behaviours can also challenge such as extreme social withdrawal and selective mutism. These are particularly important when considering individuals with ASD or more physically weak/anxious individuals (perhaps living in abusive environments) who do not dare communicate distress in a manner that may provoke others.	Thank you for the comment. We are deliberately using the Emerson definition of challenging behaviour to reflect this.
45	SH	Royal College of Psychiatrists	4	3.1 e	The use of the term “Challenging Behaviour” is controversial and although widely used is not like by some practitioners because it can be seen as simplifying a very complex condition.	Thank you for your comment, the scope has been amended to use the term ‘behaviour that challenges’ 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.
46	SH	South Essex Partnership NHS Foundation Trust	9	3.1 e k	"Challenging behaviour as a product of interaction between individual and environment is well-known among practitioners and/or carers. However, many tend to take it literally and/or have limited concept of what the term “Environment” entails. NICE should display bravado in specifying the different aspects of the environment, such as “Social environment”, “Physical environment” and “Emotional environment”. Such a differentiation would allow practitioners and carers more scope to intervene in challenging behaviour field."	Thank you for your comment, we agree that these are important issues and the social, physical and emotional environments are addressed in 3.1 l). We have amended this section to clarify.
47	SH	South Essex Partnership NHS Foundation Trust	10	3.1 e	"It is reassuring that NICE uses the phrase “The currently flavoured definition of challenging behaviour …” rather than “The definition of challenging behaviour…”. Many practitioners have the tendency to use and place all their faith in Emerson’s definition. However, such a definition is significantly restrictive in terms of intervention in the field of challenging behaviour. It just tells us about the various types of challenging behaviour and their potential impacts. It does not tell us as to what cause or influence it. There are definitely other lesser-known definitions (such as “Challenging behaviour is a mean of communication” by Jill Bradshaw 1998 and “Behaviour that challenge inadequate services” by TASH) that provide a better understanding of challenging behaviour and a more humanistic model of assessment and intervention in the field of challenging behaviour."	Thank you for your comment. The Emerson definition is not intended to define causes. We have made sure that we have referred to a variety of causes and ensured that we have referred to inadequate environments as well as other causes.
48	SH	Southern Health NHS	9	3.1 e	Challenging Behaviour is a social construct that needs to be explained. This section is very diagnostic and does not address the social	Thank you for your comment. The scope has been amended to clarify this point.

		Foundation Trust			construction of the term. Challenging Behaviour needs to be understood as something that is multi-faceted – understanding behaviour in context with the individual and their environment needs to explored in more detail and should be a key theme throughout the document. It would be helpful to include a definition of behaviour. Emerson's definition doesn't acknowledge the impact of developmental stages on behaviour and is limited in it's focus. Models of Intensive Support provide broader definitions of behaviour. To whom behaviour is challenging needs to be explored – i.e. behaviour can be more challenging to services that the individual themselves. The examples of challenging behaviour are limited – does not include e.g. withdrawal / difficult to engage Alternative definitions need discussing – 'Unified Approached' presents a useful discussion of alternative definitions.	
49	S H	Surrey County Council Adult Social Care	2	3.1 e	It is not appropriate to include stereotypic behaviour such as rocking or hand flapping in a list of challenging behaviour. These may be coping mechanisms for people on the autism spectrum, and should not be subject to behavioural interventions to reduce or eradicate them.	Thank you for your comment. These behaviours may be coping mechanisms but we would argue they still need to be recognised as a challenge. For example, if they occur in response to excessive noise or unplanned schedules, interventions may be needed. We are not implying that the individual is the 'target' of the intervention. The target may very well be the social or physical or emotional environment.
50	S H	British Psychological Society	6	3.1 f	The Society believes that this paragraph, emphasising that challenging behaviour is not a diagnosis is important and helpful. . We suggest that this could be further developed for inclusion in the guideline by adding to the third sentence (in line with the Mansell Report, DH, 2007, 7), as follows: *It is a socially constructed concept* ***that is the product of individual and environmental factors interacting together. In order for behaviour to be considered' challenging', it is necessary to take account of the environment in which it is occurring, its impact on others, and the capability of the staff/carers to support the person in that environment.***	Thank you for your comment. This phrase has been added.
51	S H	Rotherham, Doncaster and South Humber NHS Foundation Trust	6	3.1 f	Two full stops at the end of the paragraph.	Thank you, this has been amended.
52	S H	Royal College of General Practitioners	2	3.1 f	This section mentions cultural differences and could be expanded to ensure good coverage of this area and demonstrate detailed understanding of equality and diversity issues.	Thank you for your comment. This is felt to be sufficient for the Scope but will be extended in the Guidelines.
53	S	Sheffield	2	3.1	Welcome the reminder of the definition of challenging behaviour as a	Thank you for your comment.

	H	Clinical Commissioning Group		f	“socially constructed concept”	
54	SH	South Essex Partnership NHS Foundation Trust	11	3.1 f	"Good for NICE to remind practitioners that the terminology “challenging behaviour” is man-made. As such, it can be interpreted differently by different people at different times in different settings."	Thank you for your comment.
55	SH	Southern Health NHS Foundation Trust	10	3.1 f	Sentence beginning ‘Never the less, Challenging Behaviour…..’ is not necessary. The key point here is that behaviour may change according to the environment and may have a different cause / function depending on that environment.	Thank you for your comment. We felt the need for this sentence because otherwise ‘behaviour that challenges’ sounds very nebulous, whereas in reality severely challenging behaviour is not something that is nebulous.
56	SH	Hounslow and Richmond Community Healthcare Trust	4	3.1 g	"*prevalence rates of 10-15%".* This needs more clarification and exact defining - for example, Emerson et al (2001) have shown a 5-10% prevalence of more severe and demanding behaviour that challenges; yet Poppes et al (2010) found up to 82% in people with profound and multiple learning disabilities. *"higher rates in hospital settings"* - some studies have not found this, and again is a broad statement that does not reflect the research in totality.	Thank you for your comment. We are aware that a great variety of rates can be found according to the definitions used. The scope has been amended to widen the range quoted. Rates for specific populations have deliberately not been quoted (e.g. those with profound and multiple disabilities) but used rates that come from surveys of total populations of people with learning disabilities (though aware of the limitations of these surveys). We have clarified what we mean by hospital settings.
57	SH	Royal College of Nursing	3	3.1 g	We would take issue with the use of the phrase “*Challenging behaviour is relatively common among people with learning disabilities*”. This also conveys the impression to the casual reader that CB is common place when in fact only a small percentage may use CB at any one time. We would suggest that the phrase be amended to read ‘*Challenging behaviour is relatively SIGNIFICANT among people with a learning disability.’*	Thank you for your comment. We have given the range of prevalence rates and feel this is the best guide at present.
58	SH	Southern Health NHS Foundation Trust	11	3.1 g	Statistics need to be backed by with evidence. Prevalence amongst cultural / ethnic groups has not been addressed ‘Substantially higher rates are found in hospital settings than in community settings’ this sentence needs clarity. Correlations between age and Challenging Behaviour needs to be broadened e.g. recent correlation between Mental health and gender. Are you referring to In-Patient Hospital Settings or acute hospital settings? Training needs of hospital (acute) staff need to be recognised. Reasons for higher rates needs explaining….the reason people are admitted to In-Patient hospitals is often for CB…the hospital is not a cause of the behaviour. Needs to be backed up with evidence.	Thank you for your comments. This has been clarified in the scope. It does not state that hospitals cause higher rates.
59	SH	British Psychological Society	7	3.1 h	We suggest that the bracketed phrase, (*IQ of less than 20)* is removed as the debate about the definition is described in section 3.1.b.	Thank you for your comment. The wording has been adjusted.

60	SH	Hounslow and Richmond Community Healthcare Trust	5	3.1 h	*"aggression"* - this should be more topographically defined, at least as "aggression towards others" *"serious physical disabilities that limit levels of challenging behaviour".* - however SIB (self-injurious behaviour) has increased rates in those people with a profound and multiple intellectual and developmental disability.	Thank you for your comment. The wording has been adjusted.
61	SH	Southern Health NHS Foundation Trust	12	3.1 h	Correlation between Challenging Behaviour and LD is not helpful. This does not support social construction of Challenging Behaviour. There needs to be a greater emphasis on challenges to services and how they are supported to meet needs.	Thank you for your comment. All the research shows a relationship between degree of LD and behaviour that challenges. It does not mean it is not socially constructed.
62	SH	Northumberland Learning Disability Partnership Board	3	3.1 i	Local area and national estimates of current and future numbers show that people with learning disabilities are living longer than previously. Trends in increasing longevity and most significantly an expected increase in adults aged 65 and over predicted to have a moderate or severe learning disability highlight two issues for consideration: • More young people are anticipated to transfer from children's services with complex needs and challenging behaviours. • More people with a learning disability are also affected by dementia, which potentially could lead to a future increase in challenging behaviour with age when linked to early onset dementia so recognition of this has significance.	Thank you for your comment. The wording has been adjusted.
63	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	7	3.1 i	See comment 241 for inclusion of environment & mediators	Thank you for your comment. The wording has been adjusted.
64	SH	Royal College of Psychiatrists	3	3.1 i	We need to consider what is developmentally appropriate and behaviour that has been present for a long time may not be considered challenging until a child grows i.e. becomes an adolescent.	Thank you for your comment. The wording has been adjusted.
65	SH	Southern Health NHS Foundation Trust	13	3.1 i	Difficulties experienced during transitions during adolescence need to be considered in more details – physical, hormonal, changes between service providers, changes daily activities school – college etc. There is a general need for transitions to managed and coordinated effectively.	Thank you for your comment, we agree that this is an important area and transition has been added to the scope.
66	S	The Elfrida	2	3.1	Please explore the correlation between sexual frustration and CB (not	Thank you for your comment. This will be taken into

	H	Society		i	just during adolescence and young adulthood but in late years) as many PWLD are denied the right to have any type of relationship (emotional, affectionate and/or sexual)	account in the Guidelines.
67	SH	British Psychological Society	8	3.1 j	We believe that the use of the word *cause* in this and subsequent sections is incorrect as there is not a causal link as such. Instead we suggest amending the sentence to: *There are likely to be a number of underlying* ***factors that contribute to the likelihood of*** *challenging behaviour….*	Thank you for your comment. The wording has been adjusted.
68	SH	College of Occupational Therapists	4	3.1 j	In this section, we felt it important to acknowledge that one of the key underlying causes for challenging behaviour can be lack of meaningful occupation. We also felt it important to mention sensory processing disorders here, separate and distinct from sensory impairment.	Thank you for your comment. The wording has been adjusted.
69	SH	Hounslow and Richmond Community Healthcare Trust	3	3.1 j	It is really great that it has been stated that "challenging behaviour is not a diagnosis" and is a "socially constructed concept". It will be important to keep this element in mind throughout the guidance. However, the label 'challenging behaviour' by its very word structure places the locus internally to the person. This is why most professionals in the field now use the term "behaviour that challenges" - a description that places the locus external to the person, and therefore does not reflect a diagnosis. It would be helpful to use this phrase throughout the guidance.	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' 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.
70	SH	Hounslow and Richmond Community Healthcare Trust	6	3.1 j	*"underlying individual causes to challenging behaviour"* - rather than causes, should be considered as "factors contributing to". 'Cause' suggests too strong a relationship rather than considering predispositions, learning histories, current environmental stimuli etc. "*psychological trauma, and attachment difficulties"* - these are very broad terms and should be more clearly defined when discussing in terms of causes for behaviour that challenges and intellectual and developmental disabilities.	Thank you for your comment. The wording has been adjusted.
71	SH	Northumberland Tyne and Wear NHS Trust	3	3.1 j	The list given as possible underlying causes is misleading. These may be contributing factors but they do not cause the behaviour. Lots of people have communicating problems and sensory difficulties etc without presenting challenging behaviour. The list refers to vulnerability factors that increase the likelihood that behaviours that others deem challenging begin to serve a function for an individual under particular circumstances.	Thank you for your comment. The wording has been adjusted.
72	SH	Optical Confederation	2	3.1 j	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. (1) (5)	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.
73	S	Oxleas NHS	3	3.1	Within the guidance we feel more emphasis should be placed on the	Thank you for your comments, the scope has been

	H	Foundation Trust		j	communication needs of the individual, how this assessed and the importance of communication based interventions with the range of individuals and environments the person will have contact with.	amended to reflect this.
74	S H	Queen's University Belfast	1	3.1 j	In this point it is stated that *"There are likely to be a number of underlying individual causes to challenging behaviour in people with learning disabilities, including communication difficulties, sensory impairments, physical or mental health problems, neuropsychiatric disorders, pervasive developmental disorders, phenotype-related behaviours, psychological trauma, and attachment difficulties."* Communication difficulties can be an underlying cause of challenging behaviours, since individuals that cannot express their needs may exhibit challenging behaviours if this leads to having their needs met (independently of the nature of the needs, which could be sensory, tangible, social, etc.). Therefore, the condition of having a diagnosis of a Pervasive Developmental Disorder would not explain by itself the exhibition of challenging behaviours, and there are of course individuals with this diagnosis who do not exhibit challenging behaviours. Consequently, the key point as far as causes of challenging behaviours are concerned is not the diagnostic category but the specific behaviours that have led to this diagnosis, such as the lack of communication or social skills. The lack of specific skills and the presence of other behaviours in excess are the antecedents that trigger challenging behaviours and environmental factors that serve as both antecedents and consequences also play a major role.	Thank you for your comments, the scope has been amended to reflect this.
75	S H	Rotherham, Doncaster and South Humber NHS Foundation Trust	8	3.1 j	Could be expanded to include how quality of life is affected. 1. Presence 2. Choice 3. Participation 4. Respect 5. Competence O'Brien's five accomplishments (1987)	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.
76	S H	Royal College of Psychiatrists	5	3.1 j	Abuse should be added in as a possible underlying cause.	Thank you for your comment, the scope has been amended to reflect your suggestion.
77	S H	South Essex Partnership NHS Foundation Trust	1 2	3.1 j	"Service users, like anybody else, have feelings and thoughts. However, many of them have difficulties in recognising, expressing and managing their emotions. Consequently, they display challenging behaviour to express themselves. As such, "Emotional difficulties" should be one of the focal point in this section (even though it is mentioned in section 3.1 (l))"	Thank you for your comments, the scope has been amended to reflect this.
78	S	Southern	1	3.1	Evidence for causative links is weak.it isn't automatic that one thing	Thank you for your comments, the scope has been

	H	Health NHS Foundation Trust	4	j	causes another. What is important is the need to understand why behaviours occur. Factors that can contribute to behaviours occurring need to include transitions, emotional developments, medication, abuse, lack of stimulation, institutional environments staffing ratios and communication as a form of behaviour. There is a lack of a personal perspective. Behaviours that challenge service may be a way of expressing choice by the individual. An emphasis should be on the social construction not cause.	amended to reflect this.
79	S H	British Psychological Society	9	3.1 k	This paragraph, emphasising the role of the environment, is a helpful addition. We would like to amend the 2nd and 3rd sentences to read, incorporating a quote from Mansell 2007, 7: *… In particular, the social environment has a major effect on rates of challenging behaviour,* ***and where individuals with problems are cared for in environments that do not respond well to their needs, challenging behaviour is likely to develop.*** *For example, carers or staff may* ***influence the occurrence of*** *challenging behaviour by providing or removing….*	Thank you for your comment, the scope has been amended to reflect your suggestion.
80	S H	Hounslow and Richmond Community Healthcare Trust	7	3.1 k	Behaviour should be described here in terms of function (as scientifically found within the field of Applied Behaviour Analysis). This has been alluded to through the descriptions provided, but not clearly stated. For example, "other aspects of the environment" - this is clearly talking about he sensory function; but not using the terminology widely accepted within the field. Clear reference should be made to both antecedents and consequences.	Thank you for your comments, the scope has been amended to reflect this.
81	S H	Nottinghamshire Healthcare NHS Trust	4	3.1 k	From communication perspective this refers to social environment having major effect on CB and gives egs in terms of presenting or removing certain factors. This could also focus on quality of social interaction and use of interactive approaches.	Thank you for your comments, the scope has been amended to reflect this.
82	S H	Optical Confederation	3	3.1 k l	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 comments, the scope has been amended to reflect this.
83	S H	Real Life Options	1	3.1 k	We would want to see in this clause an addition regarding the importance of the 'attitudes, perceptions and beliefs of care staff working with adults', as we believe this is significant.	Thank you for your comments, the scope has been amended to reflect this.
84	S	Royal College	5	3.1	From a communication perspective the question refers to the social	Thank you for your comments, the scope has been

	H	of Speech and Language Therapists		k	environment having a major effect on CB but only as a function of presenting or removing certain factors. We would suggest it should also focus on the quality of social interaction (and use of interactive approaches). See reference document below.	amended to reflect this.
85	SH	Southern Health NHS Foundation Trust	15	3.1 k	Sentence beginning ' carers or staff may alter……. Focus should be given to understanding the nature and function of behaviour and improving quality of life, not just changing the behaviour. The impact of abuse is not considered. A paragraph on historical context may be useful – looking at the impact of institutional environments, the move from long term hospital environments to community settings changes in philosophy of care, and the impact of environments / models of care on behaviour. Environmental Risk Factors include abuse, poor staffing, neglect, abuse, lack of choice and / or control in daily lives, hate crime, lack of access to appropriate opportunities, poverty, loneliness, lack of meaningful relationships, isolation, lack of meaningful activities and valued roles, cultural / ethnic barriers, family relationships and understanding these within different cultural groups, transitions (major or minor), lack of employment opportunities, lack of appropriate services, realistic models of care and impoverished environments.	Thank you for your comments, the scope has been amended to reflect this.
86	SH	Dimensions	2	3. 1 l	It's often seen as more accurate to say 'functional behavioural analysis' rather than just 'functional analysis' because of the term now being used in other sectors, rather than solely learning disability	Thank you for your comment. We think this will be understood.
87	SH	British Psychological Society	10	3.1 l	As described in comment 10 above, we suggest that this is reworded to: *The **factors that contribute to the likelihood** of challenging behaviour for any one person….*	Thank you for your comment, the scope has been amended to reflect your suggestion.
88	SH	Hounslow and Richmond Community Healthcare Trust	8	3.1 l	"*functional analyses may be needed*" - this approach is the only evidence based method of understanding and intervening with behaviour that challenges and intellectual and developmental disabilities. Should perhaps say instead "functional analysis should be undertaken to identify the relevant factors for a person"	Thank you for your comment. We do not think this is the only approach so we have kept the wording as it is.
89	SH	Sheffield Clinical Commissioning Group	3	3.1 l	Welcome the reminder that functional analysis is a requirement relating to the multifactorial causes	Thank you for your comment.
90	SH	Southern Health NHS Foundation Trust	16	3.1 l	Why is functional analysis in the context	Thank you for your comment, we are not quite sure what you mean by this but have reworded various sections to clarify.
91	S	British	1	3.1	The word 'cases' may be viewed as a disparaging term by some	Thank you for your comments, the scope has been

	H	Psychological Society	1	m	people. It is suggested that the sentence is rephrased to read: *….In the most extreme **instances**, it may become difficult to take the person out of the house into the community. …*	amended to reflect this.
92	SH	Hounslow and Richmond Community Healthcare Trust	9	3.1 m	Clarity regarding "restrictive environments" needs to be made. If it is difficult to take the person out of the house into the community - then this is by definition a restrictive environment - not an open environment that they are then sent away from into a restrictive environment for years. Perhaps this should read instead - Behaviour that challenges affects the quality of life.... because it puts them at risk of restrictive practices (including physical, mechanical, environmental and chemical restraint).	Thank you for your comments, the scope has been amended to reflect this.
93	SH	Royal College of Speech and Language Therapists	6	3.1 m	We would suggest that an individual being sent to a restrictive environment in which to live is not a function of challenging behaviour but of commissioning practice.	Thank you for your comments, the scope has been amended to reflect this.
94	SH	Southern Health NHS Foundation Trust	17	3.1 m	Sentence 'they may be sent to ……' It should be recognised that living at home, within community settings can be restrictive environments…it is not a case of being sent to a restrictive environment.	Thank you for your comments, the scope has been amended to reflect this.
95	SH	Royal College of Speech and Language Therapists	7	3.2	We would call for 'continuing healthcare' funding to be included as a relevant consideration for understanding current practise.	Thank you for your comment. The wording has been adjusted.
96	SH	Royal College of Speech and Language Therapists	8	3.2	Communication assessments need to be detailed here as a significant aspect of current practice. Communication difficulties are associated with increased prevalence of challenging behaviour (Enderby et al 2009). A communication assessment will be part of the multi-disciplinary approach in line with best practice (e.g. Challenging Behaviour a Unified Approach, Banks and Bush, 2007; RCSLT Position Paper 2010) and will invariably be necessary at some stage, comprising consideration of the communication skills of the individual, their communication environment (including all people with whom they might have interaction) and the ways in which their communication skills are utilised within their daily lives. Communication assessment will include formal and informal speech, language and communication assessments, talking to key people involved with the clients care, and observing the person in their everyday environment. The environment itself will also be assessed, as many interventions involve altering the communicative environment, including both physical and human factors (Kelly, 2002). Such assessments should also include an assessment of hearing ability where appropriate, as hearing difficulties are prevalent in the learning disability population, but often go undiagnosed and therefore unrecognised Miller and Kiani, (2008).	Thank you for your comment. The wording has been adjusted.

					Enderby, P, Pickstone, C. John, A. Fryer, K. Cantrell, A. Papaioannou, D. (2009*) Resource Manual for Commissioning and Planning Services for Speech Language and Communication Needs*. London: Royal College of Speech and Language Therapists Kelly A. (2002). *Working with adults with a learning disability.* Speechmark. Oxon, Miller, H. Kiani, R (2008) "Inter-relationships between hearing impairment, learning disability services and mental health: are learning disability services 'deaf' to hearing impairments?", Advances in Mental Health and Learning Disabilities, Vol. 2 Iss: 2, pp.25 – 30, RCSLT (2010) Adults with Learning Disabilities: Position Paper. Royal College of Speech and language Therapists	
97	SH	Betsi Cadwaladr University Health Board	4	3.2 a	Applied Behaviour Analysis and Positive Behaviour Support not mentioned as current practice	Thank you for your comment, the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples.
98	SH	British Psychological Society	12	3.2 a	The Society is concerned that the evidence (see for example, Robertson et al, 2005; Feldman et al, 2004; McClean et al, 2005) does not appear to support the following statement: That behavioural techniques are the most commonly used interventions We suggest that the sentence is redrafted to: *Behavioural techniques, including those within a positive behaviour support framework, and CBT, are sometimes used with people with learning disabilities, but most people with learning disabilities do not receive evidence-based bio-psychosocial interventions for their challenging behaviour.*	Thank you for your comment. The wording has been adjusted.
99	SH	Hounslow and Richmond Community Healthcare Trust	10	3.2 a	Behavioural techniques should be more clearly defined, rather than just one example stated as being included (as in "behavioural techniques including cognitive behavioural therapy"). This type of therapy has limited scope for the full population of people with an intellectual and developmental disability and behaviour that challenges as (a) many do not have the cognitive or communication skills to access and (b) their behaviour and difficulty to engage often precludes them from accessing this. It would be helpful to further define in the guidance ways of tailoring interventions such as Cognitive Behaviour Therapy to make it more accessible. Techniques that have proven success with a wide range of people within the population, including Applied Behaviour Analysis / Positive Behaviour Support should be clearly stated also.	Thank you for your comment, the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples.
100	SH	National Development Team for	2	3.2 a	Positive behavioural support is often used and should be referenced here as it fully recognises the environmental/support issues. It is not a behavioural technique.	Thank you for your comment. The scope has been amended to include positive behaviour support. Most people would say it is a type of behavioural technique as its

		Inclusion				name implies.
101	SH	Northumberland Tyne and Wear NHS Trust	4	3.2 a	It is misleading to refer to behavioural techniques in this instance. There is a history of the misuse of behavioural techniques. This occurred under the guise of behaviour modification when the goal was often to modify someone's behaviour without attempting to understand it. One of the reasons for the development of Positive Behaviour Support (PBS) was in response to the misuse of behavioural techniques. Applied Behaviour Analysis, that underpins PBS, has its roots in core scientific principles, has a clearly definable ethical code and advocates that all interventions should be built upon a thorough functional analysis, delivered by a competency trained therapist. In this country there has been a failure to provide the training to ensure the adequate application of these principles. Therefore using the phrase behavioural techniques is misleading because it will invariably includes poor practice. It would be more correct to refer to interventions based upon applied behaviour analysis	Thank you for your comment, the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples.
102	SH	Nottinghamshire Healthcare NHS Trust	5	3.2 a b	The separation between 'social' and 'medical' models and the implicit criticism of psychiatric prescribing reiterates a dichotomy that is 'essentially contested' i.e. unresolvable. Structuring the guideline to maintain it entrenches a way of thinking that some commentators (including Tony Holland in IASSID keynote 2010) and many clinical staff in Nottinghamshire HCTrust regard as 'sterile'. Multi-disciplinary services for people with severely challenging behaviours indicate that a socio-therapeutic environment is often combined with psychological and pharmacological interventions (eg Tenneij, Didden & Koot JARID 2011, 142-149)	Thank you for your comment. The scope has been adjusted to clarify that pharmacological interventions may be helpful.
103	SH	Royal College of Speech and Language Therapists	9	3.2 a	We would suggest that behavioural techniques being the most commonly used interventions to manage challenging behaviour is an understandable consequence of a behavioural understanding of CB. Communication interventions would not be classed as behavioural yet are used frequently with successful outcomes.	Thank you for your comment. The wording has been adjusted.
104	SH	Royal College of Speech and Language Therapists	10	3.2 a b	We would welcome consideration of whether the separation between 'social' and 'medical' models and the implicit criticism of psychiatric prescribing reiterates a dichotomy that is 'essentially contested' i.e. unresolvable. Multi-disciplinary services for people with severely challenging behaviours indicate that a socio-therapeutic environment is often combined with psychological and pharmacological interventions (eg Tenneij, Didden & Koot JARID 2011, 142-149)	Thank you for your comment. The wording has been adjusted.
105	SH	South Essex Partnership NHS Foundation Trust	6	3.2 a 4.3.1	"Positive Behaviour Support (PBS) and Applied Behaviour Analysis (ABA) are not mentioned at all despite evidence that this model is extremely effective in reducing challenging behaviour and increasing the individual's quality of life. Functional analysis gets only one mention throughout the draft scope."	Thank you for your comment, the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples.

				a b		
106	S H	South Essex Partnership NHS Foundation Trust	1 3	3.2 a	"It is shocking that Applied Behaviour Analysis (ABA) is omitted from the list of “Current practice”. Behavioural technique is certainly neither Cognitive Therapy (CBT) nor ABA. CBT comes under the umbrella of “Talking Therapy” that includes Psychotherapy, Dialectic Behaviour Therapy, Solution-focused Therapy and so on. It uses some behavioural techniques or strategies to enable/facilitate the service user to cope with particular stresses and is appropriate only for service users who have reasonably good expressive and receptive communication abilities. ABA represents the most significant development in the past 3 decades in approaches to improve quality of life and reduce and/or prevent challenging behaviour regardless of the service user’s degree of learning disability. It offers evidenced-based frameworks in the (i) assessment and analysis of factors that potentially influence the emergence, reinforcement and maintenance of challenging behaviour (ii) functional analysis of challenging behaviour and (iii) design of suitable, effective and non-aversive behavioural intervention plans. As such, ABA should really take focal point in the list of “Current practice”"	Thank you for your comment. It was never intended to exclude ABA (since most people would consider that it is a behavioural technique). The wording of the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples. This document is providing the Scope not the Guidelines themselves. The Guidelines will provide detail and reviews of the evidence base.
107	S H	Southern Health NHS Foundation Trust	1 8	3.2 a	What is the evidence base for this? Behavioural techniques should not be the starting point, Current practice is more personalised. CBT is not routinely used. Applied Behaviour Analysis is a more commonly used approach. A range of approaches need to be explained here, reflecting a broad range of therapies and broad range of ability – tailoring therapies to individual need.. It would also be helpful to look at how services are commissioned and how this impacts on services / approaches used. There is a need to emphasis the importance of involving the individual in planning their own care.	Thank you for your comment. The wording has been adjusted.
108	S H	Surrey County Council Adult Social Care	3	3.2 a	Should this refer to Positive Behaviour Support, as a range of approaches well supported by evidence, with an underpinning value base opposed to punishment, pain compliance etc?	Thank you for your comment, the scope has been amended to include Applied Behaviour Analysis and Positive Behaviour Support as examples.
109	S H	British Psychological Society	1 3	3.2 b	The Society is not aware what evidence this statement is based on, however on the basis our clinical impressions we believe that this section should be changed to:	Thank you for your comment. The wording has been adjusted.

					*A significant proportion of the **major tranquilising** medication given to people with learning disabilities is for the management of challenging behaviour**, and most people who present challenging behaviours are prescribed such medications.***	
110	SH	South Essex Partnership NHS Foundation Trust	4	3.2 b	"How is it known that antipsychotic medication is given to manage behaviour – does this sound like people are chemically restrained? Also the statement around children accessing support via Community Learning Disability Teams – need to be careful due to the contract arrangements – in Bedfordshire the contract is for Adults and children access CAMHS"	Thank you for your comments. Research evidence is that medication is commonly used for managing behaviour that challenges. The wording has been adjusted with respect to teams.
111	SH	South Essex Partnership NHS Foundation Trust	7	3.2 b	"These services may include psychological therapy, speech therapy, occupational therapy, psychiatric and nursing input….' behaviour therapy not mentioned – though not available in all areas but should become so – (after Winterbourne View doc.)"	Thank you for your comment. On reflection we agree that listing specific therapies may lead to unintentional exclusions and have therefore removed this.
112	SH	Southern Health NHS Foundation Trust	19	3.2 b	What is the evidence base for this? Link with IHAL evidence highlighting that there are large numbers of people on taking anti-psychotic medication with little evidence of impact on behaviour. Medication needs to be prescribed in conjunction with behaviour interventions. Current practice needs to reflect published documents from the Psychiatry Profession.	Thank you for your comment. The wording has been adjusted.
113	SH	British Psychological Society	14	3.2 c	There is a factual inaccuracy concerning the assertion that social services are the main provider of support. The 3rd sentence implies that challenging behaviour is a pseudo-diagnostic entity (...have challenging behaviour…). The 3rd sentence inaccurately suggests that children and young people access community learning disability teams whereas this is not normally the case. We also believe it would be helpful to add an extra sentence specifically relating to child services. We suggest that this section is changed to: *People with learning disabilities receive the majority of their support from **a range of different support providers in the social care sector** (for example, for self-care, daily living, daytime activities and respite care)**, funded by social services.** Separately or in addition to this, **children and young people** may receive education services (such as special needs educational services in mainstream schools and colleges, and services in special schools. People who **display behaviour which is challenging may** also access additional specialist services which tend to be provided and organised in **CAMHS for children and young people and in Community Learning Disability Teams for adults.** These services may include psychological therapy, speech therapy, occupational therapy, psychiatric and nursing input as well as arts and other therapies (for*	Thank you for your comments, the scope has been amended to reflect this.

					example drama therapy, art therapy, ***physiotherapy, dietetics*** *and music therapy).* ***However services for children and young people with learning disabilities are patchy with some areas providing few specialist resources.*** *The transition from child to adult services is often badly managed, and services…*	
114	SH	College of Occupational Therapists	5	3.2c	Support: People with challenging behaviour also access home adaptations through local authority Occupational Therapy services. This can include the provision of specialist equipment, minor adaptations and major adaptations (including provision through Disabled Facilities Grants).	Thank you for your comments, the scope has been amended to reflect this.
115	SH	Hounslow and Richmond Community Healthcare Trust	11	3.2c	"*for children and young people, which tend to be provided and organised in community learning disability teams".* Many children's services do not have specific support for behaviour that challenges, and rely on CAMHS to provide this. Community Learning Disability Teams tend to focus on adult services (18+). Perhaps clarity regarding the adult aspect of IDD services should be made. *"These services include..."* a long list of many therapies is provided here, but again Behaviour Analytic Services (i.e. Applied Behaviour Analysis / Positive Behaviour Support) should be clearly included as it has a proven evidence base and a growing number of community teams throughout the country are employing their specialty.	Thank you for your comments, the scope has been amended to reflect this. On reflection we agree that listing specific therapies may lead to unintentional exclusions and have therefore removed this.
116	SH	Linkage Community Trust	2	3.2c	We do not agree that 'people with challenging behaviour <u>usually</u> also access additional specialist services for children and young people, which…include psychological therapy, speech therapy, occupational therapy, psychiatric and nursing input, as well as arts and other therapies…'. From discussions with families which include a person with a learning disability, it is apparent that access to these services is very limited and people often struggle to get the additional support they need to manage challenging behaviour. Families frequently tell us of their battles to get extra support as support budgets are further squeezed.	Thank you for your comment. The wording has been adjusted. On reflection we agree that listing specific therapies may lead to unintentional exclusions and have therefore removed this.
117	SH	Linkage Community Trust	3	3.2c	We agree that the transition from child to adult services is often badly managed. More needs to be done to offer a joined-up and smooth transition process for people with a learning disability to ensure continuity of support and to stop people slipping through the net as they move from one service to another. There is a significant need for the criteria used to determine an individual's eligibility for services to be consistent from childhood to adulthood	Thank you for your comment, we agree that transition between services is important and have therefore added this to the scope.
118	SH	National Development Team for Inclusion	3	3.2c	People with mild learning disabilities and challenging behaviour may end up in contact with the criminal justice system, particularly with poorly organised services. This needs to be recognised in order to promote better equality of opportunity for this group.	Thank you for your comments. We have adjusted the wording to include this point.

119	SH	Northumberland Learning Disability Partnership Board	4	3.2c	We would very much like to see a life-course approach with early identification, planning and intervening early, starting from childhood and including crisis planning. How challenging behaviour is managed for children and young people has implications for the individual and their families in later life. Managed well and in an integrated way, they will be more likely to cope well with the transition to adult services. Difficulties arising in childhood that are not addressed properly or sensitively can have enormous repercussions for the individuals and their families later in life. Early intervention and good practice at this stage can set the pattern for later life.	Thank you for comment, these issues are likely to be considered when developing the guideline, however the aim of this section is simply to outline current practice.
120	SH	Queen's University Belfast	2	3.2c	In this point it is stated that *"People who have challenging behaviour usually also access additional specialist services for children and young people, which tend to be provided and organised in community learning disability teams. These services may include psychological therapy, speech therapy, occupational therapy, psychiatric and nursing input, as well as arts and other therapies (for example drama therapy, art therapy and music therapy)."* Services provided by qualified behaviour analysts (e.g., professionals holding the Board Certified Behavior Analyst credential) are not mentioned here. Behaviour analysts may be psychologists, occupational therapists, speech and language pathologists, psychiatrists, teachers, or come from another clinical or educational background, so it is vital that their services are mentioned separately. These services often fall under the psychological label but since psychological services include a variety of therapeutic methods and interventions with not all of them being evidence based, it is crucial that they are separately mentioned.	Thank you for your comment. The wording has been adjusted. On reflection we agree that listing specific therapies may lead to unintentional exclusions and have therefore removed this.
121	SH	Royal College of Psychiatrists	6	3.2c	Many young people do not currently have access to **comprehensive** specialist services in health. Psychiatry is often lacking and teams are often far too small to be able to address the need adequately.	Thank you for your comment. The wording has been adjusted.
122	SH	Royal College of Speech and Language Therapists	11	3.2c	We would argue that it is important to mention both the role of private sector providers, and the significant proportion of individuals receiving support from their families, with 60% living at home. (http://www.elfrida.com/social-model.html) This is increasingly so given reductions in social care.	Thank you for your comment. The wording has been adjusted.
123	SH	Royal College of Speech and Language Therapists	12	3.2c	There have been many published accounts of parent transition difficulties over the past 15 years, but although it is a contemporary trope that all problems originate in miscommunication, the evidence about transition problems is more complex than 'bad management'. A cohort study of special school leavers found that while most parents described the process as difficult, the majority (21/28) felt a good or acceptable post-school outcome had been achieved for their young	Thank you for your comment, we agree that transition between services is important and have therefore added this to the scope. All relevant evidence will be reviewed when drafting the guideline.

					person and transition workers agreed in all but one case. There was evidence of communication difficulty and high levels of transition worker sickness that might go under the descriptor 'bad management', but our analyses also identified as problematic the taken-for-granted nature of concepts that created significant difficulties for parents and transition workers, such as 'adulthood' and 'inclusion'. Other difficulties for those negotiating the transition arose from conflicts between the personalisation agenda required by government and the legitimate aspirations and needs of parents who provided much of these young people's support. An overarching account of this study is given in: Clegg, J. A., Murphy, E. & Almack, K. (2010). Transition: A moment of change. pp 203-216, in G. Grant, P. Ramcharan, M. Flynn & M. Richardson (eds) Learning Disability: A life-cycle approach, 2nd edition, Open University Press/McGraw-Hill. For specific analyses see: Pilnick, A. Clegg, J. Murphy, E. & Almack, K. (2011). "Just being selfish for my own sake..": Balancing the views of young adults with intellectual disabilities and their carers in Transition planning. The Sociological Review, 59:2, 303-323. Murphy, E. Clegg, J. & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. Jnl Applied Research in Intellectual Disability, 24, 61-73. Pilnick, A. Clegg, J. Murphy, E. & Almack, K. (2010). Questioning the answer: Questioning style, choice and self-determination in interactions with young people with Intellectual Disabilities. Sociology of Health & Illness 32 (3), 415–436. Almack, K. Clegg, J. & Murphy, E. (2009) Parental negotiations of the moral terrain of risk in relation to young people with learning disabilities. Journal of Community and Applied Social Psychology, 19 (4), 286-299. Clegg, J. Murphy, E. Almack, K. Harvey, A. (2008) Tensions around inclusion: reframing the moral horizon. Jnl Applied Research in Intellectual Disability, 21, 81-94.	
124	SH	Royal College of Speech and Language Therapists	13	3.2 c	We would note that the appropriate description of the relevant service is 'Speech and Language Therapy' rather than 'Speech Therapy'.	Thank you for your comment, this has been amended.
125	SH	Royal College of Speech and Language	14	3.2 c	We would note that specialist services are accessed by adults as well as children and young people	Thank you for your comment. The wording has been adjusted.

		Therapists				
126	SH	Southern Health NHS Foundation Trust	20	3.2c	What is the evidence base for this? What % of people live with their families? It should say that may services are commissioned by Social Services but they do not necessarily receive support from social services. Sentence including ' access additional Specialist Services…' this needs to include adults. Speech Therapy needs to be changed to Speech and Language Therapy. Add 'Learning Disability' Nursing. 'The transition from child to adult services……badly managed needs to be changed to poorly planned, resourced and funded. Many of the resources accessed in children services (e.g. technology, equipment) are not available in adult services and can have a significant impact on the individual. For guideline it is useful to consider plans to change the transition period, starting at 15 / 16 yrs. Where transitions start early there is an improved outcome. 'Services for adults with a mild learning disability…….poorly organised' what services are being referred to here?	Thank you for your comment. The wording has been adjusted.
127	SH	The Elfrida Society	3	3.2c and 4.3.1.c	Education and training of all stakeholders involved in the care and support of PWLD (professionals at all levels, parents/carers) as well as regular educational programmes (starting with SRE in the school curriculum) are essential for PWLD to develop healthy, mature relationships, to prevent self-injurious behaviour, and to prevent abuse (specially sexual abuse)	Thank you for your comments. The wording has been adjusted to remind people of the importance of staff training.
128	SH	British Psychological Society	15	3.2d	To highlight the variation in living situations, we suggest it would be helpful to include reference to Supported Living services here. For example: *In terms of living situations, people with challenging behaviour may be supported at home with their families, in residential services of various kinds* ***or homes with their own tenancies****, sometimes with the support of specialist teams. Severe challenging behaviour is a common reason for long-term residential placement.*	Thank you for your comment. The wording has been adjusted.
129	SH	British Psychological Society	16	3.2d	In view of the recent review at Winterbourne View, we suggest section 3.2.d be extended to include: ***Some people are referred into hospital accommodation such as Assessment and Treatment Units when their services are at the point of breaking down. Although intended for short term intervention, such placements sometimes involve delayed discharges, with problems of returning the person to a community setting.***	Thank you for your comment, this level of detail will be included in the introduction to the guideline, but is too detailed for the scope.
130	S	College of	6	3.2	Living situations: Support to people with challenging behaviour living at	Thank you for your comment. The wording has been

	H	Occupational Therapists		d	home can include equipment and home adaptations through the local authority Occupational Therapy service.	adjusted.
131	SH	Hounslow and Richmond Community Healthcare Trust	12	3.2 d	*"residential"* - should also state supported living.	Thank you for your comment. The wording has been adjusted.
132	SH	National Development Team for Inclusion	4	3.2 d	Severe challenging behaviour is also a common reason for a long term in-patient placement, which can have a significant impact on disabled people's equality of opportunity.	Thank you for your comment. The wording has been adjusted.
133	SH	Southern Health NHS Foundation Trust	21	3.2 d	There is a need to distinguish between Residential Care Homes and Supported Living. Is long term Residential Care / Supported Living a bad thing? If provided within an appropriate physical environment with skilled staff this can be positive and the right thing for the individual and their families. This is very jumbled. Need to state current 1. Practice for children / adolescents / adults 2. Funding for children / adolescents / adults 3. Challenges for children / adolescents / adults How services are currently reviewed needs to be addressed - reviews don't happen quickly enough and early warning signs not picked up.	Thank you for your comment. The wording has been adjusted.
134	SH	Surrey County Council Adult Social Care	4	3.2 d	Living situations for people with challenging behaviour should include supported living arrangements as well as residential.	Thank you for your comment. The wording has been adjusted.
135	SH	Northumberland Learning Disability Partnership Board	2	4.1 4.2	We would like to see it made clearer that while the scope covers all age the care setting should also clearly include the person's own home, where for example a young person is at risk of developing increasingly challenging behaviours which their family are finding difficult, as the interventions and support does appear to cover this (4.3.1e)	Thank you for your comment, NICE guidelines are only able to make recommendations for those working in the NHS, although these recommendations are likely to be useful for families and carers.
136	SH	Northumberland Tyne and Wear NHS Trust	5	4.1	In management section it would be important to include more detail regarding the staff training element as an important intervention emphasising positive behaviour support. What about a comment about the increasing evidence base to support staff in stressful situations.	Thank you for your comment, the guideline will review any available evidence for staff training in this area – it is not for the scope to detail what that evidence might be.
137	SH	Linkage Community Trust	4	4.1.1	We agree for the need for families and carers to be included in the scope of the guidelines.	Thank you for your comment.
138	SH	Southern Health NHS Foundation Trust	22	4.1.1	How will boundaries around IQ be addressed ? e.g. IQ OF 71 / borderline LD. Different populations may require different guidance. Include older adults. Need to acknowledge impact of other diagnosis on behaviour e.g. epilepsy, Mental Health, Autism. From a	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.

					preventative viewpoint, recognising and responding to factors that have the potential to lead to challenging behaviour may prevent it from occurring - should it just be about those who have been identified as presenting challenging behaviour? 'Families and Carers' expand on who this includes – immediate family / support networks, non-specialist Clinical Staff, paid and unpaid carers.	
139	SH	Royal College of Psychiatrists	4	4.1.1 a	Will children and adolescents be differentiated or as in Mansell/CR166 the principles and concepts to be applicable to all population groups? Occasionally specific developmental issues need to be considered in the child population group, e.g. differing legislation, consent issues, physical interventions/restraint, research conducted in different populations (medication/psychotherapeutic interventions), developmentally appropriate behaviour and educational interventions/placements having therapeutic value in their own right (linked to creating a capable environment).	Thank you for your comment. Although these points are too detailed to add to the scope, it is likely they will be covered in the full guideline.
140	SH	Challenging Behaviour Foundation	4	4.2	Add " and education"	Thank you for your comment, whilst the guideline will be able to make recommendations for working with education, NICE guidelines are unable to make recommendations *for* educational settings.
141	SH	Department of Health	1	4.2	In our view, this paragraph needs to be broadened to include meeting the health and care needs of people in whatever setting they appear – so for children and young people, there is a need to explicitly include children's social care and education settings within the scope – in particular residential schools, in which this group of children would often be placed.	Thank you for your comment, whilst the guideline will be able to make recommendations for health and social care provision in such settings, NICE guidelines are unable to make recommendations specifically *for* educational services.
142	SH	Royal College of Speech and Language Therapists	15	4.2	We would suggest that private providers should be explicitly included in the coverage of the guideline, responding to Winterbourne View.	Thank you for your comment, however NICE guidelines are only able to make direct recommendations for the NHS.
143	SH	Sheffield Clinical Commissioning Group	4	4.2	NICE need to take into account that commissioners of care and support may increasingly be individuals, their families and support planners and brokers, through personal health and social care budgets and the concept of Self Directed Support, rather than the traditional health and social care commissioners. This growing area creates the most tension relating to the choice and control agenda of personalisation versus correct evidence based approaches to supporting challenging behaviour within the community. If NICE do not address this area, it is not properly advising the care and support sector on how best to approach the management of challenging behaviour, which will not enable a whole system response to the	Thank you for your comments, the scope has been amended to reflect this.

					issues faced by this population, their families and the services that aim to support them.	
144	SH	Southern Health NHS Foundation Trust	23	4.2	It is important to be aware of definitions of services – Joint Commissioned Services	Thank you for your comments, the scope has been amended to reflect this.
145	SH	Foundation for People with Learning Disabilities	1	4.2 a	It is not clear if the care setting includes children and adults living in their family home, or with other relatives. I would presume it does, if the person is being supported by a health professional who is commissioned by health/social care, but this is not clearly stated.	Thank you for your comment, NICE guidelines are only able to make recommendations for those working in the NHS, although these recommendations are likely to be useful for families and carers especially where health/social care professionals are working with the families.
146	SH	Royal College of Psychiatrists	9	4.2 a	Many of the children with an intellectual disability and the most severe challenging behaviours are resident in Special schools often a long way from their families. They receive treatment in a variety of ways from a range of professionals. Treatment can range from excellent to very poor. Education settings should therefore be included in these guidelines	Thank you for your comment, whilst the guideline will be able to make recommendations for health/social care working with education, NICE guidelines are unable to make recommendations *for* educational services themselves.
147	SH	British Psychological Society	17	4.3	We are aware that there are some limitations as to how much the structure of NIHCE guidelines can be altered. If possible, however, we believe that it would be helpful for the title of this section to be 'Management and Support', to reflect that challenging behaviour is socially constructed.	Thank you for your comment, the scope has been amended to reflect your suggestion.
148	SH	Southern Health NHS Foundation Trust	24	4.3	This should be broken down into Sections on Prevention, Assessment, Interventions and Management.	Thank you for your comment. We have covered all these areas.
149	SH	Hounslow and Richmond Community Healthcare Trust	13	4.3.1	General comment re: both prevention and intervention with already developed. Should the guidance consider risk factors such as inexperienced, undertrained staff and the impacts this can have on ability and success of assessment / intervention.	Thank you for your comments, the scope has been amended to reflect this.
150	SH	Royal College of General Practitioners	3	4.3.1	Key issues could be modified to include cultural and gender issues as specific areas in line with earlier parts of the scoping document	Thank you for your comments, the scope has been amended to reflect this.
151	SH	Royal College of Speech and Language Therapists	16	4.3.1	We would suggest that communication assessment needs to be included here. It would be useful for the group to be aware of RCSLT document 'Five Good Standards. Reasonable adjustments to communication that individuals with learning disabilities and /or autism in specialist hospital and residential settings should expect. (2013 – draft format). Liaise with Della.money@nottshc.nhs.uk regarding this.	Thank you for your comment. We have adjusted the wording to include this issue and further details will appear in the Guidelines.

					Communication interventions can be understood within a Means, Reasons and Opportunities model of communication (Money and Thurman 2002). This model of communication highlights that communicative intervention needs to encompass: ○ The person's understanding of the world ○ Their means of communication, that is, ensuring that the client has a way of expressing themselves. ○ Reasons to communicate, which is focusing on why the person is communicating with others. ○ Opportunities to communicate, which means ensuring that the individual has access to communicative partners and situations in which to express themselves and interact Money, D. and Thurman, S. (2002) Inclusive Communication – Coming Soon near you? Speech and Language Therapy in Practice. Autumn 4/6 Role of SLT The overall aim of intervention will focus on reducing risk around communication, developing inclusive relationships and building capacity and capabilities in others (see East Midlands SLT Key messages for commissioners document. Liaison with Della.money@nottshc.nhs.uk SLT Document 2010). Some national guidance on challenging behaviour focuses on communication development of the individual. (e.g. Banks and Bush 2007) However, in reality before the development of skills in the individual can be addressed, the communication environment needs to be explored. The reputation of the service user needs to be addressed sensitively with the staff team in a multidisciplinary context and needs to give consideration to staff members' perceptions and beliefs about an individual's comprehension, means and reasons and their awareness of their own influence on communication issues. Communication interventions may include: adapting partner communication and providing visual structure – to support the person's comprehension, improving recognition and understanding of the individual's communication skills, assisting communication partners to provide appropriate models of communication, facilitating development of inclusive relationships through interactive approaches (e.g. Intensive Interaction - Nind & Hewitt 2001) facilitating communication	

					partners' use of appropriate forms of communication, such as use of signs, symbols and objects in addition to spoken communication and supporting individuals to understand social situations through approaches such as comic strip conversations and social stories (TM – Gray 2004) Gray, C. (2004) Social Stories TM. 10:0 The new defining criteria and Guidelines. Jenison Autism Journal 15/4 pp2-21.	
152	SH	Tees Esk and Wear Valley NHS Foundation Trust	10	4.3.1	The need for training and education is mentioned in 4.3.1. but appears to be specifically related to the use of seclusion and physical intervention – the need for training in understanding challenging behaviour, theories, models etc and the use of proactive approaches also needs explicit reference. Further expansion required.	Thank you for your comment, this has been amended to clarify that training should be for all interventions, not only in seclusion and physical interventions.
153	SH	British Psychological Society	18	4.3.1 a	The Society suggests that the 2nd bullet point is changed to read: *Methods and tools for assessment (including assessment of sensory processing disorders and physical health status)* ***and formulation.***	Thank you for your comment. The wording has been adjusted to include formulation in section 4.3.1 b).
154	SH	British Psychological Society	19	4.3.1 a	The Society suggests that the addition: ***Effective support to care team and families to identify risk factors and prevent challenging behaviour developing***	Thank you for your comment. We feel this is already covered.
155	SH	College of Occupational Therapists	1	4.3.1 a b	As a group we are pleased to see the guidance will cover children and adults and that there will be a focus on anticipating and preventing as well as management. We wanted to stress that there needs to be a clear pathway to guide practice but with a recognition that the strategies used in childhood may differ to those used in adulthood. We also feel emphasis needs to be placed on how services best work together during the transition years.	Thank you for your comment, we agree that transition between services is important and have therefore added this to the scope.
156	SH	Linkage Community Trust	5	4.3.1 a	The key issues proposed are sensible.	Thank you for your comment.
157	SH	Luton and Dunstable Hospital NHS Trust	2	4.3.1 a	Health Action Plans and Annual Health Checks to focus more on behaviour as a form of communication (to ensure against a 'Death by Indifference scenario) to eliminate any physical health ill health by carrying out thorough examinations and investigations (before labelling as challenging behaviour and prescribing behaviour management plans &/or medication).	Thank you for your comment, the assessment of physical health is covered in sections 4.3.1 a) and b).
158	SH	Optical Confederation	4	4.3.1 a b	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, the assessment of physical health and sensory deficits is covered in sections 4.3.1 a) and b).

159	SH	Royal College of Nursing	4	4.3.1 a	Anticipating and preventing challenging behaviour in..... This section needs an additional bullet point:- • Training and education of health and social care professionals and families in Active Support. We are aware that 4.3.1 d) covers *Training and education needed to allow health and social care professionals and families to carry out* ***the above interventions***" (i.e. reducing existing challenging behaviours). However, training is also needed in proactive strategies encapsulated by the term Active Support which includes and embraces Person Centred Planning, Skills building, community, participation, Total Communication, Positive Behavioural Support and Intensive Interaction. In addition to training aimed at health and social care professionals to carry out interventions, it is vital that professionals with a commissioning role within health and social services receive a level of training so that they are more able to understand the often complex and intensive levels of support and skill needed fulfil the above interventions and 'active support'. This form of support is pivotal in proactively seeking to prevent the circumstances arising, which could lead to a person developing challenging behaviour. It is also an area that historically health and social care professionals and families have been woefully inadequate at facilitating. If we can promote service users having an engaged, fulfilling and meaningful life, then challenging behaviour will, as a multitude of research has demonstrated, either not occur in the first place or diminish drastically.	Thank you for your comment, the evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.
160	SH	Royal College of Speech and Language Therapists	17	4.3.1 a	We would call for the consideration of recent data on persistent challenging behaviours being associated with poverty, deprived neighbourhoods and single-parent households that display harsh and inconsistent parenting (Emerson Einfeld & Stancliffe JCPP 52:11 1184-1194; 28. Emerson, E. Shahtahmasebi, S. Lancaster, G. Berridge, D. (2010). Poverty transition among families supporting a child with ID. Journal Intellectual & Developmental Disability, 35 (4): 224-234.).Such parenting styles can be the consequence of histories of insecure attachment in the parents, which are likely to be setting events for insecure attachments in their children. The growing literature on attachment, ID and CB should be included in the NICE review	Thank you for your comment. The wording has been adjusted accordingly.

					Solomon, J. & George, C. (2011) (eds) Disorganized attachment and caregiving. London: Guilford. C. Schuengel, S. Kef, S. Damen, M. Worm (2010) 'People who need people': attachment and professional caregiving. Journal of Intellectual Disability Research v54, Supp 1, p38–47. de Schipper, J.C. Schuengel C. (2010) Attachment behaviour towards support staff in young people with intellectual disabilities: associations with challenging behaviour. JIDR 54 (7) 584-596. This includes the *Safe Base Safe Haven Observation Scale* P. S. Sterkenburg, C. G. C. Janssen, C. Schuengel (2008) The Effect of an Attachment-Based Behaviour Therapy for Children with Visual and Severe Intellectual Disabilities. JAppliedResID, 21, 126-135 Sterkenburg, P. Schuengel,C. Janssen,C. (2008) Developing a therapeutic relationship with a blind client with a severe id and persistent challenging behaviour. Disability & Rehabilitation. V 30 (17), 1318-1327 De Schipper, J. C. Stolk, J. Schuengel,C. (2006) Professional caretakers as attachment figures in day care centers for children with intellectual disability and behavior problems. Res DevDisv27, 203-16. Dosen, A. (2005) Applying the developmental perspective in the psychiatric assessment and diagnosis of persons with intellectual disability: part II – diagnosis. Jnl Intell Disab Res, 49, 9-15. Rutgers, A. Bakermans-Kranenburg, M. van IJzendoorn, M. & Berckelaer-Onnes, I. (2004). Autism & attachment: a meta-analytic review. Jnl Child Psychol Psychiat 45, 1123-1134. Janssen, C.G. C. Schuengel, C. & Stolk, J. (2002) Understanding challenging behaviour in people with severe and profound intellectual disabilities: a stress-attachment model. Journal of Intellectual Disability Research 46, 445-453. Clegg,J.A & Sheard,C. (2002) Challenging behaviour and insecure attachment. Journal of Intellectual Disability Research, 46(6) 503-506. Clegg,J.A. & Lansdall-Welfare,R. (1995) Attachment and learning disability: a theoretical review informing three clinical interventions. Journal of Intellectual Disability Research, 39, 295-305	
161	SH	Royal College of Speech and Language Therapists	18	4.3.1 a	We would call for the inclusion of literature on stress and poor physical and mental health in carers usually mothers: eg Bourke-Taylor, H. Pallant, J. Law, M. Howie, L. (2012). Predicting mental health among mothers of school-age children with developmental disabilities. Research in Developmental Disabilities, 33: 1732-1740. Barker, E. T. Hartley, S.L. Seltzer, M. M. et al (2010) Trajectories of emotional well-being in mothers of adolescents and adults with autism. Developmental Psychology, 47 (2), 551-561.	Thank you for your comment. As outlined in 4.3.1 g) parent and carer stress will be covered.
162	SH	Southern Health NHS Foundation Trust	25	4.3.1 a b	As part of prevention, guidance on the key factors that are important in creating an enriched positive physical and social environment should be the starting point for supporting positive behaviour – what is the gold standard? A range of environmental checklists already exist and could be referred to. Additional areas to include – background history, predicting life events, managing transitions, Risk Assessment. Things that should already be in place – Person Centred Plan /	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.

					Support Plan identifying likes, dislikes, communication needs and strategies, emotional needs, strengths, skills, abilities, Health Check and Health Action Plan and when known, individual behaviours mapped against the assault cycle identifying triggers, early interventions. It may be useful to provide a theoretical framework e.g. a Bio – Psycho- Social Framework for understanding and supporting behavioural needs. Approaches could be divided into proactive and reactive. What is the national benchmark for being a competent / specialist in supporting people with a Learning Disability and present behaviour that challenges. From the beginning it is important to emphasis the importance of placing the individual with a Learning Disability at the centre of their care – using Person Centred Approaches and being clear what this actually means in practice. Assessment should be a staged process. When do you need to do an anticipatory Assessment? Identifying and…..at risk of developing challenging behaviour' and 'interventions to prevent…' should this be about anticipating potential difficulties / challenges? / working etc. Risk Assessment needs to include risk(s) of behaviour for the individual and within the environment(s) they are living Providers need to understand nature / factors leading to challenging behaviour, importance of communication and the needs of the individual. Functional Analysis includes environmental factors. Not everyone will need a full functional analysis. What is the gold standard for Functional Analysis? Clinical judgement is important in recognising how far to progress with the functional analysis – which aspects are important in relation to the individual – a full functional analysis may not be required for everyone. Need to include Personal Assessments, assessment of staff skills and environment, physical assessment – impact of physical conditions within the environment on behaviour. Who should be carrying out the assessment – what skills do they require? Approaches should include direct and indirect assessments. Need proactive and reactive strategies. Need to identify early warning signs for deteriorating behaviour. Need to include importance of baseline assessments in order to measure progress / changes in behaviour Need to acknowledge that it is OK for individuals to express emotions / be upset which could be challenging for others. What is important is	

					the way in which the individual is supported to do this. What is labelled as challenging could be a natural response to a situation / event.	
163	SH	British Psychological Society	20	4.3.1 b	The Society suggests that some minor changes and an additional point are included: *Methods and tools for assessment (including assessment of physical health),* ***formulation*** *and risk assessment* *Assessment of environmental factors and functional* ***assessment (including functional analysis)*** ***Assessment of staff/carer stress and attributions that contribute to their capacity to support the person***	Thank you for your comment, the scope has been amended to incorporate most of your suggestions.
164	SH	Royal College of Psychiatrists	7	4.3.1 c	One of the most important interventions is a thorough psychiatric assessment and diagnostic formulation performed by a psychiatrist with the appropriate training and skills. Without it "diagnostic overshadowing" can lead to the problem behaviours being ascribed to the intellectual disability without consideration of the presence of Autism, ADHD, social or environmental factors etc..	Thank you for your comments, the scope has been amended to reflect this.
165	SH	Royal College of Psychiatrists	8	4.3.1 c	One of the main problems facing psychiatrists in the field is that when we do prescribe medication it is often used off licence. This reflects the paucity of drug trials which include young people with an intellectual disability. If the NICE review only advocates the use of licenced (often very old) medications it will set back the recent advances in the management of children with intellectual disabilities and be worse than useless. There are research studies into the use of medication but they usually have a low Cochrane index.	Thank you for this comment. We understand the problems presented by the lack of licenced medications. We will review the relevant evidence and although it is not routine for NICE to make recommendations for off-license use it is possible in exceptional circumstances when the evidence supports a recommendation.
166	SH	Betsi Cadwaladr University Health Board	1	4.3.1 c	Interventions could include establishing structures to facilitate empowerment for service users to safely disclose abuse	Thank you for your comment, the evidence for all interventions in this area will be reviewed and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.
167	SH	Betsi Cadwaladr University Health Board	5	4.3.1 c	Does not mention Positive Behaviour Support or Active Support as intervention approaches.	Thank you for your comment, the evidence for all interventions in this area will be reviewed and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.
168	SH	British Psychological Society	21	4.3.1 c	The Society suggests that a minor change to the 2nd point and final points are included: *Psychological (including a broad range of therapies),* ***functional communication,*** *and psychological interventions for the short- and long-term reduction and management of challenging behaviour* ***Safe use of*** *restrictive interventions, such as physical restraint,*	Thank you for your comments, the scope has been amended to reflect this.

					seclusion, ***and alternatives to restrictive interventions***	
169	S H	College of Occupational Therapists	2	4.3. 1 c	From an Occupational Therapy perspective we are keen that our role is seen in its broadest sense in this guidance which we hope will consider our unique contribution around in depth assessment and treatment related to meaningful occupation. We would also like to see the inclusion of different types of therapy interventions such as, environmental analysis and management (including the physical, social and psychological elements of the environment), activity analysis, sensory integration, dialectical behavioural therapy, intensive interaction, active support etc. We also felt there was an important consultancy role for professionals such as OT's in supporting staff to implement appropriate care plans.	Thank you for your comment, the evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.
170	S H	College of Occupational Therapists	7	4.3. 1 c	'Environmental adaptations' would be better written as 'changes to the environment (social and physical)'. "Environmental adaptations" automatically makes people think of physical adaptations.	Thank you for your comments, the scope has been amended to reflect this.
171	S H	Foundation for People with Learning Disabilities	3	4.3. 1 c	There is no reference made to the socio-economic status or cultural background of the person presenting with challenging behaviour. Interventions can vary according to the financial, material circumstances and the cultural sensitivities and expectations of each person and their family.	Thank you for your comments, the scope has been amended indicate more clearly that we will consider issues to do with ethnicity and socioeconomic status.
172	S H	Hounslow and Richmond Community Healthcare Trust	1 4	4.3. 1 c	Psychosocial, psychological and pharmacological therapies are specifically mentioned. Also included should be "behaviour analytic interventions for short and long term management of challenging behaviour" - again as there is a proven evidence base and a growing number of community teams throughout the country are employing their specialty. Restrictive interventions - this list should include chemical restraint (i.e. PRN medication) and confinement / containment (as opposed to only seclusion).	Thank you for your comments, the scope has been amended to reflect this.
173	S H	Linkage Community Trust	6	4.3. 1 c	There is a need for clear descriptors and guidelines of when pharmacological and restrictive interventions should be used to avoid extreme measures being taken unnecessarily. Best practice guidelines on these matters would be helpful to ensure they are only used as a last resort, with an emphasis on lower-level, more holistic approaches being the preferred methods.	Thank you for your comment, these issues will be considered when drafting the guideline.
174	S H	Luton and Dunstable Hospital NHS Trust	3	4.3. 1 c	Interventions to also include physical health investigations/procedures and interventions.	Thank you for your comment, this guideline is for those working in mental health and therefore is unable to make recommendations about physical health interventions. However, the need for a physical health assessment is

						included in sections 4.6.1 a) and b).
175	SH	Queen's University Belfast	3	4.3.1 c	In the previous point (4.3.1.b.), conducting a functional analysis has been mentioned as an assessment method but no mention of behaviour analytic interventions has been explicitly made here. Given the extension of the behaviour-analytic research literature in the topic of challenging behaviours and functional analyses and, especially, given the fact that the professionals who are trained in conducting functional analyses are behaviour analysts (see Behavior Analysts Certification Board 3rd and 4th Task List, www.bacb.com), it is warranted that this is explicitly mentioned here and behaviour-analytic interventions are included in a separate yet concrete category.	Thank you for your comments, the scope has been amended to reflect this.
176	SH	Royal College of Psychiatrists	5	4.3.1 c	Whilst generally agreeing with licenses and robust evidence-base, licenses are limited by drug companies recommendations (sometimes linked to profit) which can be limiting/constraining and occasionally overcautious and a robust evidence base although growing is still small within the child learning disability population. Child LD populations often have to extrapolate evidence from research conducted on adult LD populations or the generic child population. This may prevent access to medications which could potentially be helpful. There needs to be some scope for discussion on this. Whilst we need to recommend cautious prescribing there needs to be leeway for specialists (i.e. doctors with specific training in this field) to judicially prescribe off-license medication which is based on careful interpretation of limited evidence and peer guidance/support.	Thank you for this comment. We understand the problems presented by the lack of licenced medications, in particular for children and young people. We will review the relevant evidence and although it is not routine for NICE to make recommendations for off-license use it is possible in exceptional circumstances when the evidence supports a recommendation.
177	SH	Royal College of Speech and Language Therapists	19	4.3.1 c	Research evidence concerning the efficacy of behavioural interventions should be reviewed with appropriate hesitancy. Although the weight of evidence is in their favour, there are critiques of limited or absent follow-up data, & of good outcomes ensuing mainly from special projects carried out by university-trained staff working in controlled conditions.	Thank you for your comment, all evidence reviewed will be assessed against GRADE criteria to ensure the quality of included studies.
178	SH	Royal College of Speech and Language Therapists	20	4.3.1 c	We would argue that specific mention should be made of improving communication skills of clients and staff or improving the communication environment.	Thank you for your comment. The wording has been adjusted accordingly.
179	SH	Royal College of Speech and Language Therapists	21	4.3.1 c	We would call for "interventions aimed at reducing health risks e.g. choking, respiratory disease etc in those with eating, drinking or swallowing difficulties" or similar to be added.	Thank you for your comment. The wording has been adjusted accordingly.
180	SH	Royal College of Speech and Language Therapists	22	4.3.1 c	We would call for "interventions aimed at improving health outcomes for people with challenging behaviour e.g. increase in health literacy, reasonable adjustments in accessing health care etc" or similar to be added.	Thank you for your comment. The wording has been adjusted accordingly.
181	S	Sheffield	5	4.3.	In referring to restrictive practices, I would wish to see NICE refer to	Thank you for your comment. The wording has been

	H	Clinical Commissioning Group		1 c	alternatives to restraint practices as a positive process to reduce these (such as work developed in Sheffield Health and Social Care Trust) https://www.signpostsheffield.org.uk/healthy-safe/healthy/laws/restraint-sheffield	adjusted accordingly.
182	SH	South Essex Partnership NHS Foundation Trust	1	4.3.1 c	"Using medication only within currently licensed indications will allow for virtually no medications to be used, as challenging behaviour has not seemingly been an area for which drug companies have sought a license, possibly due to the relatively small population involved and ethical difficulties of involving people with learning disabilities in trials. To effectively prevent the use of medication will cut off an essential resource for people particularly with severe challenging behaviour for whom psychological or behaviour therapy interventions do not work, or are in crisis, and may lead to their injuring themselves and others or placements breaking down and hospital admission where perhaps a low dose of antipsychotic could have been effective and safe. Of course nobody would want to see people with learning disabilities sedated or behavioural interventions not used where effective, but I would see this as a case of "don't throw out the baby with the bathwater"."	Thank you for this comment. We understand the problems presented by the lack of licenced medications. We will review the relevant evidence and although it is not routine for NICE to make recommendations for off-license use it is possible in exceptional circumstances when the evidence supports a recommendation.
183	SH	South Essex Partnership NHS Foundation Trust	14	4.3.1 c d e	"Good from NICE to advocate intervention at different levels (such as, service user's level, stake holders' level and service level) to cope with and manage challenging behaviour."	Thank you for your comment.
184	SH	South Essex Partnership NHS Foundation Trust	15	4.3.1 c	"The term "Environmental adaptations" may be wrongly perceived as just being Occupational Therapy's input. The phrase "Enhancing the service user's social and emotional environment" would give it a more humane feel. The list of interventions should include: (i) Enhancing service user's self-management skills to cope with many of everyday stresses (ii) Enabling and facilitating the service user to acquire and develop socially-appropriate skills to replace their challenging behaviour and (iii) Enabling and facilitating the service user to acquire and develop general skills to reduce or prevent their dependency on carers."	Thank you for your comment. The wording has been adjusted accordingly. The interventions you mention are covered under psychosocial interventions.
185	SH	Southern Health NHS Foundation Trust	26	4.3.1 c d e	Interventions need to include improving quality of life. It should not just focus on reducing and managing behaviour. Use of Positive Behaviour Framework may be helpful but need to consider a range of models / take a multi –dimensional approach. Specific treatment approaches / therapies may need separate guidance.It is important to emphasise the need to understand the function of the behaviour has for the individual, using this to inform which interventions are required. Where the functions are multi-	Thank you for your comment. Quality of life is included as an outcome measure (i.e. we agree it is not just about reducing behaviour that challenges). We have adjusted the wording regarding some of the other issues you mention. The remaining issues will be covered in the Guidelines. This is only the Scope.

					factorial, which do you target first? Physical health should be the first point of call. In addition to environmental adaptations it is important to consider the development of 'capable environments' which includes getting the environment right (include total communication) but also ensuring that staff have the right knowledge, skills and support. Supervisions, debriefing, exploring feelings with staff teams and time to discuss / review what they are doing (formulations), Root Cause analysis and applying learning are all important interventions. More detail on what relates to offending behaviour needs exploring. Many behaviours have the potential of being offending but the individuals are never 'caught' or action against them is not taken for a variety of reasons – what is the overlap between challenging behaviour and offending behaviour? It would be helpful to consider what approaches are required re: offending behaviour that are not linked to specific therapies e.g. fire setting, sex offending. Personal / Occupational Interventions / activities and sensory therapies / activities need to be included. Training for people with a learning disability as an intervention needs to be included e.g. functional communication, functionally equivalent behaviours Restrictive interventions: It is important to recognise that a wide range of interventions could be 'restrictive' e.g. medication – this needs defining An emphasis needs to be place on the least restrictive options. This needs to be addressed within the context of Best Interests and Deprivation of Liberties (DoLs) (MCA). Physical interventions are primarily a management tool rather than a therapeutic intervention although they can be used to support individuals to access e.g. health care interventions / procedures in a positive way. May be helpful to proactive and reactive strategies. It is important to ensure that training re: Physical Interventions include values that underpin approaches and the broad range of act ivies used from de-escalation to friendly come alongs and full restraint. Use of Physical Interventions needs to be built into the individuals overall care package There has been a general consensus that there needs to be a National Accreditation of Physical Interventions clearly identifying clear minimum standards for initial and refresher training, procedures for safety, techniques not to be used i.e. pain compliance etc. 'General Services' is accredited by BILD and all techniques are risk assessed. However there is not a consensus on which approach to Physical interventions should be used. There is a general need for a more robust evidence based to underpin the use of physical intervention.	

					Positive Risk Taking, Risk Management, Relapse Prevention and Crisis Management need to be addressed. There is a strong consensus that in complex cases, Assessment, Interventions, Management and Evaluation / Review need to be effectively coordinated within an Multi – Professional / Multi-Agency Framework e.g. CPA. However some concerns were expressed about how CPA is interpreted across all agencies and may specific reference may have a detrimental effect on their engagement.	
186	SH	Surrey County Council Adult Social Care	5	4.3.1 c	Is the 'psychosocial' heading here the right place to talk about positive behaviour support?	Thank you for your comment. We have given it as an example.
187	SH	British Psychological Society	22	4.3.1 d	The Society believes that paid carers should be referenced here, to highlight the variety of support settings that people with learning disabilities live in. For example: *Training or education needed to allow health and social care professionals, families and **paid carers** to carry out the above interventions*	Thank you for your comment. The wording has been adjusted accordingly.
188	SH	Linkage Community Trust	7	4.3.1 d	We agree that training and education on these interventions are of paramount importance.	Thank you for your comment.
189	SH	Optical Confederation	5	4.3.1 d	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 comment. The wording has been adjusted accordingly.
190	SH	Queen's University Belfast	4	4.3.1 d	There is a clear need for carers and for professionals who work with people who exhibit challenging behaviours to receive training on effective evidence-based interventions (i.e., behaviour analytic interventions and methods, such as conducting functional analyses, manipulating environmental variables, etc.). This should be clearly stated here. For an exhaustive list of skills, including the skills required to address challenging behaviours, see Behavior Analysts Certification Board 3rd and 4th Task List (www.bacb.com).	Thank you for your comment. The wording has been adjusted accordingly.
191	SH	Royal College of Speech and Language Therapists	23	4.3.1 d	We would suggest the need for the inclusions of data on dysregulation as a cause on CB and a predictor of poor long-term outcomes, eg Althoff, R. Verhulst, F. Rettew, D. et al. (2010). Adult outcomes of childhood dysregulation: a 14 year follow up study. Journal American Academy Child Adolescent Psychiatry, 49 (11) 1105-1117.Focus on relationship between severity of the problems experienced by children with neurodevelopmental disorders and high risk of negative outcomes as adults. Seek to focus attention away from diagnosis onto childhood characteristics that can frame treatments that lead to better outcomes,	Thank you for your comment. Although this is too detailed to add to the scope, it may be explored in the full guideline.

					arguing that the core difficulty is dysregulation, Data drawn from from Zuid Holland longitudinal study of 2,600 children in 13 birth cohorts. Childhood dysregulation at any age is significantly associated with a wide range of adult psychopathological conditions. We would also welcome consideration in the evidence of a conceptual analysis by a philosopher of how to work with people who challenge by inviting people to take responsibility without adding the 'sting' of blame: Pickard, H. (2011) Responsibility without blame: Empathy and the effective treatment of personality disorder. Philos Psychiat Psychol, 18 (3) 209-223	
192	SH	Royal College of Speech and Language Therapists	24	4.3.1 d	RE: training of staff, we would note the need to highlight the evidence base around how best people learn about supporting people with challenging behaviour; Campbell, M. (2007) Staff training and Challenging Behaviour. Who needs it? *Journal of Intellectual Disabilities*. 11/2 143-156 - The capacity/competence of the environment to respond to a person's challenging behaviour is determined by several factors, including organisational structure, appropriateness of current responses and their flexibility, staff numbers/skills/deployment, staff attitudes and attributions, capacity to learn/think differently (see Campbell 2007), and the stability, leadership and robust supervision of the people supporting the individual service user. If an environmental assessment is placed alongside the other forms of assessment it will indicate the extent to which intervention strategies need to be solely or largely directed toward improving that environment. In some cases this is not appropriate, but invariably some degree of environmental improvement is warranted irrespective of the degree of focus on individual change. We also note that there are no specific mentions of support mechanisms for professionals. In terms of both assessment and interventions, there are no specific mention of delivery co-ordinated MDT and a multiagency approach as key management issue. We would finally observe the need to highlight Supervision is embedded in psychologically minded practice where staff are supported to be interested and are able to recognise their own feelings in relation to the people they work with, and recognise the relationship between how they feel about people and how they communicate with them.	Thank you for your comment. We will be including staff/carer training and support to ensure staff are able to provide 'good quality services' and systems to support this, which is likely to include a multidisciplinary approach.
193	SH	Linkage Community Trust	8	4.3.1 e	It is right that interventions for families and carers are also considered.	Thank you for your comment.

194	SH	Northumberland Learning Disability Partnership Board	6	4.3.1 e	We recognise the value of informal care arrangements and believe by improving support, a more preventative approach can lead to better outcomes for all. Therefore we would like to see greater emphasis on the involvement of the person, family and carers particularly in the assessment processes and development of appropriate interventions in a holistic partnership approach to addressing issues. This would include recognition of the potential for families to contribute to the design and implementation of interventions. Family members are often the best placed people to advise on the triggers of challenging behaviour and on the most effective forms of intervention and their contribution can be both very relevant and financially beneficial. Section 4.3.1e could perhaps read: "Interventions and support for family and carers, combined with the development of processes for engaging family and carers as a resource in the design, implementation and monitoring of interventions".	Thank you for your comments. We have adjusted the wording regarding the importance of involving families and service users.
195	SH	Royal College of Speech and Language Therapists	25	4.3.1 e	The College would welcome an examination of the literature on the high levels of aggression that staff experience [Martin, J. P. (1984). Hospitals in trouble. Oxford: Basil Blackwell; Tsiouris, J. Kim, S. Brown, W.T. Cohen, I.L. (2011). Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: a large-scale survey. *Journal Intellectual Disability Research, 55*: 636-649.] and on the emotional exhaustion and depersonalisation resulting from this [eg Hensel JM, Lunsky Y, Dewa CS (2012). Exposure to client aggression and burnout among community staff who support adults with intellectual disabilities in Ontario, Canada. *Journal of Intellectual Disability Research, 56:* 910-5]. We would also welcome critical consideration of the ethics of staff 'training' that does not value the human qualities that they bring to and exercise at work (see Feder-Kittay 1999 for critical examination of unthinking criticisms of care staff) nor attend to their employment conditions and circumstances, not least a considered account of how open to 'training' emotionally exhausted staff are likely to be. Reference could be made to the RCP's *Enabling Environments* accreditation system; and to the course *Psychologically-Minded Environments in ID* available at University of Nottingham at graduate: http://www.nottingham.ac.uk/nmp/learning-beyond-registration/grad-certs/index.aspx & post-graduate levels http://www.nottingham.ac.uk/nmp/postgraduate/courses/index.aspx Finally, we would welcome discussion of whether further research is needed to address the gap between the behavioural and therapeutic	Thank you for your comments. These issues will be included under staff stress and staff training.

					environments literature, and the burnout literature.	
196	SH	College of Occupational Therapists	3	4.3.2	We felt there needed more clarity about which behaviours are considered challenging. We are all aware that physical and verbal aggression and self harm often constitute challenging behaviour but we are concerned that people who withdraw and neglect their own social and psychological need for occupation are also a very challenging group who are often not recognised.	Thank you for your comment. We have clarified that we are including such behaviours in the section on definitions (and are using the Emerson definition because it includes these behaviours).
197	SH	Optical Confederation	6	4.3.2	We recognise these guidelines do not cover the treatment and management of co-existing conditions such as sight loss but stress the presence of sensory impairment will impact on not only a patient's behaviour but on their ability to communicate with health professionals to achieve effective assessment and treatment of their condition.	Thank you for your comment. Sensory deficits will be included in relation to their impact on behaviour that challenges (and communication skills are relevant to this).
198	SH	Royal College of Paediatrics and Child Health	2	4.3.2	We do hope that the impact of epilepsy and anti-epileptic medication on challenging behaviour will be included.	Thank you for your comment. These issues will be included where they impact on behaviour that challenges.
199	SH	Southern Health NHS Foundation Trust	27	4.3.2	Dementia have not been referred to. They are co-existing conditions but may have a significant impact on presentation on behaviours and how they are managed. Impact of Dual Diagnosis and diagnostic overshadowing may need to be addressed.	Thank you for your comment. These issues will be included where they impact on behaviour that challenges.
200	SH	Surrey County Council Adult Social Care	6	4.3.2	It would be useful to have a recognition in the scope that autism spectrum conditions relate closely to challenging behaviour, and that a high proportion of people in learning disability services have autism (see IHAL LD observatory work). If support is delivered with a good understanding of autism, this can help prevent or ameliorate challenging behaviour.	Thank you for your comment. These issues will be included where they impact on behaviour that challenges,
201	SH	Betsi Cadwaladr University Health Board	7	4.4	The aim of the guideline must be to reduce placement breakdown and keep service users with LD and behaviour that challenges within their local communities. Measurement of placement breakdown and out of area placement not mentioned as an outcome.	Thank you for your comment. The wording has been adjusted to include this as an outcome,
202	SH	British Psychological Society	25	4.4	The Society suggests the addition of 3 new points: ***i) Effect of incidents of challenging behaviour on QoL of other people (including service users, family carers and paid carers)*** ***j) increased carer resilience and reduction of carer burnout*** ***k) service user reported outcome measures*** ***l) impact of the behaviour on other service users, carers and staff***	Thank you for your comment, this has been amended in the scope.
203	SH	Cumbria Partnership NHS Trust	1	4.4	Our comments are as follows: Might it be worth including an outcome with respect to carer well-being.	Thank you for your comment, this has been amended in the scope.
204	S	Foundation for	2	4.4	Main outcomes – it is not clear what the list of outcomes mean. Are	Thank you for your comment, these are the tools that will

	H	People with Learning Disabilities			they the tools that the NICE process will gather to measure the list of outcomes. Or should they be more clearly written, e.g. 'Severity, frequency….' will be recorded and reduced?	be assessed in evaluating evidence.
205	SH	Hounslow and Richmond Community Healthcare Trust	15	4.4	How will these outcomes be measured and defined - are there to be tools defined? If so, or not so, this should be stated in the scope.	Thank you for your comment, the tools will be considered in detail in the Guidelines.
206	SH	Linkage Community Trust	9	4.4	The proposed outcomes seem sensible.	Thank you for your comment.
207	SH	Royal College of Speech and Language Therapists	26	4.4	We would suggest that managing transitions should be explicitly added as being of relevance in measuring outcomes in challenging behaviour.	Thank you for your comment, we agree transition is an important issue and have added this to section 4.3.
208	SH	Royal College of Speech and Language Therapists	27	4.4	We would suggest that outcomes for families should be described and included as a relevant metric.	Thank you for your comment, this has been amended in the scope.
209	SH	Sheffield Clinical Commissioning Group	6	4.4	NICE need to ensure that their guidance sensitively distinguishes inpatient assessment and treatment beds from other inpatient settings, and also needs to consider the response of adult mental health acute services around challenging behaviour as distinct from mental health conditions. It would be beneficial to state (within the context of the Winterbourne concordat recommendations) when an inpatient bed actually would be considered to be a suitable response, with what intended outcomes explicitly stated. This would help to differentiate that inpatient beds should just be places for "treatment" and immediate safety for a determined period, and are not considered to be consistent with Professor Jim Mansell's notion of care in "the least restrictive environment" nor considered as a "home for life". Explicit guidance from NICE would reinforce this concept.	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.
210	SH	Southern Health NHS Foundation Trust	28	4.4	Key outcomes that need to be included are Service Users / patient and family / carer experience and satisfaction, Outcomes measures – did the work meet the need, have outcomes improved for the individual, Improved Quality of Life, Improved inclusive relationships and networks, Evidence of clearly documented multi – professional (where appropriate) plans of care with action plans and measureable outcomes that are reviewed regularly, high quality discharge planning. Statistics / rates need to be understood in context with the individual if they are to have real meaning. There is a need to define the purpose of recording rates – are they required for Trust Governance Reports to demonstrate e.g. a fall in use or are they to be used operationally to	Thank you for your comment. The wording has been adjusted.

					help understand their use. The focus should not be on simply reducing behaviours e.g. frequency may remain the same but impact and severity may be significantly reduced.	
211	SH	British Psychological Society	23	4.4 g	The Society suggests that this point is made broader: *g) Use of **psychoactive medication***	Thank you for your comment. The wording has been adjusted.
212	SH	British Psychological Society	24	4.4 i	Residential placements are a common option for people with learning disabilities, and therefore we believe that this would not be a helpful outcome measure. We believe it would be more helpful to say:: The overall number of out of area placements that someone has not specifically requested or that are not clearly documented to be in their best interests.	Thank you for your comment. The wording has been adjusted to clarify.
213	SH	National Development Team for Inclusion	5	4.5	I think it important that costs to family carers are also considered, as Mansell (Services for People with learning disabilities and challenging behaviour or mental health needs 2007) notes, *services cannot succeed without the contribution made by carers and because as a matter of principle one group of people's needs should not be met at the expense of another.* Failure to consider the costs to family carers is likely to impact on equality of opportunity in terms of age, gender and socio-economic status.	Thank you for your comment. We do agree that costs to family carers for people with learning disabilities and behaviour that challenges are considerable. However, in NICE clinical guidelines we do not usually include costs of informal care. In this guideline, the costs considered will usually be only from an NHS and personal social services (PSS) perspective, although economic analyses will attempt to incorporate wider costs associated with the care of people with learning disabilities and behaviour that challenges if appropriate cost data are available. The text of the economics section has been amended to indicate this.
214	SH	Royal College of Psychiatrists	3	4.5	The use of Qaly in making decisions for people with disability has been disputed as it puts disabled people under a kind of double jeopardy (Singer et al 1995) "Not only do they suffer from the disability but because of it, a low priority is given to forms of health care that can preserve their lives" The GDG should explore alternatives to Qalys that do not disadvantage people with LD who have challenging behaviour	Thank you for your comment. The paper you cite examines this 'double jeopardy' and actually rejects the claim that QALYs are unjust or unfair because they lead to double jeopardy. Use of QALYs as a common metric ensures comparability across different conditions and populations, and this is why it is the preferred unit of effectiveness in NICE guidance. However, we acknowledge that use of QALYs may not be suitable for people with challenging behaviour and learning disabilities, due to lack of appropriate relevant data. We have amended the section on 'economic aspects' of the scope to reflect this issue.
215	SH	Association for Family Therapy and Systemic Practice	1	General	This response is submitted by AFT, the Association for Family Therapy and Systemic Practice (www.aft.org.uk). AFT is committed to supporting developments in practice, research, training and delivery of high quality therapeutic services for children, young people and adults with learning disabilities and their families and other caring groups. It is the UK's leading organisation for professionals working systemically with individuals, couples, families and other networks of care across the lifespan. AFT's membership is multi-disciplinary and includes	Thank you for your comments.

					Family and Systemic Psychotherapists (aka family therapists), clinical psychologists, psychiatrists, GPs, nurses, social workers, teachers, occupational therapists, health visitors and others committed to developing their systemic practice skills and understandings.	
216	SH	Association for Family Therapy and Systemic Practice	2	General	AFT requests this draft scope be changed to better promote equality of opportunity by including Systemic Family Therapy in its list of recommended therapeutic interventions for people with challenging behaviour and learning disabilities and their families and/or networks of significant relationships. The relational and contextual orientation of Systemic Family Therapy acknowledges the impact on and importance of people's significant relationships, and of their familial, social and cultural contexts and experiences. It is especially mindful of people's experiences of marginalisation relating to age, disability, gender, gender identity, ethnicity, religion and belief, sexual orientation, education or socio-economic status. Current Systemic Family Therapy understandings and practices draw on a range of conceptual ideas including systemic, narrative and cognitive-behavioural. They are informing recent key developments in therapeutic supports for people with learning disabilities, their families and those who work with them. Systemic Family Therapy approaches to challenging behaviour not only support the person with learning disabilities and their families/ networks of significant relationships, but also seem to increase staff resilience, resourcefulness and understandings, and their abilities to implement recommendations and changes when working with this client group Ansu, H. & Ruddle, A. (2011). Controlling 'the human hulk'. Context, 114, April, 12. Baum, S. (2006). Evaluating the impact of family therapy for adults with learning disabilities and their families. Learning Disability Review 11, 1, 8 – 18. Baum, S. (2007). The use of family therapy for people with learning disabilities. Advances in Mental Health and Learning Disabilities, 1, 2, 8 – 13. Baum, S. (2011). Positioning theory and relational risk-taking: connections when working with adults with learning disabilities and their families, Context, April, 14 – 17. Baum, S. & Lynggaard, H. (2006). The person in a relationship: a systemic approach. In M. Jukes & J. Aldridge (Eds.), Person-Centred Practices: A therapeutic Perspective (pp. 231-240). London: Quay Books.	Thank you for your comment, the role of the scope is not to recommend specific interventions, but rather to outline the areas that the guideline will focus on. The evidence for the interventions in this area will be reviewed and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.

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217	S H	Betsi Cadwaladr University Health Board	6	General	Clarity is needed re definition of challenging behaviour, it states that challenging behaviour is not a diagnosis but document refers to people as 'having' challenging behaviour rather than displaying challenging behaviour	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' throughout. 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.
218	S H	British Psychological Society	1	General	The Society very much welcomes the development of NIHCE guidance in this area. We are pleased the scope has developed from that presented at the initial scoping workshop, in reflection of many of the views presented on the day. We feel that it would be helpful to spell out even more explicitly that 'challenging behaviour' is not a diagnostic category, but rather is socially constructed and that the origins of the term were to provide a reminder to services that such behaviour should be seen as a challenge to *services* rather than a manifestation of psychopathological processes. (Challenging Behaviour: a unified approach, RCPsych et al., 2007, 1p14)	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' throughout and amended the scope to clarify that this is not a diagnostic category but rather a social construct.
219	S	British	2	Ge	The Society welcomes the way that the title has been developed from	Thank you for your comment. The Guidelines need to be

	H	Psychological Society		neral Title	the earlier draft, but would like to see a further addition to reflect the post-Winterbourne promotion of more positive approaches to supporting people. Our recommendation is: ***Challenging Behaviour: positive approaches to prevention, and support of people with learning disability and challenging behaviour.***	able to review evidence and comment on the not so positive methods too (such as restrictive practices). If we changed the title that would exclude these practices.
220	SH	Cumbria Partnership NHS Trust	3	General	Our comments are: Might it be worth having something specific about the organisation and delivery of care, especially with respect to support staff competencies/skill set; similar to what was included in the Autism Guidelines.	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.
221	SH	Department of Health	2	General	This outline: a) uses an overly medical model which, we feel, is no longer appropriate in the modern integrated world; b) does not relate to current major polices issues such as Winterbourne View; c) does not place the proposed work in the framework of the law, the Mental Capacity Act. It addresses epidemiology, but not social care. It addresses why there is a clinical need for the guide, but not why there is a corresponding social care need. It discusses the relationship with IQ scores, but not with social conditions. For example, it states that challenging behaviour is found to correlate with severity of learning disability. Some of the most severely learning disabled people are very compliant, so it is not an inevitable correspondence. Furthermore, there is no discussion of the correlation between inappropriate institutionalisation and challenging behaviour. Also, there is no reference to current issues like Winterbourne, where the evidence is that a history of inappropriate restraint causes challenging behaviour, and is an appropriate response to it. The paragraph on 'underlying causes' mentions a whole range of issues but none of these appear to relate to social context. The next paragraph, which is about environmental factors, notes issues such as noise and unpredictable environments, but not the role of lack of personalised care. There appears to be no mention of the need to 'understand' challenging behaviour - only to managing it - with a range of interventions including restrictive interventions.	Thank you for your comment. We have changed various parts of the Scope including the use of the term behaviour that challenges. We have referred to Winterbourne View. The legal framework will be referenced in the Guidelines. We will discuss why severity of LD is correlated with behaviour that challenges in the Guidelines. Social and environmental context are repeatedly referred to in the Scope.

					There appears to be no mention of the legal basis for caring for people with learning disabilities, which is the Mental Capacity Act, no reference to any attempt to address what the legislation means for people with challenging behaviour; to attempt to guide professionals on the need to use the Mental Capacity Act, to hold themselves accountable for all interventions in a human rights framework. In our opinion, there is a need to include the right to liberty and to family life, for people who have challenging behaviour as well as the right to privacy and the right to inclusion.	
222	SH	Department of Health	3	General	As part of the post-Winterbourne View programme of work, DH will be commissioning guidance on Positive Behaviour Support (PBS), which will replace the DH/DfE 2002 guidance on physical interventions for people with learning disabilities or autism and include guidance on physical restraint. In our view, it would be helpful to refer to our guidance (which is due by the end of 2013) in the NICE guidelines. In addition, under post-Winterbourne View (Transforming Care), PBS is also included in the service specification for adults with learning disabilities, or autism with mental health problems and behaviour that challenges (developed by NHS England and ADASS and due for publication fairly soon alongside a service spec for children). Again, we feel that these could usefully be referred to in the NICE guidance, as they are developed.	Thank you. We are aware of this and will refer to these in the Guidelines.
223	SH	Dimensions	3	General	It would be useful if the guidance included mention of Positive Behaviour Support, as this is being recommended by the DH in the post Winterbourne View recommendations.	Thank you for the comment. PBS in included at various points in the Scope.
224	SH	Kingwood Trust	1	General	As significant number of people with Learning Disability who display challenging behaviour also have a diagnosis of autism. Successful interventions for people with autism and challenging behaviour may be very different, and focus on a range of e.g. triggers	Thank you for the comment. This will be considered in the Guidelines.
225	SH	Kingwood Trust	2	General	The design of buildings , furniture etc can have an important role in minimising the need to respond, which in itself can assist in managing situations in a non- interventional manner	Thank you for your comment, adaptations to the environment are highlighted in section 4.3.
226	SH	Linkage Community Trust	10	General	There is not an agreement between education and health on how they define learning disabilities and the terminology they use. The terms learning disabilities and learning difficulties are not always used in the same way to describe the same conditions.	Thank you for the comment. The wording in the early part of the Scope has been adjusted to comment on this.

227	SH	Linkage Community Trust	11	General	Health and education use different descriptors for degrees of disability. There is not an agreement even now in different settings.	Thank you for the comment. The wording in the early part of the Scope has been adjusted to comment on this.
228	SH	Linkage Community Trust	12	General	IQ scores shouldn't be used – below a certain level they are not reliable or meaningful. Relying on IQ scores to the degree proposed is a mistake. Behaviour should be measured functionally.	Thank you for the comment. The wording in the early part of the Scope has been adjusted to comment on this.
229	SH	Linkage Community Trust	13	General	Communication difficulties can also be down to life experience and do not test the same in IQ tests.	Thank you for the comment. The wording has been adjusted in various parts of the Scope to refer to the importance of communication skills.
230	SH	Linkage Community Trust	14	General	Challenging behaviour is a descriptor for behaviour but is dependent on the environment. It is a descriptor of the relationship between the behaviour and the environment. Behaviour can be changed by making adaptations to the environment.	Thank you for your comment, adaptations to the environment are highlighted in section 4.3.
231	SH	Luton and Dunstable Hospital NHS Trust	4	General	As a Learning Disability Nurse in an acute setting I am regularly reminding people that behaviour is often the only way we will know that there is something 'physically wrong' with the person, and it is our duty to find out what that is. We will work closely with family and carers (and the persons 'All about Me' document) to help us to gather a history of the person and especially how they will show they are in pain to support any investigations and treatments.	Thank you for your comment, we agree that exploring all reasons for such behaviour is incredibly important.
232	SH	Northumberland Learning Disability Partnership Board	1	General	Our local area Joint Strategic Needs Assessment (JSNA) provides a definition of serious and challenging behaviour in people with a learning disability but we welcome national standardisation of definitions and guidelines.	Thank you for your comment.
233	SH	Northumberland Learning Disability Partnership Board	5	General	Ensuring services are integrated to include good access to physical and mental health services as well as social care to support underlying causes of challenging behaviour such as expression of pain due to unaddressed health conditions is key.	Thank you for your comment.
234	SH	Northumberland Learning Disability Partnership Board	7	General	Our local area Joint Strategic Needs Assessment (JSNA) provides a definition of serious and challenging behaviour in people with a learning disability but we welcome national standardisation of definitions and guidelines. We would like to see it made clearer that while the scope covers all age (4.1/4.2) the care setting should also clearly include the person's own home, where for example a young person is at risk of developing increasingly challenging behaviours which their family are finding difficult, as the interventions and support does appear to cover this (4.3.1e).	Thank you for your comments, you raise some very important points that will be considered during development of the guideline.

					Local area and national estimates of current and future numbers show that people with learning disabilities are living longer than previously. Trends in increasing longevity and most significantly an expected increase in adults aged 65 and over predicted to have a moderate or severe learning disability highlight two issues for consideration: • More young people are anticipated to transfer from children's services with complex needs and challenging behaviours. • More people with a learning disability are also affected by dementia, which potentially could lead to a future increase in challenging behaviour with age when linked to early onset dementia so recognition of this has significance. (3.1 i) We would very much like to see a life-course approach with early identification, planning and intervening early, starting from childhood and including crisis planning. How challenging behaviour is managed for children and young people has implications for the individual and their families in later life. Managed well and in an integrated way, they will be more likely to cope well with the transition to adult services. Difficulties arising in childhood that are not addressed properly or sensitively can have enormous repercussions for the individuals and their families later in life. Early intervention and good practice at this stage can set the pattern for later life. Ensuring services are integrated to include good access to physical and mental health services as well as social care to support underlying causes of challenging behaviour such as expression of pain due to unaddressed health conditions is key. We recognise the value of informal care arrangements and believe by improving support, a more preventative approach can lead to better outcomes for all. Therefore we would like to see greater emphasis on the involvement of the person, family and carers particularly in the assessment processes and development of appropriate interventions in a holistic partnership approach to addressing issues. This would include recognition of the potential for families to contribute to the design and implementation of interventions. Family members are often the best placed people to advise on the triggers of challenging behaviour and on the most effective forms of intervention and their contribution can be both very relevant and financially beneficial.	

					Section 4.3.1e could perhaps read: “Interventions and support for family and carers, combined with the development of processes for engaging family and carers as a resource in the design, implementation and monitoring of interventions”.	
235	SH	Northumberland Tyne and Wear NHS Trust	1	General	The broad scope of the document was thought to be good and provide a well balanced introduction to the main areas of concern. It was thought that the Short title should not be challenging behaviour ‘in’ people with LD. It would be more suitable to say challenging behaviour ‘and’ people with LD . It was thought helpful that the document covers carer interventions and training required. Given its influence in the literature Positive Behaviour Support needs more prominence and emphasis on interventions that may help develop functional alternatives and skills teaching and a systems approach. It feels like a section relating to legal considerations is missing, particularly in relation to restrictions and restraint, and role of court of protection. This could include ethical considerations around behavioural change and best interest decision making.	Thank you for your comment, the guideline title has been amended to reflect your suggestion. All evidence for relevant interventions will be reviewed when developing the guideline.
236	SH	Optical Confederation	1	General	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. (1) There is under detection of visual impairment in all groups of patients with learning disability. (1) (2) 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. (3) It should also be noted that the effectiveness of any 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. 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. (4) This provides	Thank you for the comment. The wording has been adjusted in various parts of the Scope to comment on the need for sensory deficit assessments. Evidence for specific interventions will be reviewed in the Guidelines.

					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.	
237	SH	Optical Confederation	7	General	**References:** 1.) Emerson E, Robertson J. Estimating prevalence of visual impairment among people with learning disabilities in the UK. Lancaster University: Centre for Disability Research, 2011. 2.) 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 3.) Pilling, R. (2011). The management of visual problems in adult patients who have learning disabilities. Ophthalmic Services Guidance, The Royal College of Ophthalmologists. 4.) LOCSU Enhanced Service Community Eye Care for Adults & Young People with Learning Disabilities Pathway [Revised June 2012, Version 1.2] 5.) Turner S,Kill S, Emerson E. (2013) Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities	Thank you.
238	SH	Optical Confederation	8	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. The Local Optical Committee Support Unit (LOCSU) provides quality, practical support to Local Optical Committees in England, to help them to develop and implement local objectives, in respect of primary eye care services. LOCSU has developed a number of eye care pathways including cataract and low vision to provide expert advice, associated business cases, clinical training packages and implementation tools to assist with the commissioning of these pathways. For more information, please visit: www.locsu.co.uk	Thank you for your comments.
239	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	1	General	Scope need to be clear that challenging behaviour is not a diagnosis and is not an issue/problem that is situated within the individual. It is a social construct; it has a multitude of potential causations and suitable interventions across biopsychosocial domains.	Thank you for the comment. We have adjusted the wording throughout the Scope to comment on this.

240	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	2	General	Any work with people with learning disability should take place within a strong value base, supported by ethical and legal frameworks. Valuing People Now - DoH Mental Capacity Act Challenging Behaviour: A Unified Approach Disability Discrimination Act MDT (coordinated and shared) duty of care, CPA, professional guidelines and competencies All strongly suggest that services should take a proactive person centred stance to offer: • Prevention • Early detection • Long term support • Crisis response	Thank you for the comment. We have adjusted the wording of the Scope to comment on the need for individually designed and ethical interventions. We have commented on the need to consider prevention. Other guidance (like the VP, Unified Approach, etc) will be referred to in the Guidelines.
241	SH	Rotherham, Doncaster and South Humber NHS Foundation Trust	3	General	Evidence from Winterbourne and disability rights highlights that the environment has to be central to how challenging behaviour is understood. Ecological considerations include physical and relational issues such as staff knowledge, training, awareness and attitudes. As such it places commissioning, care-coordination, contract monitoring, independent advocacy, whistle blowing and safeguarding central to the understanding and management of challenging behaviour.	Thank you for your comment, adaptations to the environment are highlighted in section 4.3.
242	SH	Royal College of General Practitioners	4	General	The areas of religion, sexual orientation and socio economic factors are not explicitly described. Older children and young people with learning disabilities may have specific issues in relation to these areas that may impact on challenging behaviours. This may be useful to consider in the guidance.	Thank you for your comments, the scope has been amended to reflect this.
243	SH	Royal College of Nursing	1	General	The Royal College of Nursing welcomes proposals to develop this guideline. It is timely.	Thank you for your comments.
244	SH	Royal College of Paediatrics and Child Health	1	General	This is a really useful and very large piece of work. We look forward to the final product.	Thank you for your comments.
245	SH	Royal College of Psychiatrists	1	General	It is unusual to cover people with mild learning disability in guidelines for challenging behaviour. Most recent publications e.g. Emerson and Einfeld (2011) and RCPsych (2007) focus on people with moderate and severe learning disability. If this guidelines covers the whole range then it will have to give guidance which will help clinicians deal with the	Thank you for your comment, we agree this is an important area for review.

					interface between challenging behaviour and offending behaviour as there can be a overlap in the way behaviours are assessed and treated. It is not uncommon for people with learning disability to be sent ot secure services on account of behaviour that is proving to be challenging to ordinary services	
246	SH	Royal College of Psychiatrists	1	General	The document should reinforce the need for Children and young people with a learning disability to have access to a comprehensive assessment and treatment within their local area. There should be access to a suitably skilled psychiatrist. At present there are many areas of the country where they are denied a service by virtue of their learning disability	Thank you for your comment, these issues will be considered when drafting the guideline.
247	SH	Royal College of Psychiatrists	2	General	As this guideline is covering all ages it needs to provide specific guidance to manage the period of transition when people with learning disability and their families encounter a fairly predictable set of barriers when moving from childrens' to adult services	Thank you for your comment, we agree that transition between services is important and have therefore added this to the scope.
248	SH	Royal College of Psychiatrists	6	General	We need to be aware of different service configurations across the U.K. and access to specialist support being difficult in some areas. However, there needs to be a recommendation which seems 'fit' for all children in the U.K. and not dependent on services i.e. a document that is led by patient-need rather than service-need.	Thank you for your comment, the aim of all NICE guidelines is to be patient-led and to raise the standard of care for all those accessing services in England and Wales.
249	SH	South Essex Partnership NHS Foundation Trust	5	General	"As an overall comment I think something along the lines of Positive Behaviour Support needs to be embedded across all areas of practice. There has been much regarding this following the Winterbourne View investigation. Hopefully, there will be emphasis on supporting people at home with access to out of hours support – I think a lot could be gleaned from the IST model."	Thank you for your comment. PBS has now been mentioned several times.
250	SH	South West Yorkshire Partnership NHS Foundation Trust	1	General	Should the terminology used be changed to "behaviours that challenge?"	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' 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.
251	SH	South West Yorkshire Partnership NHS Foundation Trust	2	General	More emphasis should be included on physical health as a contributing factor.	Thank you for your comment, the assessment of physical health is included in sections 4.3.1 a) and b).
252	SH	South West Yorkshire Partnership NHS Foundation	3	General	The scope paper does not seem to mention an underpinning model such as PBS.	Thank you for your comment. PBS has now been mentioned several times.

		Trust				
253	SH	Southern Health NHS Foundation Trust	1	General	Our comments are as follows: Throughout the document there needs to be a greater emphasis on involving the person with a learning disability in all aspects of their care. Focus should be on what we do 'with' the person not what we do 'to' the person. At times the level of choice that the individual has may be affected by their capacity or legal restrictions place upon them. However, there is no reference to the Mental Health Act, Mental Capacity Act (MCA), Deprivation of Liberties (DoLs), Best Interests and Safeguarding Vulnerable Adults which are essential issues that need to be addressed at different points throughout the document.	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.
254	SH	Southern Health NHS Foundation Trust	2	General	Challenging behaviour is a social construct which needs to explored at the beginning of the document. A greater emphasis needs to be place on 'prevention' and the need to understand behaviour in relation to the individual and the environment they are living in. Challenges can be created by services and communities through lack of understanding of individual need and how to support them.	Thank you for your comment. These issues are now mentioned at various points in the Scope.
255	SH	Southern Health NHS Foundation Trust	3	General	The need for high quality,well managed and skilled workforce are key factors is being able to support people with a learning disability who present challenges in relation to their behaviour. Challenging behaviour can be a greater service issue than a personal issue.	Thank you for your comment, we agree that staff training is an important issue and one that we highlight in section 4.3.1.
256	SH	Southern Health NHS Foundation Trust	4	General	The document needs to be supported by current evidence. There is a lack of robust research in many areas. It is important to link with organisations that have undertaken reviews e.g. British Psychological Society, Improving Health and Lives (IHaL), Royal College of Psychiatry.	Thank you for your comment, all relevant evidence will be reviewed during development of the guideline.
257	SH	Tees Esk and Wear Valley NHS Foundation Trust	1	General	Respondents within the Trust feel the title of the guideline is much improved. However it is felt that there is still no specific reference to values.	Thank you for your comment. The wording has been adjusted accordingly.
258	SH	Tees Esk and Wear Valley NHS Foundation Trust	2	General	Trust feel the emphasis on person centred approaches, with autonomy as one of the guiding ethical principles has improved. There should be a lesser emphasis on management	Thank you for your comment. The wording has been adjusted accordingly.
259	SH	Tees Esk and Wear Valley NHS Foundation Trust	3	General	In terms of definition we agree with the concerns expressed at the scoping event that we should be referring to behaviours that challenge services rather than placing emphasis on the term challenging behaviour to better reflect the recent philosophical shift in use of terminology. There still remains reference to people who have Challenging Behaviour like it is a contagious infection, consideration should be	Thank you for your comment, the scope has been amended to use the term 'behaviour that challenges' 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.

					given to wording throughout the guidance.	
260	SH	Tees Esk and Wear Valley NHS Foundation Trust	5	General	The Trust agree that there needs to be a link to social care settings and a comment on the quality (including well trained staff) and range of services available to support people whose behaviour is described as challenging with a clear steer towards relevant policy and guidance; e.g. Unified Approach, Winterbourne View reports etc. This is improved however the Trust feel further improvement could be made if direct links were available throughout the guidance.	Thank you for your comment, these issues will be considered when drafting the guideline however NICE guidelines rarely refer directly to policy as these may change over time. Rather recommendations are made about the principles that underpin good quality services.
261	SH	Tees Esk and Wear Valley NHS Foundation Trust	6	General	Related to the last point we feel the scope needs to set a clear intention that the guidelines will provide a brief but explicit reference to the historical context of the treatment of people with learning disabilities and challenging behaviour over the ages, right up to Winterbourne, to give the reader an appreciation of the legacy of failure and abuse that has gone on and the importance of addressing behavioural challenges in the appropriate manner. Alongside this could be a section or statement on the appropriate values and beliefs that are expected, and what factors can constitute abuse or be viewed as punitive when behavioural interventions are being utilised.	Thank you for your comment, these issues will be considered when drafting the full guideline.
262	SH	Tees Esk and Wear Valley NHS Foundation Trust	7	General	We feel there should be an explicit intention to consider approaches such as PBS and a look at short-term and longer term interventions, addressing sustainability of interventions, etc. The Trust feel this has been improved however there should be specific reference to approached such as PBS.	Thank you for your comment, positive behaviour support has been added as an example of an intervention to section 3.2 a).
263	SH	Tees Esk and Wear Valley NHS Foundation Trust	8	General	There needs to be explicit reference to the importance of Mediator Analysis including supporting staff working with people whose behaviours are challenging for example (supervision). Further reference required.	Thank you for your comment, this is too detailed for the scope but may be explored in the full guideline.
264	SH	Tees Esk and Wear Valley NHS Foundation Trust	9	General	There needs to be an explicit reference to formulation as part of behavioural assessment and intervention.	Thank you for your comment. The wording has been adjusted accordingly.
265	SH	Tees Esk and Wear Valley NHS Foundation Trust	11	General	Further improvement could be made to emphasise on the roles and responsibilities of all sectors providing support so their workforce are prepared and skilled enough to provide the ‘right ‘ support.	Thank you for your comment. The wording has been adjusted accordingly.
266	SH	Tees Esk and Wear Valley NHS Foundation Trust	12	General	The scope indicates that guidance will give specific consideration regarding PMLD & those in CJS, however, indications of this being addressed are not clear from what is currently written.	Thank you for your comment. The wording has been adjusted accordingly.

267	SH	Tees Esk and Wear Valley NHS Foundation Trust	13	General	An equal emphasis should be on environment/ecological manipulation, and the non-negotiables in these areas in making interventions work (consistency, etc). Further detail required in guidance.	Thank you for your comment, adaptations to the environment are highlighted in section 4.3.
268	SH	Tees Esk and Wear Valley NHS Foundation Trust	14	General	The impact of Physical health issues could be made more explicit.	Thank you for your comment, the inclusion of physical health assessments in sections 4.3.1 a) and b) was deemed sufficient.
269	SH	Tees Esk and Wear Valley NHS Foundation Trust	15	General	Need more citations/references to support statements included in the guidance. Further references required.	Thank you for your comment, it is the NICE style to not include references within the scope.
270	SH	Tees Esk and Wear Valley NHS Foundation Trust	16	General	The Trust felt an improved sense that the scope does not convey the complexity of working with people whose behaviours are challenging.	Thank you for comment, we are unclear what you are referring to here and therefore unable to respond.
271	SH	The Elfrida Society	1	General	As many studies have already shown that sexual frustration results in anger and aggression, and as many people with learning disabilities are denied appropriate educational support around developing sexuality, or lack the capacity to understand their developing sexuality, the link between sexual frustration and challenging behaviour ought to be explored together with options for education and intervention.	Thank you for your comment. Sexual issues will be addressed in the guideline.when we look at the assessment of emotional needs.

These organisations were approached but did not respond:

Action for Advocacy
Alder Hey Children's NHS Foundation Trust
Ambitious about autism
Assocation of NHS Occupational Physicians
Association for Cognitive Analytic
Association of Anaesthetists of Great Britain and Ireland
Association of Psychoanalytic Psychotherapy in the NHS
Bangor University
Barchester Healthcare
Birmingham Community Healthcare NHS Trust
Black and Ethnic Minority Diabetes Association

Bournemouth University Dementia Institute
British Association for Music Therapy
British Association of Dramatherapists
British Institute of Learning Disabilities
British Medical Association
British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Paediatric Mental Health Group
BSPGHAN
CALM - Crisis, Aggression, Limitation and Management
Capsulation PPS
Care Quality Commission (CQC)
Castlebeck
CIS' ters
Citizens Commission on Human Rights
College of Mental Health Pharmacy
Contact a Family / The Lady Hoare Trust
Crisis Prevention Institute
Croydon Health Services NHS Trust
Department of Health, Social Services and Public Safety - Northern Ireland
Derbyshire Healthcare NHS Foundation Trust
Dorset Healthcare University NHS Foundation Trust
East and North Hertfordshire NHS Trust
Economic and Social Research Council
Empowerment Matters
English Community Care Association
FBA and Brook
Federation of Ophthalmic and Dispensing Opticians
Five Boroughs Partnership NHS Trust
Foundation for People with Learning Disabilities
George Still Forum
Guidelines and Audit Implementation Network
Havencare
Health and Safety Executive
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Hertfordshire Partnership NHS Foundation Trust
Hertfordshire Partnership NHS Trust

Humber NHS Foundation Trust
Independent Children's Homes Association
Islington Learning Disabilities Partnership
JKP Analysts, LLC
Lancashire Care NHS Foundation Trust
Lancaster University
Leeds and York Partnership Foundation Trust
Leicestershire county council
Lincolnshire County Council
Medicines and Healthcare products Regulatory Agency
Mental Health Group - British Dietetic Association
Mental Health Providers Forum
Ministry of Defence
National Autistic Society
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Institute for Health Research Health Technology Assessment Programme
National Treatment Agency for Substance Misuse
National Youth Agency
Neonatal & Paediatric Pharmacists Group
Newcastle, North Tyneside and Northumberland Mental Health NHS Trust
NHS Connecting for Health
NHS Direct
NHS England
NHS Halton CCG
NHS Plus
NHS Protect
NHS Sheffield
NHS Somerset
Noblecare
North of England Specialised Commissioning Group
Northamptonshire Healthcare NHS Foundation Trust
Nottingham City Council
Nottinghamshire Healthcare NHS Trust

Parents' Education as Autism Therapists
Partnerships in Care
Play Therapy UK
POhWER
Prospect PBS Training Ltd
Public Health Wales NHS Trust
Respond
Rotherham Doncaster and South Humber NHS Foundation Trust
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Pathologists
Royal College of Physicians
Royal College of Radiologists
Royal College of Surgeons of England
Royal Pharmaceutical Society
Salford Learning Disability service
Salisbury Autistic Care LTD
Scottish Intercollegiate Guidelines Network
SharedLives Plus
Sheffield Childrens Hospital
Sheffield Teaching Hospitals NHS Foundation Trust
Sing & Grow UK
Skills for Care
Social Care Institute for Excellence
South London & Maudsley NHS Trust
South of Tyne & Wear PCT
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
Speak Out Against Psychiatry
St Andrews Healthcare
Step by step school
Suffolk County Council
Sussex Partnership NHS Foundation Trust
The College of Social Work
The Judith Trust
The UK Society for Behaviour Analysis
Tizard Centre
Treating Autism
Tuberous Sclerosis Association

Turning Point
United Kingdom Council for Psychotherapy
University Hospitals Birmingham
Voluntary Organisations Disability Group
Way Ahead Care
Welsh Government
Welsh Local Government Association
Western Sussex Hospitals NHS Trust
Worcestershire Health and Care NHS Trust
York Hospitals NHS Foundation Trust