Learning disabilities and behaviour that challenges: service guidance

Consultation on draft scope
Stakeholder comments table

15/07/15 – 02/09/15

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Challenging Behaviour Foundation	General	General	Terminology: "people WITH learning disabilities and behaviour that challenges" suggest that the behaviour is located in the person rather than a symptom of an unmet need. Suggest "people with learning disabilities who display behaviour described as challenging"	Thank you for your comment. We agree that the use of sensitive terminology is important. We agree too that the terminology used should not suggest that the behaviour is located in the person; rather, that it may be a result of unmet need. As the service model guideline is intended to complement and correspond to existing NICE guidance, we will continue to use "people with learning disabilities and behaviour that challenges" for the sake of consistency and to assist readers in making the link between two guidelines. However, we will make it clear that we do not consider challenging behaviour to be a condition or diagnosis and that it may instead be the result of unmet need.
Challenging Behaviour Foundation	General	General	The focus of the whole document implies that admission to in patient settings will always be necessary and does not do enough to emphasise the importance of early intervention, prevention and high quality community support and services to meet individual needs	Thank you for your comment. We agree that admission to inpatient settings is not always necessary. To make this clearer, the scope has been amended to reference both inpatient and community based settings explicitly. Also, questions on services and capacity in both inpatient and community have been amended in the scope.
Challenging Behaviour Foundation	3	49	The order here is wrong. It should start with community settings, otherwise the implication is that people will be in inpatient settings	Thank you for your comment. It was not the intention to imply that people would necessarily need to use inpatient services. We have changed the order of the settings in the scope so that community based settings appear first, as is more logical.
Challenging Behaviour Foundation	3	76	Residential schools should not be defined as community settings- they are often segregated settings, with limited community integration and long distances from the child's family home,	Thank you for your comment. We have now differentiated between community based specialist schools and residential schools in the settings section of the scope.
Challenging Behaviour	3	general	There is no mention of short breaks settings, respite settings or local crisis response settings (for children or adults)	Thank you for your comment. We have now added these settings to the scope.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Foundation				
Challenging Behaviour Foundation	4	93	Add "early years"	Thank you for your comment. We have not used this term specifically as consider this to be encompassed under the umbrella of children's services.
Challenging Behaviour Foundation	4	86	Suggest "service availability, development and capacity"	Thank you for your comment. These have been added to the scope
Challenging Behaviour Foundation	5	117	Service delivery should be referenced to outcomes for individuals, not just cost	Thank you for your comment. These have been added to the scope
Challenging Behaviour Foundation	5	120	Service capacity is not only about inpatient capacity! Community provision and capacity must come before inpatient services	Thank you for your comment. It was not the intention to exclude community capacity. We agree that this was unclear in the draft scope and therefore this has been added, before inpatient capacity.
Challenging Behaviour Foundation	5	125	Outcome focus needs to be stressed here	Thank you for your comment. These have been added to the scope
Challenging Behaviour Foundation	6	138	Child development outcomes must be included. Also skill development for children and adults. For children outcome related work see: • practice-based paper for Clinical Psychology Review 2013 • Children and young people with learning disabilities, their families and networks Chapter in Guide to Using Outcomes and Feedback Tools with Children, Young People and Families 2014, available at http://www.cypiapt.org/routine-outcome-monitoring/outcomes-resources.php • presentations from 2 practitioner days for those who work with Children and young people with LD organised by CORC, CYP-IAPT 2014/2015. Available at http://www.corc.uk.net/ldworkshop/	Thank you for your comment. Child development outcomes have been added to the list of person-centred outcomes

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			• Chapter in ACAMHS Occasional Paper Intellectual disabilities and challenging behaviour. See http://www.acamh.org/publications/occasional-papers/op32-intellectual-disabilities-and-challenging-behaviour • Revised guidance paper based on all above, May 2015	
Challenging Behaviour Foundation	6	152	Service focussed outcomes should include PBS. It is currently reads as restrictive practices will automatically be used. Re-order and refocus on proactive approaches	Thank you for your comment. Positive Behaviour Support has been added to the service-focussed outcomes
Challenging Behaviour Foundation	9	246	Good practice examples - include the DH funded Paving the Way http://www.challengingbehaviour.org.uk/learning-disability-files/Paving-the-Way.pdf	Thank you for your comment. We will note this reference, and consider how best to identify additional good practice examples in developing our review protocols and search strategy.
Challenging Behaviour Foundation	9	208	Data paper to include: (recommendations re children, pages 8-9) http://www.challengingbehaviour.org.uk/learning-disability-files/Briefing-Paper.pdf	Thank you for this reference which we will add to our database for the main development phase.
Challenging Behaviour Foundation	9	233	The focus is on getting people out of hospital- there needs to be a focus on stopping people from going in in the first place (by providing the right local support), as well as getting them out	Thank you for your comment. We have amended the scope so that it includes reference to both in patient and community based services
Challenging Behaviour Foundation	7	168	Include NICE(2013) "Antisocial behaviour and conduct disorder in children and young people"	Thank you for your comment. This guideline excludes people whose conduct disorder may be due to mental health issues and for that reason may not overlap with our review population.
Department of Health	General	General	Thank you for the opportunity to comment on the draft scope for the above social care guideline.	Thank you.
Halton Borough Council	3	66	Most children with learning disabilities and behaviour that challenges attend special schools up to at least age 18yrs. Therefore, these schools should be included in the settings that will be covered. This is particularly important with regard to early intervention and prevention.	Thank you for your comment. Specialist schools and residential schools are in scope for this guideline, and are within the settings listed.
Hesley Group	5	117	Hesley Group's Service Model is Residential Care and our	Thank you for your comment and signpost to good practice

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			approach is -The Hesley Enhancing Lives Programme (HELP) – a modern, ethical approach to positive behavioural support, based on the principles of Therapeutic Crisis Intervention (TCI) and Applied Behavioural Analysis (ABA). The key principle behind HELP is the concept that recognising that our actions and reactions powerfully shape the emotional well-being and development of those we support. A mixed economy of services is required for those with complex needs. Hesley Group deal with a highly varied and complex group of people and one size does not fit all.	examples. We have included joint working with related services, including the voluntary sector under the key areas that will be covered in the scope. We will look to the outcomes for measures of effectiveness of different service models.
Hesley Group	5	118	Patients have a right to True Supported Living, however the practical reality of delivering that for certain cohorts of the patient community is complex. Indeed the system fails many for a variety of reasons: • The provider is not skilled enough to work with people who have complex needs. • The environment is not able to meet the individual's needs due to practical issues such as space, surrounding community (i.e. neighbours), challenging behaviour that causes damage to property and other factors • Availability of specialist staff who can provide appropriate clinical interventions. An even mix of Hospital, Residential Care and Supported Living is required in each area/region. This allows for a simple Pathway of services and the ability to move people up and downstream as and when required. A more realistic planning process and a sharper understanding of evidence based commissioning need (rather than an unfounded ideal of what we would like to be able to do), this would make services more effective and in turn cost effective.	Thank you for your comment. Evidence and recommendations regarding the training and the availability of skilled staff is included in the clinical guideline that complements this service delivery guideline scope. We have also added a sentence on strategic planning for lifelong needs, which we feel should address this point. This point would also be relevant to the integrated services and continuity of care in the key areas that will be covered.
Hesley Group	5	121	This is a complex area to empirically define as there is a	Thank you for your comment. We agree this is a complex area

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			history of inappropriate admissions of people with learning disabilities and behaviour that challenges into hospital settings, or through sectioning under the Mental Health Act. In this context the appropriate amount of required beds needs to be judged on the amount of people who continue to be inappropriately detained under the Mental Health Act on a yearly basis.	and, indeed, many of the complexities were highlighted and discussed at the stakeholder workshop. We have added more detail to the section of community as well as in patient capacity. Where evidence is available, the effectiveness of a service will include data on the appropriateness of use.
Hesley Group	5	129	Geography is an important factor in ensuring effective transition between services along the care pathway. That transition plays a significant part in the cost effectiveness of services generally. Care must be planned to suit the needs of the individual who needs them. There is a risk that a headlong drive towards community care will undermine an approach that is focused on the needs of a particular person. One type of care, wherever it is located, is not suitable for all people. The debate around residential care versus community care is somewhat of a false conflict. Unfortunately not every local community is equipped to provide specialist care, and sometimes a patient's needs are acute enough that only very specialised care is required. Therefore it is important that in ensuring a patient is on the right pathway they are not arbitrarily treated in the community to satisfy targets or save money. A key here is consistency in commissioning and consistency in training. In terms of training, in a commissioning region, it would in the best interest of users, to receive some consistency of approach throughout their care. Therefore training and behaviour support	Thank you for your comment. We have added more detail to the section on community as well as inpatient capacity. Where evidence is available, the effectiveness of a service will include data on the appropriateness of use. Thank you for your comment. Evidence and recommendations regarding the training and the availability of skilled staff is included in the clinical guideline that complements this service delivery guideline scope.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			should have similarities across the services, then movement from one service to another is then hopefully less traumatic. In terms of commissioning, users of Hesley's service are particularly adversely affected when a joined up approach fails to work. Forward planning is an important part of the dynamic. All too often local authorities are aware of an individual who is likely to have pending needs, but not enough provision is planned in advance until the issue has hit crisis point because the health and social care elements have failed to sufficiently link up. Hesley supports current proposals (No voice unheard, no right ignored) that individuals and families should be able to interact with a single shared commissioning framework between the health, care and support functions of local authorities. An important part of this may be, where the needs of people with learning disability and autism relate to both health and social care services and there is a need for joint individual care planning for lifelong needs, that NHS commissioners should share new Local Authority duties around promoting individual wellbeing.	Strategic planning for lifelong needs has been added to the key activities that this guideline will cover.
Hesley Group	5	133	One of the clear advantages Hesley Group offers is instant access to our own Multi-Disciplinary Teams (MDT). The immediate access to this resource can often prevent a crisis and a situation can soon become manageable, which prevents placement breakdown. In community based services, patients will only have access to the local community team, which will often involve a referral that takes weeks before any intervention is received, and unfortunately a placement breakdown can happen during this time frame. Therefore more readily available access to community based MDT's would often help people remain in their homes.	Thank you for your comment. The examination and review of different models of care will include searching for examples of multidisciplinary working relevant to the outcomes in scope, such as continuity of care Thank you, we also think this is highly relevant and timely access to services is included in the scope.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Medicines Advice (Medicines and Prescribing Centre)	General	General	We don't have any specific comments on the scope, however we wanted to highlighted related guidelines that may overlap with some of the recommendations: • Medicines optimisation – NG5 (in particular sections 1.2 and 1.8) • Managing medicines in care homes – SC1	Thank you for your comment. We found the Medicines optimisation guideline most relevant to this scope and have added this to the list of overlapping guidelines
NHS England	General	General	Thank you for the opportunity to comment on the above Guideline. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you.
Optical Confederation	General and especially 5 5 6 6 6 6 6	 117-119 124-127 142 143 144 146 147-148	Our request is that wherever health care workers or carers interact with people with learning disabilities and behaviour that challenges, they are nudged to think about sensory impairment and to check that issues are not being exacerbated by people not wearing or having their spectacles (or hearing aids). We have responded in depth to the scope consultation on care and support of older people with learning disabilities on these issues and will not repeat those submissions here. However, we do wish to provide a brief reminder in the context of this consultation that people with learning disabilities experience serious sight problems and visual impairments at a rate of 10 times the general population. These issues often arise earlier in life among people with learning disabilities, with approximately 14% of people over 50 diagnosed as visually impaired or blind and a further 56% experiencing refractive error (Emerson and Roberson. 2011.; commissioned by RNIB and See Ability, accessible at: http://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-VI-learning-disabilities). Recognising the need to improve access to good eye care services, the Local Optical Committee Support Unit (LOCSU) has developed a new Community Eye Care Pathway for Adults	Thank you for your comment. We agree that this is highly relevant to our population and we have added people with sensory impairment to the Equality Impact Assessment.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			and Young People with Learning Disabilities. The pathway, which can be viewed here: http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe, has been developed in conjunction with two leading charities, Mencap and SeeAbility, to ensure that it reflects the needs of people with learning disabilities and is based on established, successful learning disability services provided by community optometrists in a number of areas in England. The pathway gives Local Optical Committees the basis for a proposal to improve the way eye care for people with learning disabilities is delivered in their local area. Vision and other sensory loss among this population is often overlooked by health and social care providers and carers, who may not fully understand the importance of good sensory functioning for people who may not read, work or drive. However, communication and social inclusion are important aspects of valuing and supporting people with learning disabilities to lead as comfortable and participatory lives as possible; both depend greatly on sensory functioning – at a minimum through either vision or hearing, though ideally through both. Health and social care professionals and carers may need additional education and support – and informal carers reminding – to ensure that changes in vision are noted and referred on for appropriate care as early as possible, particularly given the high prevalence of sight problems and the fact that people with learning disabilities may be less able to communicate such changes.	
Positive Response	3	General	The listing in this section is too narrow and focussed on 'bricks and mortar' and implies that services equate to settings. In	Thank you for your comment. The draft review questions in the scope reflect a service models framework, or how different

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Training & Consultancy			particular, there is no mention of how support is provided to these settings (e.g. via community support teams or specialist behavioural teams). It is the latter inputs that will/should contribute significantly to the quality or otherwise of the former. Evidence for the effectiveness or otherwise of support services therefore needs to form part of the scope.	services may be configured. When looking at the evidence, so far as possible, we will examine the individual interventions, components, inputs and outcomes to assess the effectiveness of different models.
Positive Response Training & Consultancy	4	101	Following on from the above, I think that this is a really tricky statement. It is what goes on in a service (i.e. the 'treatment, therapy & management') that will determine service quality, not how the service is physically structured or where it is located. I'm not sure that you can separate this element out as suggested therefore- in fact, I know you cannot.	Thank you for your comment. The draft review questions in the scope reflect a service models framework, or how different services may be configured. When looking at the evidence, so far as possible, we will examine the individual interventions, components, inputs and outcomes to assess the effectiveness of different models.
Positive Response Training & Consultancy	6	General	Continuing the theme, it's interesting that you are focussing on outcomes in the absence of looking at inputs. Though there will be little available data on this, having some measure of whether a service is delivering the type of interventions listed in the recently published CB guideline is central to evaluating outcomes, whether user or service based.	Thank you for your comment. The draft review questions in the scope reflect a service model framework, or how different services may be configured. When looking at the evidence, so far as possible, we will examine the individual interventions, components, inputs and outcomes to assess the effectiveness of different models.
Positive Response Training & Consultancy	6	153 - 155	Could these be more positively expressed as 'reductions in the use of seclusion' etc.	Thank you for your comment. The outcomes are expressed in neutral terms as we would be interested in the use and rates of seclusion as well as the reduction in the use and rates of seclusion.
Positive Response Training & Consultancy	6	140 -150	I know it's implicit, but it would make sense to include a specific reference to reductions in the frequency, severity and/or duration of CB as a user outcome	Thank you for this comment. We agree that this is relevant to the scope and this has been added to the list of outcomes.
Positive Response Training & Consultancy	9	General	This work needs to acknowledge that the current formulation of the 'Winterbourne problem' is incorrect (i.e. it's not about getting people out of NHS services but developing competent community services that obviate the need for them to be so placed in the first instance)	Thank you for this comment. We agree not enough emphasis was placed on both inpatient and community based settings in the draft scope. Questions on services and capacity have been edited to ensure both inpatient and community settings are referenced appropriately.
Positive Response Training &	3	General	You should consider making direct reference to looking at the effectiveness of in vs. out of area services here.	Thank you for this comment. We agree not enough emphasis was placed on both inpatient and community based settings in the draft scope. Questions on services and capacity have been

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Consultancy			You might also need to make similar reference to the data on deinstitutionalisation and its impact (or lack of it) on CB	edited to ensure both inpatient and community settings are referenced appropriately.
Positive Response Training & Consultancy	General	General	There needs to be an awareness from the outset that the data set around this whole topic is limited, in some case quite old (in NICE terms) and often not up to any great experimental standard (but that's because it can't be in many instances). There is a particular lack of data on independent sector services.	Thank you for your comment. This is an important point and was discussed during scoping work. Following the NICE manual on guideline development, we will have the opportunity to call for expert witnesses where published literature may be lacking. The guideline committee can also develop consensus recommendations based on their experience and expertise.
Research Autism	3	77	Community settings should include schools as this is where many of the intractable behavioural patterns and problems are established.	Thank you for your suggestion. We have added specialist schools to community settings.
Research Autism	5	135	Ethical considerations. The ethical basis for intervention. To include harms v benefits and best interests.	Thank you for your comment. In considering the evidence, the guideline committee is prompted to consider benefits versus harms, and ethical implications. Detail of this will be provided in the full guideline.
Research Autism	6	152	Is section should include restrictions on liberty and freedom of movement/false imprisonment	Thank you for your comment. Where evidence on these issues emerges, within the parameters of the review questions, this would be reported,
Research Autism	12	309	Commissioning – mention should be made of the need for commissioning to take account of values, in particular human rights and personalisation.	Thank you for your suggestion. Personalisation of services (which would include ethical considerations) is within the outcomes in scope for this work.
Research Autism	General	General	More should be made of the need for the development of a good evidence base for supporting this group based on scientific evaluation of service models. The role of research in particular should be emphasised.	Thank you for your comment. Where there are gaps in evidence base, the guideline committee is able to develop research recommendations.
Research Autism	General	General	Training that is values led and practical leading to sustainable outcomes and cultural change. At present too much training is technique focussed and fails to address systemic issues.	Thank you for your comment. Evidence and recommendations regarding the training and the availability of skilled staff is included in the clinical guideline that complements this service delivery guideline scope.
Research Autism	General	General	Advocacy. The role of independent advocacy should be emphasised	Thank you for your comment.
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop this guideline. The draft scope seems comprehensive.	Thank you for your comment.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Royal College of Nursing	General	General	It is good to see health and Justice included.	Thank you for your comment.
Royal College of Nursing	General	General	We would be keen to see workforce implications thought through.	Thank you for your comment. Evidence and recommendations regarding the training and the availability of skilled staff is included in the clinical guideline that complements this service delivery guideline scope.
Royal College of Nursing	General	General	It is important to see 'Positive and safe' weaved through this guideline and the LEAST restrictive interventions being paramount. Recent publication: *Equal Access Equal Care (Equal Access, Equal Care - A Toolkit for Prison Healthcare Staff treating Patients with Learning Disabilities (2015)* is a useful reference.	Thank you for your comment. We will add this reference to our database for consideration as part of the main review work. For the scope, the outcomes we are looking for are phrased in neutral terms so that we can capture both positive and indeed any negative outcomes.
Royal College of Nursing	General	General	Finally the work around the confidential inquiry on learning disability - *National Learning Disability Mortality Review Programme led by Bristol University / Norah Fry Research Centre for NHS England* should also be considered.	Thank you for your comment. We will add this reference to our database for consideration as part of the main review work.
Royal College of Paediatrics and Child Health	3	Section 1.2	Include non-residential special schools and units and residential respite care settings for children and young people.	Thank you for your comment. Based on your suggestion we have separated the community based and the residential schools in the settings section.
Royal College of Paediatrics and Child Health	5	Section 1.5	Timely access to service must include access to out of hours support and intervention and access to emergency care including inpatient care. Too often young people whose behaviour is out of control are held in police cells as the only "place of safety".	Thank you for your comment. We have included timely access to services in the list of outcomes relevant to this guideline.
Royal Pharmaceutical Society	2	46	The current draft scope currently excludes adults with learning disabilities whose behaviour that challenges may be attributed to dementia. We believe that these adults should be included in this guidance as much of the treatment and models of care, including service delivery, will be similar. There needs to be clarity around patients with both a learning disability and dementia in that the source of the challenging behaviour needs to be identified and the patient cared for in conjunction with	Thank you for your comment. We agree with this statement and have removed this population from our list of groups that will be excluded. We will include all people with learning disabilities who may display behaviour that challenges, irrespective of the cause of that behaviour.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			NICE guidelines to ensure that no-one falls through a crack in the pathways if separate guidelines are in place.	
Royal Pharmaceutical Society	General	General	It is key that medical and / or pharmaceutical care is identified as an integral part of the care package for people with learning disabilities. Currently medicine (prescribing, dispensing, administration and optimisation) is not seen as part of the integrated service provision and service model for such patients. There are major issues around the nature of the medicines used, how the medicines are given and the potential for abuse i.e. patients with learning disabilities are sometimes prescribed and given medicines that are inappropriate but are used to prevent agitation. It is therefore vital that you include within your scope the nature of the optimal medical and pharmaceutical care for patients with learning disabilities.	Thank you for your comment. We found the Medicines optimisation guideline most relevant to this scope and have added this to the list of overlapping guidelines
Somerset County Council	2	35	Equality Impact Assessment: Page nr 1 Section 1.1 Age – as well as mentioning "older adults", YP should also be listed, as there are also access issues for YP (certainly as part of transition processes)	Thank you for your comment. We have added reference to children and young people to the equality impact assessment.
Somerset County Council	2	35	Equality Impact Assessment: Page nr 1 Section 1.1 Gender impact should be listed – as service models may need to be different depending on gender	Thank you for your comment. We have added reference to gender impact to the equality impact assessment.
Somerset County Council	2	35	Equality Impact Assessment: Page nr 1 Section 1.1 Sexual Orientation – if this concerns a person's identity and who they are / identify as, then this should also include	Thank you for your comment. We have added reference to sexual orientation to the equality impact assessment.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			'transgender' as a consideration. However, it is important to underline that in this context "sexual orientation" should not be confused with sexual and /or forensic behaviour	
Somerset County Council	general	general	Transitions is not specifically mentioned anywhere. There is on page 5, line 128 a referral to "Integration of services" – but I read this as referring to joint commissioning / joint working / integrated funding streams etc. I am aware that there are already specific NICE guidance documents on transition (either currently worked on or already published) however, I think there is a need to look at transition as part of this service delivery model work. Because when service delivery models don't join up or don't consider transition issues, person-focused comprehensive outcomes cannot be achieved for YP and adults with LD.	Thank you for your comments. Transitions between services are in scope. The transition guideline currently underway examines interventions to facilitate effective transition from hospital to community, but does not consider in depth the optimal configuration or organisation of services. This guideline will look at transitions from any site and multiple transitions where a person with learning disability and behaviour that challenges may receive health or social care.
Somerset County Council	11	293	Legislation: The Equality Act 2010 as well as the Human Rights Act 1998 should be mentioned in this list. (For example considerations as to article 3 HRA)	Thank you for your comment. This detail has now been added.
The National Autistic Society	General	General	Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives with limited support. However, others may need a lifetime of tailored specialist support. Some people with autism may also have more complex needs, including a learning disability or mental health needs (or both). People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. More than 1 in 100 people in the UK have autism. We estimate that at least half of people on the autism spectrum do	Thank you for this comment. People with autism who also have a learning disability and display behaviour that challenges are also included in this review, for the reasons you suggest. We have made clearer in the scope that this group has not been excluded.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			not have a learning disability. However, some people with autism who do not have a learning disability may still have challenging behaviour and are therefore excluded by the scope. We believe that all people with autism who display challenging behaviour must be included, *regardless of where they are on the spectrum.* The draft scope rightly refers to Transforming Care (reference in section 3.1), which aims to move people with autism and/or learning disabilities and challenging behaviour from inappropriate inpatient mental health units in to the community. Central to this is that the right services in the community are available and to that end NHS England has developed a draft service model – with which it is important that this guideline should link. The service model looks at challenging behaviour regardless of whether this is linked to a learning disability or autism. It is also worth noting that with regards to Assessment and Treatment Units (ATUs) that NHS England *Assuring Transformation* data (http://www.hscic.gov.uk/catalogue/PUB17638) shows that 35% of inpatients had a diagnosis of autism, with 12% having a diagnosis only of autism and 23% having autism and a learning disability. In order for services in the community to be appropriate for people on the autism spectrum, who make up over a third of the inpatient population, autism will need to be carefully considered. Furthermore, the NAS believes that Positive Behavioural Support will apply to people on the autism spectrum, whether or not they have a learning disability. Examples of this Positive Behaviour Support for people with autism and no learning disability include: • J, who has Asperger syndrome. J was verbally and	NICE have suggested we refer to the NHS England service model in the scope. We will keep in close liaison with the Transforming Care work and use any learning and outcomes to inform the guideline Thank you for your comment. People with autism who also have a learning disability and display behaviour that challenges are also included in this review, for the reasons you suggest. We have made clearer in the scope that this group has not been excluded.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			physically aggressive. A behaviour support plan was developed alongside J and included methods for how staff should ask J to move onto another activity, how staff should start and end their shift (including how to enter J's flat) and a structure for activities that enabled J to choose what he wanted to do each day. • M, who has a diagnosis of 'high functioning' autism and lives in supported living. M was verbally and physically aggressive. M shared a home with another person and behaviour would be presented when the other person was receiving support and he had none. Strategies included education, attention at frequent intervals and social skills education to enable M to start a conversation. In sum, the contents of the guideline are likely to be highly relevant for many people on the autism spectrum. It would therefore be a missed opportunity for the guideline to be developed explicitly with people on the autism spectrum included.	
The National Autistic Society	7,8	165 -206	We note that NICE Guideline CG170 and NICE Quality Standard QS51 have been referenced as being linked to this guideline. The NAS fully supports this link and believes that it would be more appropriate to make the link more explicit, by including people on the autism spectrum formally in the scope of the guideline.	Thank you for your comment. People with autism who also have a learning disability and display behaviour that challenges are also included in this review, for the reasons you suggest. We have made clearer in the scope that this group has not been excluded.
The National Autistic Society	10	253 -255	This passage further highlights that this guideline should include people on the autism spectrum. It notes that many autistic adults currently receive costly residential care, often out-of-area.	Thank you for your comment. People with autism who also have a learning disability and display behaviour that challenges are also included in this review, for the reasons you suggest. We have made clearer in the scope that this group has not been excluded.
The National Autistic Society	10	275 -292	This section should reference the Government's adult autism strategy and the statutory guidance implementing it.	Thank you for your comment. The government adult autism strategy will be referenced in the associated existing NICE

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				guidance for people with Autism. In this guideline, our primary focus is on people with learning disabilities who display behaviour that challenges, to include people with autism who also meet this definition.
The National Autistic Society	11	293 -308	This section should also reference the Autism Act.	Thank you for your comment. The government adult autism strategy will be referenced in the associated existing NICE guidance for people with Autism. In this guideline, our primary focus is on people with learning disabilities who display behaviour that challenges, to include people with autism who also meet this definition.
The Royal College of General Practitioners	General	General	The scope provides a solid basis to examine the models of care or people with learning disabilities and behaviour that challenge. I think there are several areas that need to be considered: 1. Area age sex registers to allow planning of local services particularly for young adults transitioning to adult services. 2. The mental capacity act and deprivation of liberties should be specifically identified as a key area to cover as there remains confusion amongst practitioners since the Cheshire West Judgement. A deprivation of liberty authorisation affecting one client can inadvertently affect other clients in the same residential home. 3. Models of service delivery (line 85) needs to cover the size of the unit. I believe that large residential units struggle with people with behaviours that challenge. Clients benefit from having continuity of care. 4. Location of services – services need to be local to ensure family and friend's relationship can be maintained when leaving home. 5. International comparators and experience of different models from other countries. 6. Consideration of using a standardised assessment	Thank you for your suggestions. 1. It is possible, within the scope of the guideline, to refer to a range of data sources, which may include local area data, to triangulate with evidence found in the relevant literature. 2. We will refer to relevant legislation and policy in the guideline. In developing recommendations, we will draw on the guideline committee's experience of providing and using services in the context of legislation and policy. 3. Where available, this information and other factors would be presented with the evidence in forms of evidence tables. 4. We have included continuity of care, and location of services in the scope. 5. It is possible, within the scope of the guideline, for us to consider evidence from similar welfare systems for comparison. 6. It is possible, within the scope of the guideline, for us to consider different approaches to supporting people with behaviour that challenges.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			methodology such as the Newcastle psychosocial model used in people with dementia and behaviours that challenge.	
United Response	2	43	We think that autism should be explicated included in the scope as a group which will be covered by this guideline. Autism is later referenced in line 254 but this needs to be explicit throughout the guidance.	Thank you for your comment. People with autism who also have a learning disability and display behaviour that challenges are also included in this review, for the reasons you suggest. We have made clearer in the scope that this group has not been excluded.
United Response	General	General	We think that the guidance needs to explicitly include models for community support teams and other outpatient services as we know that these are key to building up community support and preventing admission – or readmission – to Assessment and Treatment Units.	Thank you for your comment. When looking at the evidence, where data are available, we will examine the individual interventions, components, inputs and outcomes to assess the effectiveness of different models.